



# **BEYOND SURVIVAL: SHAPING THE FUTURE OF CANCER CARE OF YOUNG PEOPLE**



Project funded by the European Commission  
Grant Agreement No. 101056918  
EU4Health Programme

## **Publisher**

Childhood Cancer International – Europe (CCI-E) & Youth  
Cancer Europe (YCE), on behalf of the EU-CAYAS-NET project

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## **Acknowledgements**

This project – along with its results, materials, and the network it fostered – could only come to life thanks to the incredible beneficiaries, associated partners and of course our amazing community. We extend our heartfelt thanks to everyone involved for your collaboration, dedication, and the effort you put into making this possible.

A very special thank you goes to all the young people with lived experience who contributed their energy and free time to the project, its outcomes, and the events surrounding it – all while balancing their primary professional commitments. Your generosity and commitment made this journey truly remarkable.

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## INTRODUCTION

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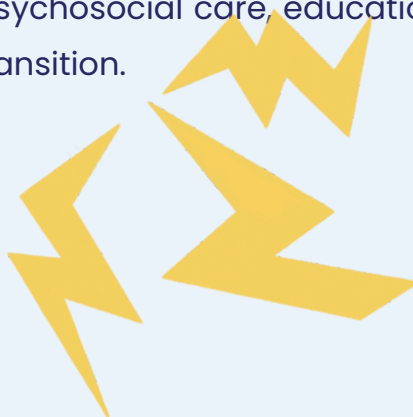
In Europe alone the population of childhood, adolescent and young adult cancer (CAYA) cancer survivors is estimated at 500,000 individuals and is expected to increase by 12,000 each year (van Kalsbeek et al., 2022).

While survival rates have steadily improved thanks to advances in treatment, the journey does not end with remission. Survivors, especially Children, Adolescents and Young Adults (CAYAs), often face lifelong challenges. These challenges are not limited to physical health, but also encompass mental wellbeing, social integration, education, and career development.

Despite their unique needs, many young cancer patients still encounter significant disparities in access to specialised care, particularly in regions outside major urban centres in Western and Northern Europe. These gaps underscore the urgent need for uniform standards of care across the continent to ensure that all young people affected by cancer receive the holistic, person-centred support they deserve.

To address these challenges, the EU-CAYAS-NET project was launched in September 2022 with support from the EU4Health Programme (Grant No. 101056918), as part of Europe's Beating Cancer Plan. The project unites 9 core partners and 28 associated organisations across 18 countries, creating a cross-border alliance of patients, survivors, researchers, healthcare professionals, and policymakers.

EU-CAYAS-NET's mission is to improve the quality of life of CAYA cancer patients and survivors by promoting collaboration, co-creation, and knowledge exchange. Central to this mission are patient-led initiatives that define and promote a higher standard of cancer care across Europe. Key areas of such initiatives include mental health and psychosocial care, education and career, long-term follow-up, and healthcare transition.



## INTRODUCTION

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Cancer's impact does not end when the treatments end. Young people living beyond their illness often face persistent physical late effects, emotional distress, disrupted education and employment, and challenges integrating into adult healthcare systems. These burdens can be especially pronounced during adolescence and early adulthood, which are crucial periods of identity formation, growing independence, and personal development.

Through EU-CAYAS-NET, a European Network of Youth Cancer Survivors and an Interactive Knowledge Centre and Platform is being built dedicated to equity, inclusion, quality of care, and survivorship support. The project alliance aims to ensure that young people not only survive, but thrive; supported by evidence-based practices, strong communities, and person-centred care systems.

To follow the project and explore more, visit: [www.beatcancer.eu](http://www.beatcancer.eu)



## HOW TO USE THIS COLLECTION

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This digital brochure brings together all academic publications, conference presentations, research outputs, and hands-on material generated through the EU-CAYAS-NET project. It serves as a central, evolving resource for researchers, CAYAs with lived experience of cancer, caregivers, and healthcare professionals. It explores the scientific evidence, innovations, and lived experiences shaping the future of cancer and survivorship care for young people.

All project deliverables are organised into eight key thematic areas reflecting the core focus of the project:



1. Project Ambassadors
2. Discord Community & Website
3. Mental Health and Psychosocial Care
4. Education and Career Opportunities
5. Healthcare Transitions
6. Late Effects and Long-Term Follow-Up Care
7. Setting AYA Cancer Care Standards Across Europe
8. Equity, Diversity, and Inclusion

Each thematic area includes a short introduction to the topic, followed by a curated list of related project outputs. Every entry includes a formal title and, where helpful, a lay title to ensure accessibility for both professional and non-specialist readers. The authors and institutions involved are listed to recognise contributors and promote collaboration. Where relevant, a Patient and Public Involvement and Engagement (PPIE) highlight explains how young people with lived experience and their families helped shape the work—an essential element of person-centred research and care.

## HOW TO USE THIS COLLECTION

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Entries are clearly marked with the type of output (e.g. academic article, webinar, guidelines), with direct links for quick access. Each summary also provides the motivation and aims of the work, methodology used, main findings and takeaway points, future directions, as well as key implications for HCPs, CAYAs, and other stakeholders such as policymakers.

This structured, user-friendly format allows readers to quickly understand what was done, why it matters, and how it can be applied to improve care and support across Europe.

**NOTE:** This is a living document and will continue to grow as additional project outputs become available and new publications emerge. Please revisit this brochure regularly for updates, and to use it as a tool for learning, advocacy, collaboration, and change.



Educational Video - [A Milestone in Cancer Advocacy and Research: 34 Months of EU-CAYAS-NET](#)



Final Webinar - Have a look at [34 Months of EU-CAYAS-NET](#), outcomes and next steps!



## HOW TO USE THIS BROCHURE/ COLLECTION

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**To enhance clarity and ease of use, we have incorporated symbols in this brochure. Look out for them throughout the brochure!**



This resource is available in multiple languages. Click the icon to find out!



This resource is a video that can be found on the YouTube channel of European Cancer Survivors Network.



This resource is reading or hands on material that you can directly implement into your daily work!



This resource is a set of pocket cards with practical tips that you can use for your daily work!



This resource is a scientific paper! All scientific publications that have been done under EU-CAYAS-NET are available with free access.



This resource is an interactive map!



The outcomes on Quality of Life are published in a more extensive way in a separate position paper. Click on the icon and find out!



Your call to action: Visit the platform and join the community!



This resource is still a work in progress. Please check back later for updates!

# THEMATIC AREA 1: PROJECT AMBASSADORS

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“They play a key role in raising awareness, engaging in national and international events, and contributing to policy discussions.”

## THEMATIC AREA 1: PROJECT AMBASSADORS

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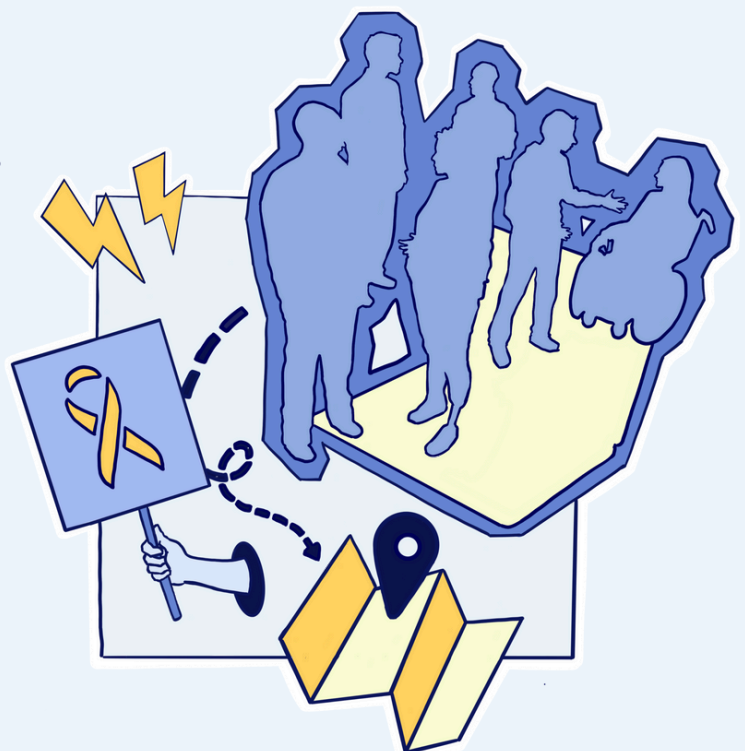
In early 2023, EU-CAYAS-NET launched the Youth Cancer Survivor Ambassador Programme. Ambassadors are young people with lived experience of cancer participating in the network to communicate the project objectives and disseminate the project results to stakeholders in their Member State. They are an integral part of EU-CAYAS-NET and participate in project activities, such as peer visits, guidelines, workshops, focus group discussions. Ambassadors also connect the network with new survivors and other stakeholders to build the community and generally promote the project.

Ambassadors were recruited from within the networks of CCI-E and YCE, as well as from other Beneficiaries and Associated Partners. As of May 2025, a total of 55 youth cancer survivors from 29 European countries have joined EU-CAYAS-NET as official Ambassadors.

EU-CAYAS-NET Ambassadors now serve as national contact points for cancer survivorship, bridging European and national efforts. They play a key role in raising awareness, engaging in national and international events, and contributing to policy discussions. Ambassadors also support survivor communities, including by inviting peers to join the Discord platform (see thematic area 2) and encouraging future Ambassadors to get involved. HCPs and policymakers can connect with this diverse network for future consultations and collaboration.



Find more details about each of our EU-CAYAS-NET Ambassadors [here](#).



## THEMATIC AREA 2: WEBSITE & DISCORD COMMUNITY

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"The Discord community serves as a safe space where young cancer survivors and supporters can connect, share experiences, and find support."



## THEMATIC AREA 2: WEBSITE & DISCORD COMMUNITY

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The EU-CAYAS-NET website serves as a comprehensive hub for information, resources, and guidance for young cancer patients and survivors across Europe. It offers a knowledge centre with curated and structured resources including articles, guidelines, position papers, educational outputs as well as project updates and events relevant for young patients and survivors. Additionally it provides tools to empower young people in their advocacy and self-care journey. The website also highlights best practices and policy developments, making it a valuable resource not only for young people living with and beyond cancer but also for professionals and other stakeholders involved in survivorship care.

**Website:** [www.beatcancer.eu](http://www.beatcancer.eu)

In contrast, the EU-CAYAS-NET community on Discord offers an interactive space for real-time connection and conversations, sharing and support. It offers the option to exchange in topic-specific channels (e.g. mental health, fertility, education, lifestyle) but also to find local connections or support in country specific channels. Community events are held on a regular basis that give the opportunity to connect with others in the video channel. The Discord community serves as a safe space where young cancer survivors and supporters can connect, share experiences, and find support.



Join our [Discord Community](#)!



# **THEMATIC AREA 3: ADDRESSING MENTAL HEALTH AND PSYCHOSOCIAL CARE GAPS**

**“Following the biopsychosocial model, it is vital that mental health care is integrated into routine follow-up care to improve the quality of life for CAYA cancer survivors.”**

### THEMATIC AREA 3:

#### ADDRESSING MENTAL HEALTH AND PSYCHOSOCIAL CARE GAPS

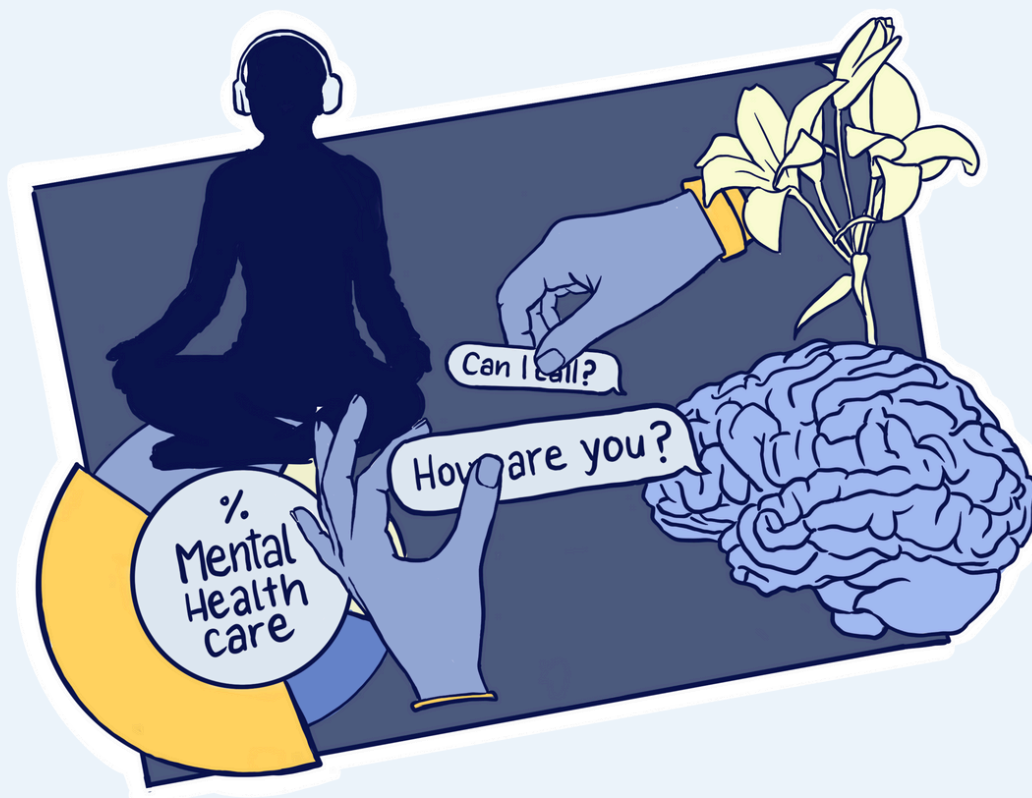
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A cancer diagnosis at a young age – whether in childhood, adolescence, or early adulthood – can have a lifelong impact on the young person as well as their family. Long hospital stays, aggressive treatments, and disruptions to school, work, and social life often lead to lasting emotional and psychological challenges. Many survivors experience anxiety, depression, fatigue, or cognitive difficulties. Unfortunately, these needs are often overlooked or misunderstood, and mental health support is rarely included in routine follow-up care. A major barrier to proper care is the lack of specialised survivorship clinics that offer personalised psychosocial support. Following the biopsychosocial model, it is vital that mental health care is integrated into routine follow-up care to improve the quality of life for CAYA cancer survivors.

Through close collaboration with people living with and beyond cancer, healthcare professionals, and other stakeholders across Europe, a holistic approach was adopted to explore the mental health and psychosocial needs of young cancer survivors.



The outcomes on Quality of Life are published in a more extensive way in a separate position paper. Click on the icon and find out!



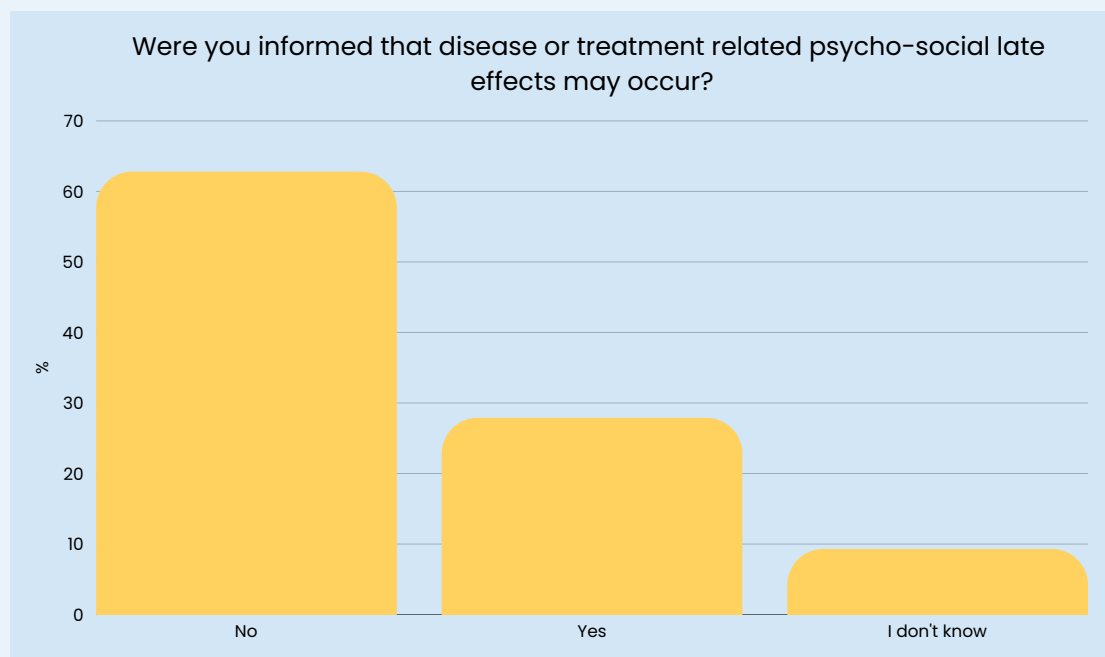
### THEMATIC AREA 3:

#### ADDRESSING MENTAL HEALTH AND PSYCHOSOCIAL CARE GAPS

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##### **Assessing the Current Status and Gaps in Psychosocial Care for CAYA Cancer Survivors across Europe**

The survey among 194 survivors from 24 European countries revealed significant gaps in mental health monitoring and psychosocial support after CAYA cancer.



##### Methodology

A scoping literature review was performed. Additionally, a European-wide online survey of young cancer survivors was conducted and consensus meetings were held to collect both quantitative and qualitative data.

##### PPIE Highlight

In line with the principles of participatory research, the study was conducted in close collaboration with patient experts, patient advocates, and HCPs throughout the entire research process. All stakeholders were actively engaged in each phase, from designing the research tools and collecting data to analysing results, interpreting findings, and planning dissemination. This collaborative approach aimed to ensure that the design, content, and methodology of the needs assessment accurately reflected the diverse perspectives and experiences of those involved.

## THEMATIC AREA 3:

### ADDRESSING MENTAL HEALTH AND PSYCHOSOCIAL CARE GAPS

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#### Main results

Survivors reported unmet needs in areas such as anxiety, fatigue, financial stress, relationships, and neuropsychological challenges. Many felt that psychosocial late effects were not adequately addressed in LTFU care. In particular, they lacked information about the risk of developing these issues and the support services available to them. Common barriers included financial limitations and a shortage of follow-up care providers offering psychosocial support.

Key results from this survey highlight the need for support vs. actual support received on:

- Disease- or treatment related implications on the social dimension:
  - Isolation: 51% needed support – of those only 5.7% received support
  - Increased anxiety, anxiety disorder: 57% needed support – of those only 8.2% received support
  - Fear of cancer recurrence: 54% needed support – of those only 4.9% received support
  - Financial constraints: 52% needed support – of those only 4.1% received support
- Psycho-social burden due to physical late effects from disease or treatment:
  - Fatigue: 52% needed support – of those only 4.1% received support
  - Neuropsychological issues (e.g. memory, attention):
  - 50% needed support – of those only 4.1% received support



The link to the paper can be found here soon!



**THEMATIC AREA 3:****ADDRESSING MENTAL HEALTH AND PSYCHOSOCIAL CARE GAPS**

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**EU-CAYAS-NET Pocket Cards for Mental Health Awareness and Guidance**

The EU-CAYAS-NET pocket card set is designed for young cancer survivors, caregivers, HCPs, educators, and peers. Co-created by survivor representatives and HCPs, the cards ensure inclusivity and relevance. Each card focuses on a key topic, offering psychoeducation, prompts for discussion, and guidance for policy work. The set outlines key issues, needs, recommended actions, and includes referral contacts, definitions of key terms, and a link to the EU-CAYAS-NET Platform for more information. The current set includes nine cards, with the option to expand as needed. The cards are currently available in 13 languages and cover the following topics:

- 10 Key Points on Mental Health
- Talking about Serious Matters
- Do's and Don'ts in communication
- Social Dimension
- Education Support
- Career Support
- Fear and Hope
- Grief and Depression
- My Right to Grieve



Have a look at our [Pocket Cards for Mental Health Awareness and Guidance for Cancer Patients and Beyond!](#)



This resource is also available in [13 other languages!](#)

**THEMATIC AREA 3:****ADDRESSING MENTAL HEALTH AND PSYCHOSOCIAL CARE GAPS**

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**Educational Video on Mental Health in Survivorship**

To raise awareness, an educational video was developed to highlight the importance of prioritizing both mental and physical health during and after cancer treatment. Featuring insights from psychology and social work professionals, the video shares strategies for mental well-being, encourages seeking professional support, and emphasises the role of education and strong social networks in recovery.



[Educational video – Mental Health in Survivorship](#)



This resource is also available in [German!](#)

**Webinar on Mental Health and Psychosocial Care**

The webinar explores strategies for healthy emotional processing, mental health risks, and effective communication with CAYA cancer survivors. Topics include balancing hope and fear, distinguishing grief from depression, available psychosocial support, care gaps, and sensitive communication such as the talk What (Not) to Say to CAYA Cancer Survivors. A panel discussion with patient representatives and healthcare professionals is also featured. The webinar is aimed at survivors, families, professionals, and anyone else interested. It is available to watch on YouTube.



[Webinar – Mental Health & Psychosocial Care](#)



**THEMATIC AREA 3:****ADDRESSING MENTAL HEALTH AND PSYCHOSOCIAL CARE GAPS**

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**Joint Recommendations for Mental Health and Psychosocial Care in CAYA Cancer Survivorship**

A diverse team of CAYA cancer survivors, mental health experts, and HCPs reviewed existing psychosocial care guidelines to assess their relevance and identify key gaps.

Methodology

Existing psychosocial care guidelines and standards, as well as grey literature, were reviewed. For qualitative data, consensus meetings were held with survivors, mental health experts and HCPs. Recent research and survey data were used to develop joint recommendations on psychosocial care in CAYA cancer survivorship.

PPIE Highlight

Young cancer survivors played a central role in shaping the development of these joint recommendations. Through structured involvement in consensus meetings, CAYA cancer survivors shared their lived experiences and highlighted key gaps in existing guidelines. Their insights ensured that the new recommendations reflect real-world needs beyond clinical care. By working alongside HCPs and mental health experts, survivors helped to co-produce recommendations that are age-appropriate, inclusive, and relevant to young cancer patients and survivors.





**THEMATIC AREA 3:****ADDRESSING MENTAL HEALTH AND PSYCHOSOCIAL CARE GAPS**

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Main results

The conclusion of two consensus meetings was that most current guidelines focus primarily on paediatric cases, often overlooking the specific needs of adolescents and young adult survivors. Important topics such as peer support, communication, and fertility preservation were often missing.

Based on this, new, unified European recommendations on psychosocial care in CAYA cancer survivorship were developed.



[Joint Recommendations for Mental Health and Psychosocial Care in CAYA Cancer Survivorship](#)

**Vienna Declaration on Mental Health and Psychosocial Health Needs**

A health policy symposium entitled “Surviving Survival” was held in Vienna, where a declaration was presented and signed by all participating national stakeholders, proposing a set of actions to improve psychosocial health after CAYA cancer.



[EU-CAYAS-NET | Vienna Declaration](#)



This resource is also available in German!



# THEMATIC AREA 4: STRENGTHENING EDUCATION AND CAREER OPPORTUNITIES

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“With more understanding and tailored resources, many of these barriers could be reduced, allowing survivors to rebuild their educational and professional lives with greater confidence and opportunity.”

## THEMATIC AREA 4: STRENGTHENING EDUCATION AND CAREER OPPORTUNITIES

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Cancer and its treatment can significantly disrupt a young person's education and career development. Extended absences from school or work are more common, yet many institutions are not equipped to offer the flexible support that is needed. When options like homeschooling, remote learning, or hospital-based education are unavailable, young patients often fall behind academically and lose important ties with friends, classmates, and teachers.

The effects of treatment can also lead to long-term physical, cognitive, and emotional challenges that make returning to school or work especially difficult. Survivors may face pressure to keep up with peers or feel isolated if they are placed in a different class or need to repeat a year. Some may have to switch educational tracks or rethink their career goals entirely due to limitations caused by the illness or its treatment.

Even after recovery, gaps in education or employment history can make it harder to find and maintain a job. Late effects, such as fatigue or decreased stamina, may require ongoing accommodations or result in reduced ability to work or study full-time. These challenges can force survivors to change career paths or experience workplace discrimination. Often, schools or employers lack awareness of what is possible during and after treatment, and fail to provide the support that could help young cancer survivors succeed. With more understanding and tailored resources, many of these barriers could be reduced, allowing survivors to rebuild their educational and professional lives with greater confidence and opportunity.



The outcomes on Quality of Life are published in a more extensive way in a separate position paper. Click on the icon and find out!

## THEMATIC AREA 4: STRENGTHENING EDUCATION AND CAREER OPPORTUNITIES

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### Digital Information, Awareness and Training Materials on Education and Career Support

#### Educational Video

The video highlights the unique challenges young cancer survivors face, while also showcasing their strengths and the opportunities available for education and career support.



[Educational video – Education and Career Support](#)



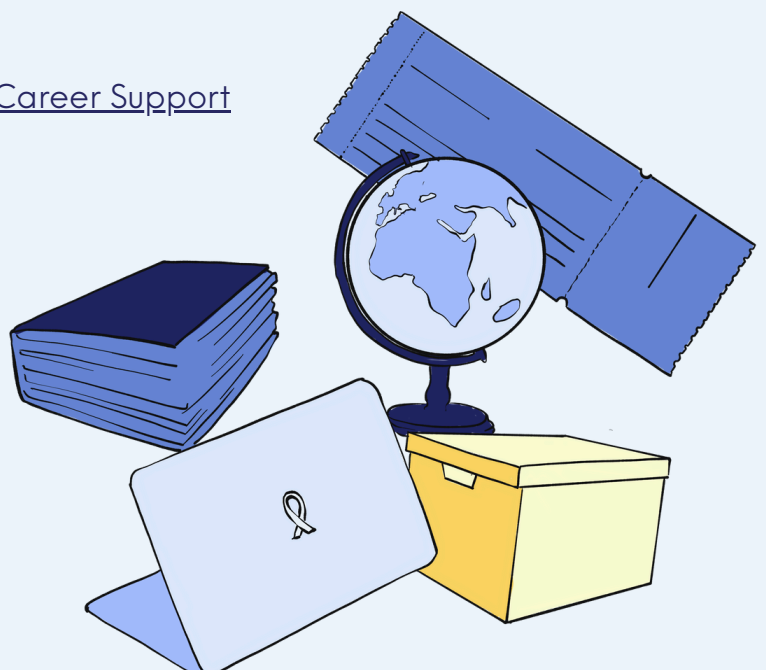
This resource is also available in [German!](#)

#### Webinar on Education and Career Support

The webinar examines barriers to education and career development for young cancer survivors, highlights best practices, and features experiences shared by survivors and healthcare professionals. It also presents preliminary findings from focus group discussions held in Vienna and Utrecht, providing important insights to inform the development of improved career support concepts for CAYA cancer survivors.



[Webinar – Education and Career Support](#)



## THEMATIC AREA 4: STRENGTHENING EDUCATION AND CAREER OPPORTUNITIES

### Map of Best Practices for Education and Career Support

An interactive map on the EU-CAYAS-NET Platform now provides country-specific education and career support materials in local languages. Systematically collected during the project, these resources include brochures, website links, and support programs tailored to the needs of young cancer survivors, as well as their parents and teachers.



Scroll down and explore [Education and Career Materials around Europe](#)



## THEMATIC AREA 4: STRENGTHENING EDUCATION AND CAREER OPPORTUNITIES

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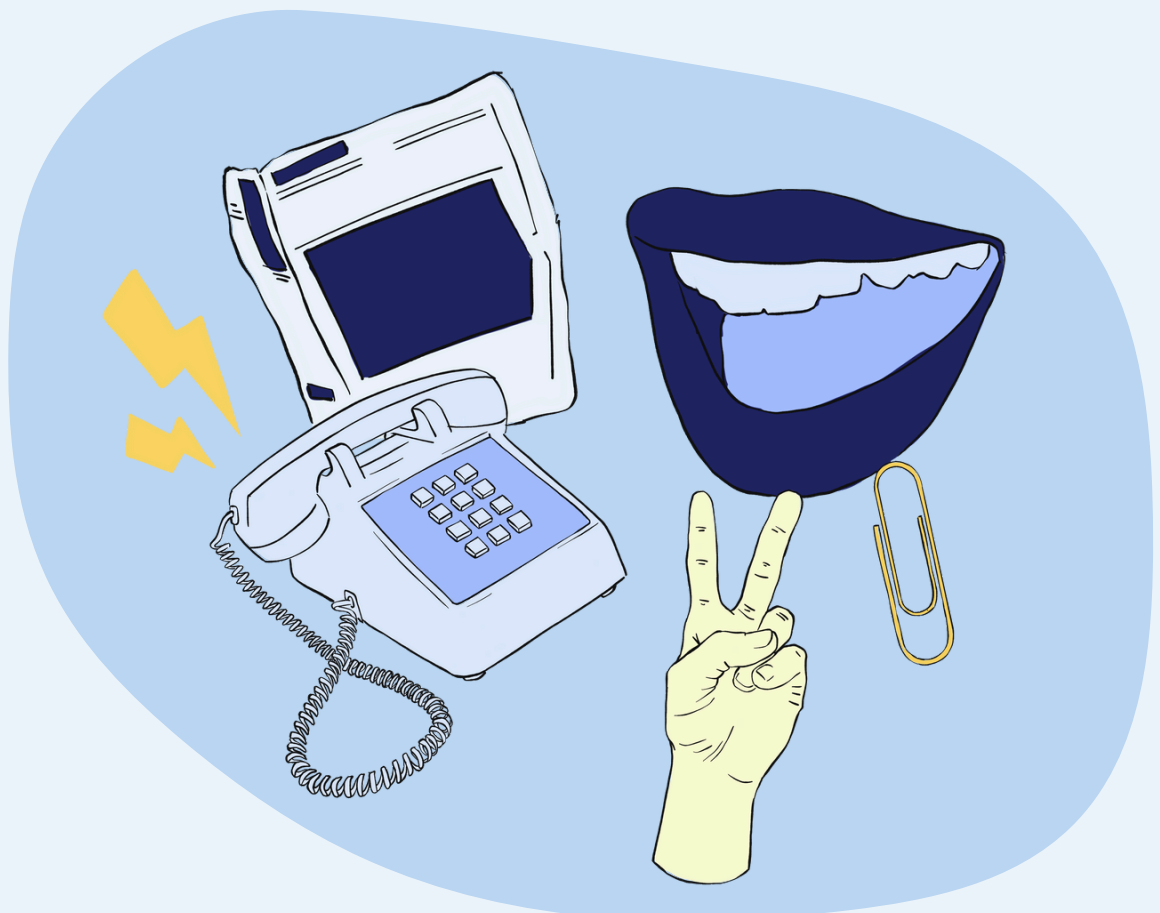
### Train-the-Trainer Curriculum

The Train-the-Trainer Curriculum is a comprehensive manual consisting of nine modules, addressing key topics such as personal strengths and weaknesses, environmental factors, and workplace conditions. Each module clearly defines its objectives, recommended methods, and required materials, while also providing theoretical insights from Train-the-Trainer principles, developmental psychology, and examples of group work activities.

Developed for individuals with prior Train-the-Trainer experience, the manual equips participants to deliver future sessions, ideally in collaboration with patient advocates and healthcare professionals. It is intended for professionals engaged in education and career support, as well as for those aiming to establish new initiatives in this field.



Supporting Educational and Career Pathways for AYA Cancer Survivors with the [Train-the-trainer Manual for Education & Career Support](#).



## THEMATIC AREA 4: STRENGTHENING EDUCATION AND CAREER OPPORTUNITIES

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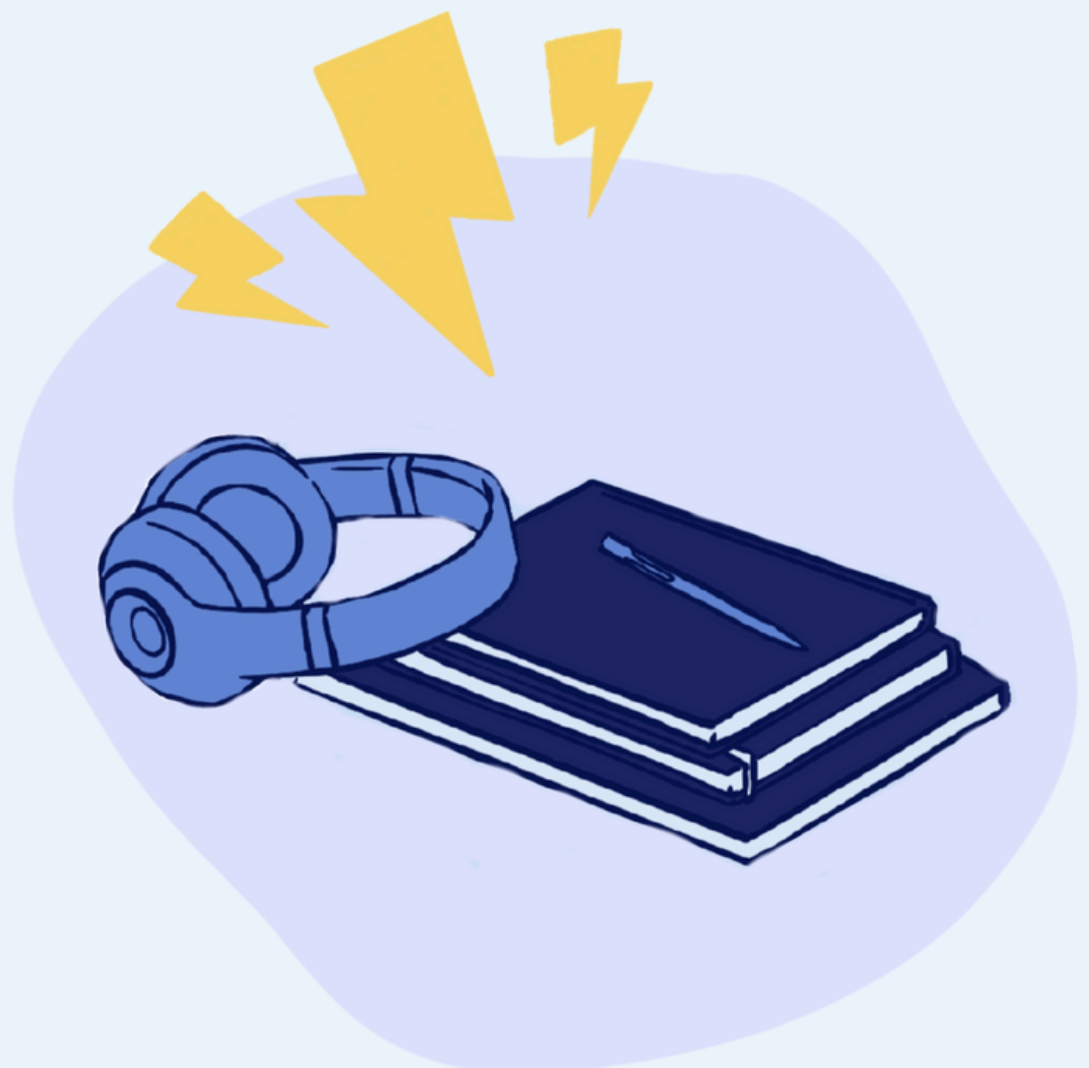
### Career support for young people living with and beyond cancer

Choosing and completing a suitable vocational training program is a significant milestone in the development of AYAs, as is finding a job that aligns with their skills, opportunities, and aspirations. A person's ability to participate in the workforce has a profound impact on their physical, mental, and social well-being.

This report highlights the challenges faced by young people living with and beyond cancer in education and employment. It offers valuable insights, practical interventions, and a call to action to enhance career opportunities and improve their overall quality of life.




#### Career Support Report



# THEMATIC AREA 5: FACILITATING SEAMLESS HEALTHCARE TRANSITIONS

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"A well-designed transition process empowers young survivors to manage their health, supports their development into adulthood, and helps them reach their full potential."



## THEMATIC AREA 5: FACILITATING SEAMLESS HEALTHCARE TRANSITIONS

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Transition in healthcare is defined as *“an active, planned, coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to effectively and harmoniously transfer from child-centred to adult-oriented healthcare systems. The transition of care process should be flexible, developmentally appropriate and consider the medical, psychosocial, educational and vocational needs of survivors, their families and caregivers and promote a healthy lifestyle and self-management”* (PMID: 26735352).

Transition processes are essential, as many survivors require LTFU care due to late effects of treatment or the disease itself. Such late effects include chronic health issues, secondary cancers, psychological challenges, and socioeconomic difficulties. Unfortunately, the lack of formal transition programs leaves many young survivors navigating complex healthcare systems alone, disrupting continuity of care and negatively impacting their quality of life.

This issue is widespread across the European Union, where fragmented care and a lack of dedicated services often make proper transitions impossible. Without structured support, survivors' evolving needs are frequently unmet.

A well-designed transition process empowers young survivors to manage their health, supports their development into adulthood, and helps them reach their full potential. Investing in robust transition programs not only improves individual outcomes but also benefits society by fostering long-term well-being and independence.



The outcomes on Quality of Life are published in a more extensive way in a separate position paper. Click on the icon and find out!

## THEMATIC AREA 5: FACILITATING SEAMLESS HEALTHCARE TRANSITIONS

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### Transition Guideline

The first evidence-based transition guideline for young cancer survivors has been developed, promoting continuity of care from paediatric oncology to adult long-term follow-up services.

Key elements of the transition process: The transition must be patient-centred, with survivors' needs and preferences guiding the process.

Core components include:

- A formal transition policy to structure the process;
- Clear and coordinated transition management;
- Gradual, personalised planning tailored to each survivor;
- An individualised transition plan reflecting specific goals and needs;
- Transfer of care only after the individual has demonstrated readiness for transition, as determined by established criteria.



## THEMATIC AREA 5: FACILITATING SEAMLESS HEALTHCARE TRANSITIONS

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Conditions for a successful transition:

- Educating and involving survivors and their families to navigate the adult care system;
- Training healthcare providers to understand and meet the needs of young survivors;
- Using e-health systems to facilitate seamless communication and data sharing;
- Regularly evaluating transition processes through measurable outcomes;
- Prioritising transition planning in national and EU health policies;
- Engaging institutional leadership and stakeholders for broad policy support;
- Developing accessible transition resources for survivors and families;
- Encouraging visits to best-practice centres to promote knowledge exchange and strengthen transition strategies.



[Visual Summary of Transition Guideline](#)



The visual summary of Transition Guideline is also available in [8 other languages!](#)



A scientific paper on the Transition Guidelines is currently being prepared. Please check back later to find it here.



## THEMATIC AREA 5: FACILITATING SEAMLESS HEALTHCARE TRANSITIONS

### Educational Video about Transition

This video, created for young people affected by cancer, explains the transition from paediatric to adult medical care. It highlights what to expect, important steps to ensure a smooth transition, and how to stay engaged with LTFU care.



[Educational video – Navigating Care Transition](#)

### Webinar to Disseminate Findings and Recommendations to Stakeholders

The webinar shares the same goal as the educational video: to raise awareness among all stakeholders about the transition from paediatric to adult care. It highlights current gaps in the process and discusses strategies for improving support and outcomes for young cancer survivors.



[Webinar – Transition of Care for Childhood, Adolescent and Young Adult Cancer Survivors](#)

### Vilnius Declaration on Transition Needs

A health policy symposium was held in Vilnius, Lithuania, focusing on the transition from paediatric to adult care for young cancer survivors. During the event, a declaration was presented and signed by all participating stakeholders, outlining a series of recommended measures to strengthen and improve the transition process for children and adolescents living with and beyond cancer.



[EU-CAYAS-NET Vilnius Declaration on Transition Needs](#)

### PPIE in Guideline development



A scientific paper about PPIE in Guideline development is in preparation at the moment. Come back later to find it here!

# THEMATIC AREA 6: LATE EFFECTS & LONG-TERM FOLLOW-UP CARE

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“When guided by established clinical recommendations, LTFU care enables early detection and timely management, helping to prevent more serious complications later in life.”

## THEMATIC AREA 6: LATE EFFECTS AND LONG-TERM FOLLOW-UP CARE

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Around 75% of CAYA cancer survivors experience late effects that require LTFU care. These effects vary based on cancer type, stage, and treatment, and can impact not just physical health, but also emotional well-being, cognitive abilities, and participation in daily life.

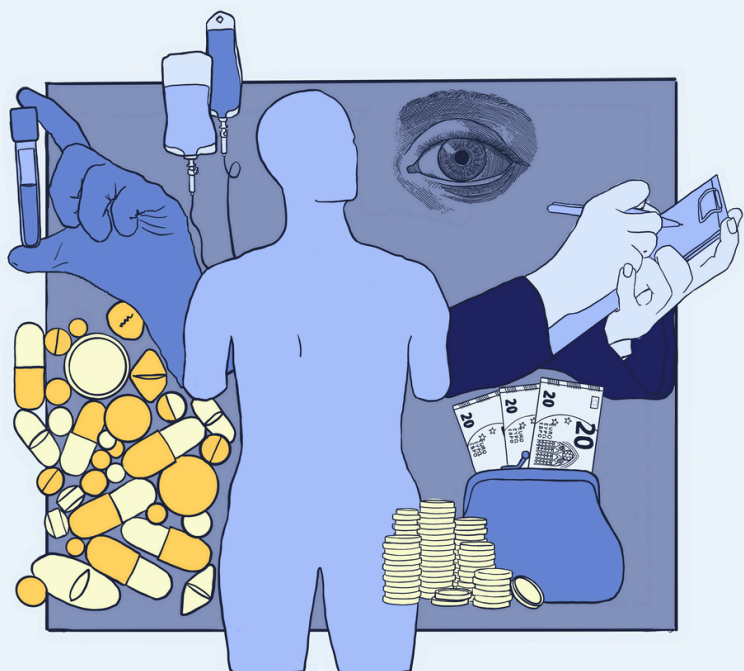
Personalized LTFU care is essential to manage these late effects and improve survivors' quality of life. When guided by established clinical recommendations, LTFU care enables early detection and timely management, helping to prevent more serious complications later in life.

Despite its importance, access to adequate LTFU care remains uneven across Europe, with significant differences between countries. Many survivors fall through the cracks and are "lost to follow-up", missing vital opportunities for monitoring and support.

Closing these gaps requires coordinated efforts to establish consistent, comprehensive LTFU care systems across Europe. Ensuring access to such care is key to improving long-term health outcomes and supporting the well-being of all CAYA cancer survivors.



The outcomes on Quality of Life are published in a more extensive way in a separate position paper. Click on the icon and find out!



## THEMATIC AREA 6: LATE EFFECTS AND LONG-TERM FOLLOW-UP CARE

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### LTFU Care Recommendations

Building on project activities, insights from the International Guideline Harmonization Group (IGHG), previous PanCare projects, and existing care models, a set of recommendations was developed to optimise LTFU care for CAYA cancer survivors across Europe.

Organised into key thematic areas, these recommendations provide a clear framework for establishing and delivering LTFU care that enhances survivors' quality of life.

Key thematic areas:

- Access to Care: Ensuring equitable access to appropriate care for all CAYA cancer survivors;
- Organisation of Care: Defining the structures and processes needed for effective, coordinated care;
- Personalised Care: Emphasising the need for care tailored to the individual needs of each survivor;
- Collaboration, Representation, and Improvement: Promoting international collaboration, survivor representation, and professional training for HCPs;
- Support Systems for Survivors and Families: Highlighting the critical role of strong, accessible support networks for survivors and their families.



Have a look at the [Recommendations for Long-Term Follow-Up Care!](#)

## Thematic area 6: Late Effects and Long-Term Follow-Up Care

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### Roadmap for optimal LTFU

A visual summary outlining the final step of successful cancer treatment is available on the EU-CAYAS-NET Platform in 8 languages. This resource offers an accessible overview of the roadmap and key guidelines for supporting young cancer survivors.



Have a look at the [Roadmap for Optimal Long-Term Follow-Up Care](#)!



The Roadmap for Optimal Long-Term Follow-Up Care is also available in [7 other languages](#)!

### Recommendations on Effective Communication about Late Effects

Through open discussions, survivors shared their preferences for how communication about late effects should be approached. Their insights led to recommendation for HCPs across four key areas:

- Survivor-Centred Care;
- Early Communication and Information Sharing;
- Emotional and Psychosocial Support;
- Respect and Empowerment

These guidelines aim to foster open, compassionate conversations between survivors and healthcare providers, helping ensure better, person-centered follow-up care.



[From Experience to Action: A Guide to Talking with Survivors About Late Effects](#)



## THEMATIC AREA 6: LATE EFFECTS AND LONG-TERM FOLLOW-UP CARE

### Awareness Materials

#### Virtual Map of LTFU Care across Europe

As part of the EU-CAYAS-NET project, an updated virtual map of LTFU care facilities was created based on findings from the LTFU survey. This interactive map offers an up-to-date overview of available services across Europe, helping survivors more easily identify and access the care they need.



View the [Virtual Map of Long-Term Follow-Up Care in Europe!](#)

#### Webinars

Long-Term Survivorship Care – Navigating Fertility and Intimacy Challenges: This webinar showcases tools, strategies, and solutions to improve survivorship care, with a focus on navigating the challenges of fertility and intimacy after cancer treatment. Experts and survivors share insights and personal experiences, offering practical guidance and encouraging open, supportive dialogue.



[Webinar – Long-term Survivorship Care](#)



[Webinar – Long-term Survivorship Care: Navigating Fertility and Intimacy Challenges](#)

#### Educational Video

The educational video titled “Addressing Late Effects in Young Cancer Survivors” highlights the significant challenges faced by survivors of CAYA cancer. Approximately 75% of these survivors experience late effects that can profoundly impact their quality of life. This video shares insights about late effects and what the EU-CAYAS-NET project is doing to change things for the better.



[Educational video – Addressing Late Effects in Young Cancer Survivors](#)

### PLAIN Summaries

To bridge gaps in access to specialised care, 45 PLAIN summaries (Person-Centred, Lay Language, Accessible, International, and Navigable) that are based on existing IGHG and PanCare Guidelines Group recommendations have been enhanced. These user-friendly materials empower survivors to:

- Understand late effects and the recommended surveillance practices.
- Advocate for their care needs when working with non-specialist HCPs.

Updated during the EU-CAYAS-NET project, the PLAIN summaries now feature graphics and info boxes with additional information.



View the [PLAIN Summaries](#)!



The PLAIN Summaries are at the moment also available in 4 other languages! More to come, so stay tuned!



More languages to come, so stay tuned!

### Barcelona declaration on LTFU needs

A health policy symposium was held in Barcelona, focusing on LTFU care for young cancer survivors. During the event, a declaration was issued outlining a series of measures to enhance LTFU care, which was signed by all participating stakeholders.



[EU-CAYAS-NET Declaration of Barcelona on Improving the Long-Term Follow-Up Care for Young Cancer Survivors](#)



The EU-CAYAS-NET Declaration of Barcelona is also available in Spanish!

# THEMATIC AREA 7: SETTING AYA CANCER CARE STANDARDS ACROSS EUROPE

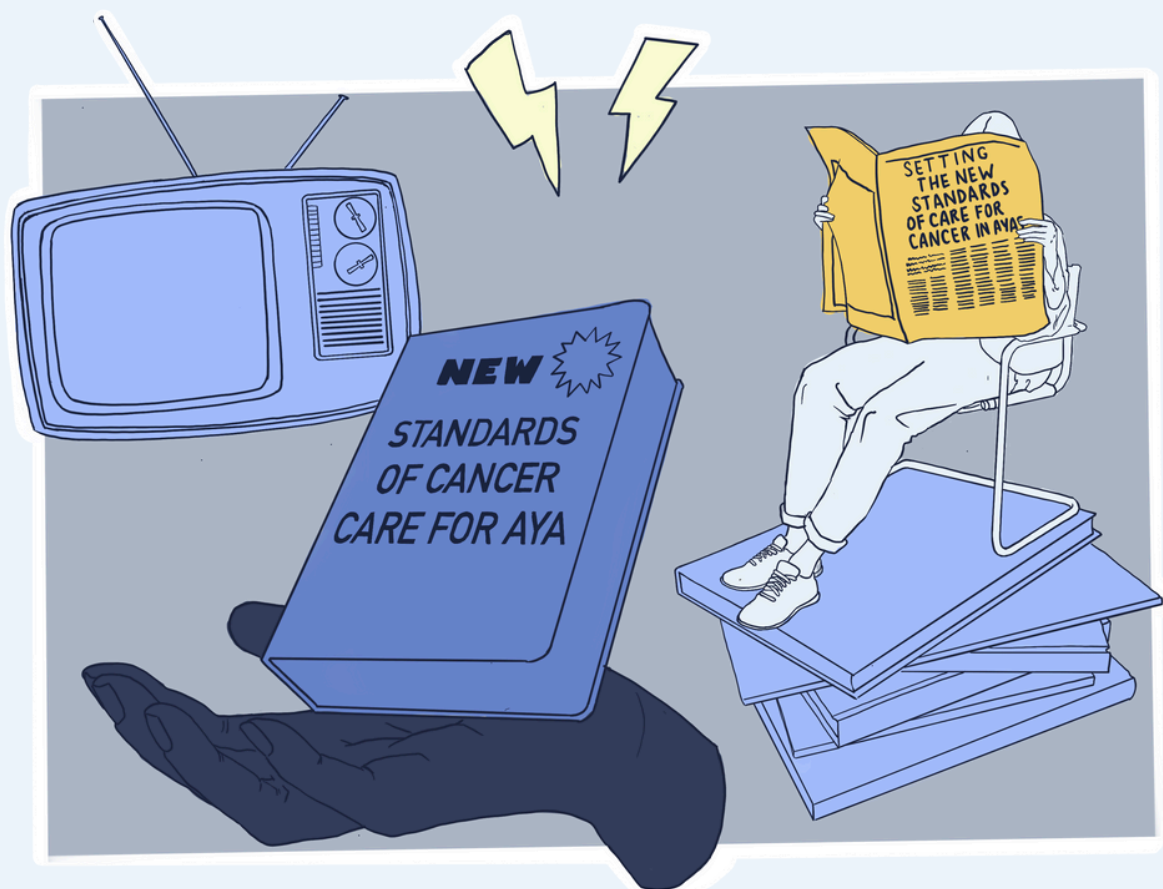
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“Adolescents and young adults (AYA), between the age of 15-39, with cancer often fall into a gap between paediatric and adult oncology services, facing a fragmented and inconsistent care experience across Europe.”

## THEMATIC AREA 7: SETTING AYA CANCER CARE STANDARDS ACROSS EUROPE

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Adolescents and young adults (AYA), between the age of 15–39, with cancer often fall into a gap between paediatric and adult oncology services, facing a fragmented and inconsistent care experience across Europe. Despite growing recognition of their unique developmental, medical, and psychosocial needs, access to specialised AYA care remains highly unequal. In Western and Northern Europe, some progress has been made through the development of dedicated AYA programmes, while many regions in Southern, Eastern, and rural Europe continue to rely on non-specialist services. This disparity results in variable care quality, unmet needs, and poorer outcomes for young people navigating cancer and life after treatment.



## THEMATIC AREA 7: SETTING AYA CANCER CARE STANDARDS ACROSS EUROPE

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### Peer Visits as a Research Method

Youth Cancer Europe hosted the “Peer Visit as Research Method” Training in Brussels, Belgium, in preparation for future observational and participatory research activities in EU-CAYAS-NET.



[View the video about Peer Visits as a Research Method here!](#)

Youth Cancer Europe (YCE) led the work on Adolescent and Young Adult Cancer Care (AYA oncology) in the EU co-funded European Network of Youth Cancer Survivors project, between May and July 2023. For the project, YCE facilitated Peer Visits by 30 young people from 16 countries with lived experience of cancer, visiting a total of 5 hospitals in Italy, Belgium, and the Netherlands.

The primary goal of the Peer Visits was to better understand how care delivery models work, observe best practices, and identify any gaps in the already existing services. The overarching objective was to enhance our understanding of how AYA cancer care can be elevated and transformed across European countries. These valuable insights were meticulously gathered through structured peer observation forms, structured surveys, personal notes, and semi-structured interviews with both local patients and healthcare personnel.



[Read the full report here!](#)



[View the video about the 5 Peer Visits on AYA Care here!](#)

## THEMATIC AREA 7: SETTING AYA CANCER CARE STANDARDS ACROSS EUROPE

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### **Virtual Roundtable: Upscaling AYA Cancer Care: Towards Establishing Minimum Standards of Care for Adolescents and Young Adults (AYA) across Europe**

The virtual roundtable on December 11th, 2023 brought together leading experts and stakeholders under the theme “Upscaling AYA Cancer Care: Towards Establishing Minimum Standards of Care for Adolescents and Young Adults (AYA) Across Europe.” The focus was on addressing the burden of disease in the 15–39 age group and advocating for improved standards of care.



[Report – AYA Roundtable report](#)

### **Minimum Standards of Specialist Adolescent and Young Adult (AYA) Cancer Care Units: Recommendations and Implementation Roadmap**

Adolescents and Young Adults (AYAs) with cancer face unique medical, emotional, and social challenges that require tailored, age-appropriate care. There exist significant disparities in care quality, experience, and outcomes between and even within the countries.

To address these challenges, this paper aimed to outline Minimum Standards for Specialist AYA Cancer Care Units. These standards are designed to provide a clear benchmark for high-quality services and act as a practical roadmap for implementation across diverse healthcare systems.

#### Methodology

Multi-step process involving peer-visits, literature review, qualitative interviews, modified two-part e-Delphi study, and an online roundtable.

## THEMATIC AREA 7: SETTING AYA CANCER CARE STANDARDS ACROSS EUROPE

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### PPIE Highlight

This publication was led and developed with meaningful involvement of over 30 AYAs from across 17 different countries. Their lived experiences and insights guided the study design, data collection and analysis, and were instrumental in shaping the priorities, language, and recommendations presented in this paper.



Learn [here](#) more about the details of PPIE work in this publication.

### Main results

AYAs benefit from multidisciplinary teams (e.g., oncologists, psychologists, social workers) and age-appropriate environments (e.g., peer spaces, Wi-Fi, personalization options).

Mental health support, fertility services, and long-term survivorship care are essential but often under-prioritized outside of AYA-specialty centres.

### Implementation Roadmap & Checklist

Eight actionable recommendations were proposed, including:

- Establishing national knowledge hubs for standardized AYA resources;
- Integrating AYA-specific care across all cancer settings (even without dedicated wards);
- Expanding mental health services and digital health interoperability;
- Advocating for policy changes (e.g., "right to be forgotten" laws, fertility preservation coverage).



[Position paper – AYA Position Paper](#)



The AYA Position Paper is also available in [9 other European languages!](#)

## THEMATIC AREA 7: SETTING AYA CANCER CARE STANDARDS ACROSS EUROPE

Awareness  
Materials

### Specialist Adolescent and Young Adults Units Minimum Standard

This webinar brought together healthcare professionals, AYAs with lived experience, and advocates to address these challenges, offering recommendations for creating inclusive, effective healthcare systems across Europe. The discussions emphasized collaboration, education, and systemic change to empower AYAs to thrive beyond cancer.



[Webinar – Specialist Adolescent and Young Adults Units Minimum Standard](#)

### Educational Video: Setting AYA Cancer Care Standards Across Europe

In this video, we show you how we addressed this question in the EU-CAYAS-NET project. Through the information we gathered, we developed standards for AYA cancer care across Europe.



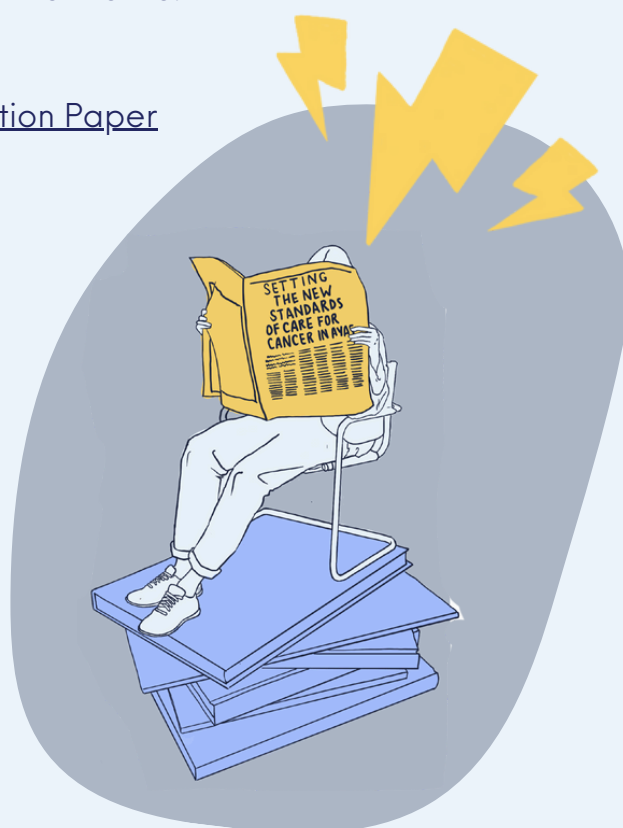
[Educational Video – Setting AYA Cancer Care Standards Across Europe](#)

### Promotional Cards for the AYA Position Paper

These cards were created in order to have accessible and easy-to-read materials to promote the work done under this theme.



[Promotional Cards for the AYA Position Paper](#)





## THEMATIC AREA 8: EQUITY, DIVERSITY & INCLUSION

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“Without deliberate action, the needs of minority CAYAs risk being overlooked in practice, research, and policy.”

## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

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Equity, diversity, and inclusion (EDI) are essential to ensuring that every child, adolescent, and young adult affected by cancer receives care, support, and representation that reflects their unique experiences and identities. Yet, many AYAs from ethnic, sexual, gender, and other underserved or underrepresented groups continue to face barriers, both in accessing adequate healthcare and in participating in advocacy or research. Across Europe, representation in AYA communities and grassroots movements often fails to reflect the full diversity of its population, and healthcare professionals often lack the training and tools needed in order to offer inclusive and culturally sensitive care. Without deliberate action, the needs of minority CAYAs risk being overlooked in practice, research, and policy.



## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

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### Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe

While the right to healthcare is guaranteed under Article 35 of the EU Charter of Fundamental Rights, access to quality cancer care for young people remains uneven across Europe. Many disparities, such as those related to ethnicity, migrant status, gender identity, sexual orientation, or neurodiversity are not fully captured by current European data and evidence, yet they significantly impact treatment outcomes. This position paper presents the outcomes of a collaborative, multi-stakeholder process to identify actionable recommendations that promote greater equity in cancer care.

#### Methodology

A scoping literature review was performed. For data collection, an online survey of HCPs and AYAs, as well as a stakeholder focus group, were used.

#### PPIE Highlight

All aspects of this position paper were led, analysed, and written by young people with lived experience of cancer. The position paper presents three main recommendations for patient organisations, HCPs, and researchers, along with ten targeted actions to address key disparities in cancer care for CAYAs.



[White Paper on Recommendations for Equitable, Diverse and Inclusive Cancer Care in Europe](#)



The White Paper on Recommendations for EDI in Cancer Care is also available in [7 European languages](#).

## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

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### Main results

Launch of the Recommendations at the European Parliament

At an event hosted by MEP Stelios Kypourouopoulos, the EU-CAYAS-NET consortium launched its Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe at the European Parliament.

The webinar brought together authors, speakers, and stakeholders to discuss the challenges faced by marginalised and underserved groups such as Roma, LGBTQ+ individuals, immigrants, and other vulnerable populations, in accessing fair and inclusive cancer care.

- a. AYA survey showed: 41% of AYAs do not feel represented by booklets and other information provided to them by the healthcare facilities.
- b. HCP Survey showed: 90% believe it is the responsibility of the healthcare setting to provide support to both patients and HCPs.

Developed by a diverse working group led by young people living with and beyond cancer, our recommendations focus on four key areas to promote fairness and inclusivity in cancer care:

#### *Race, Ethnicity, Culture, Refugee or Migrant Status*

- Tackle disparities in access and outcomes for racially, ethnically, and culturally diverse populations, including refugees and migrants.

#### *Gender Identity and Sexual Orientation*

- Ensure LGBTQ+ individuals receive inclusive, respectful care tailored to their identity and experiences.

#### *Age, Development & Mental Wellbeing*

- Recognise age, mental health, and neurodiversity as essential factors in delivering appropriate care for CAYAs.

#### *Education, Career & Socioeconomic Status*

- Reduce barriers linked to education, employment, and financial hardship to ensure equitable access to quality cancer care for all.

## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

	Strengthening EDI in research: improving patient data collection and enhancing research team diversity	Improving EDI in cancer services: providing culturally sensitive care and promoting diverse representation in care teams		Fostering diversity and inclusion within patient organisations
Focus areas	Data and monitoring	Representation and advocacy	Services and accessibility	Knowledge and education
Race, ethnicity, culture, refugees, and migrants	Integrate ethnicity and migration experiences into cancer research and data monitoring	Embed diverse community representation in decision making  Improve public health messaging for diverse populations	Provide interpreters and translate public health messaging  Provide culturally informed services	Provide cultural humility training for healthcare providers
Gender identity & sexual orientation	Encourage and support LGBTIQ+ research	Increase visibility and awareness  Include sex, gender, and sexual orientation in health strategies	Provide comprehensive psychosocial support  Design tailored interventions for reproductive and sexual health	Provide awareness and support strategies for gender, sexuality, fertility and family support
Age, physical and mental wellbeing	Implement psychosocial cancer care for all ages and all types of cancer  Promote research on visible and invisible disabilities	Include young people in health decisions and co-create holistic care models  Address negative bias in public health messaging	Create accessibility policies and audits to support people with disabilities  Offer prehabilitation and rehabilitation	Co-produce training for age-appropriate communication with people with and beyond cancer
Education, career, and socioeconomic status (SES)	Create a taskforce within the EU Commission to monitor the education and employment rights of young cancer survivors	Legislate for inclusive employment policies for people living with and beyond cancer  Co-create programmes to support patients and families facing financial difficulties and/or educational challenges	Expand health insurance coverage for young adults without stable jobs  Promote best practices in cancer care to overcome geographic disparities	Educate patients and family about their employment rights and opportunities  Improve public health messaging in rural and low SES populations

## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

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### **Equity, Diversity, and Inclusion in Cancer Care Webinar**

YCE hosted a webinar exploring the current landscape and future of EDI in cancer care across Europe. The event gathered researchers, HCPs, patient advocates, and members of the public for a discussion on how to build a more inclusive and equitable cancer care system for all.

The webinar brought together authors, speakers, and stakeholders to discuss the challenges faced by marginalised and underserved groups such as Roma, LGBTQ+ individuals, immigrants, and other vulnerable populations, in accessing fair and inclusive cancer care.



[Webinar – Equity, Diversity and Inclusion in Cancer Care](#)

### **Educational Video: Equity, Diversity, and Inclusion in Cancer Care**

This video explores how we promoted equity, diversity, and inclusion (EDI) in EU-CAYAS-NET, and explains specific recommendations and focus areas that arose through the project.



[Educational Video – Equity, Diversity and Inclusion](#)

### **“Equity, Diversity, and Inclusion Principles in Cancer Care” Training Sessions and Train-the-Trainer Toolkit**

This toolkit was developed in response to the clear need for greater awareness and skills around EDI in youth cancer care. It offers practical tools and insights to help healthcare professionals, researchers, and advocates deliver more inclusive, personalised, and equitable care for all young people affected by cancer.



Have a look at our [Train-the-Trainer EDI Toolkit!](#)



The toolkit for EDI in Cancer Care is also available in [7 European languages](#).

## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

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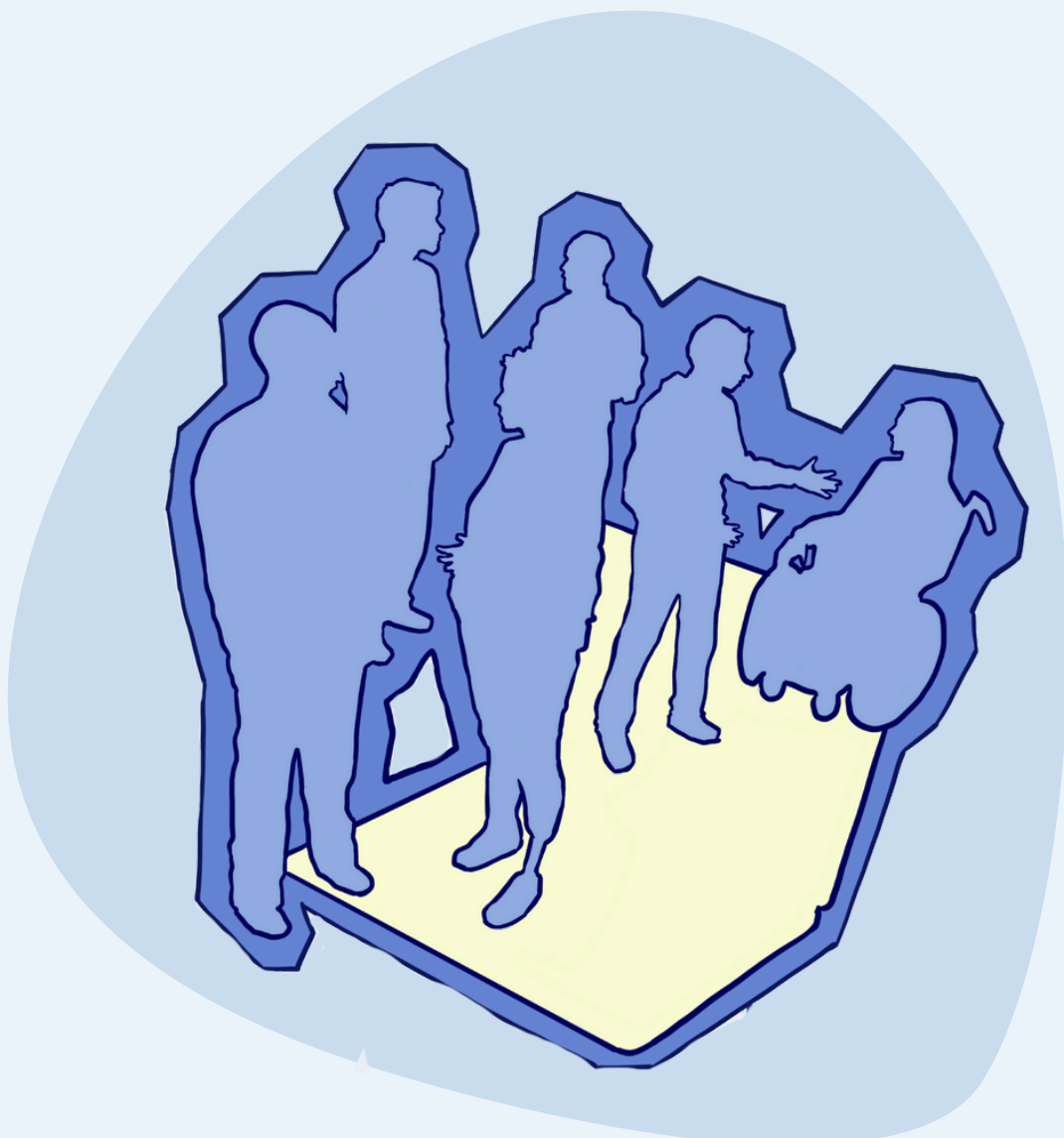
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[Webinar – Equity, Diversity and Inclusion in Cancer Care](#)



## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

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### Equity, Diversity, and Inclusion Webinar Series

As part of the project's commitment to advancing EDI in cancer care, YCE hosted a series of webinars. These sessions aimed to spotlight the voices and experiences of underrepresented groups, explore the systemic barriers they face, and spark dialogue on how to create more inclusive, equitable healthcare systems for all young people affected by cancer.

Several webinars delved into the lived realities of neurodiverse individuals navigating cancer care, the unique needs and challenges within cancer care and LGBTQI+, neurodiversity, migrant status, and socioeconomic status. Moreover, the webinars explored how access to diagnosis, treatment, and support can be shaped. With contributions from experts, advocates, and AYAs with lived experience, each session combined personal narratives with data-driven insights to inform practical steps toward patient-centred, inclusive care.



[Webinar – Neurodiversity and cancer](#)



[Webinar – Inclusivity, Barriers, and Best Practices in LGBTQI+ Cancer Care](#)



[Webinar – When Circumstances Decide: Socioeconomic Status and Cancer Inequalities in Europe](#)



[Webinar – Migration and Cancer](#)



## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

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### **Inclusivity Training for 100 Romanian People**

YCE hosted an inclusivity training in Romanian for 100 Romanian people living with and beyond cancer including Roma community members (and other historical ethnic minorities) in Timisoara, Romania. The aim of the training was to disseminate the local language translation of the Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe and the “Equity, Diversity and Inclusion Principles in Cancer Care” Training sessions and Train-the-Trainer Toolkit.

### **High-Level Inclusivity Roundtable in Moldova**

The High Level Inclusivity Roundtable was delivered at the Moldovan Parliament in Chişinău with Members of Parliament, health authorities, and YCE. During the Roundtable, the work in European cancer care policy, patient advocacy, and legislative initiatives by EU-CAYAS-NET was introduced, focusing on the inclusivity policy recommendations developed. In the context of its EU accession process, the event also aimed to explore potential areas where Moldova can align with European best practices. , European opportunities for Moldova were discussed, including participation in EU-funded programmes (EU4Health, Horizon Europe). Another aim was to reflect on Moldova’s healthcare priorities and explore possible collaboration in addressing existing challenges.



## THEMATIC AREA 8: EQUITY, DIVERSITY, AND INCLUSION

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### The Equity, Diversity & Inclusion in Cancer Care Stakeholder Forum in Brussels

YCE hosted the Equity, Diversity & Inclusion in Cancer Care Stakeholder Forum at (Re)space Skyline Europa in Brussels, Belgium. This event was designed as a key meeting point for those actively driving change in EDI across European cancer care, focusing on socioeconomic status, migrant and refugee populations, and people living with disability and neurodiversity within cancer care. The Forum included the participation of 15 EU-funded projects and 26 European and international organisations. The event highlighted cancer care projects focused on prevention, understanding, and quality of life, especially for vulnerable groups. Emphasis was placed on stakeholder collaboration, citizen engagement, and outreach efforts like the European Health Forum and a pilot roadshow to involve communities.



# CONCLUSIONS & GOING FORWARD

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“By actively involving survivors, HCPs, researchers, and policy makers, the project has highlighted the need for systemic change in key areas such as mental health and psychosocial care, education and career support, transition, LTFU care, AYA care, and EDI.”

## CONCLUSIONS & GOING FORWARD

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The EU-CAYAS-NET project has marked a significant milestone in redefining cancer survivorship care for CAYAs across Europe. Through its participatory, patient-led approach, the project has produced a comprehensive set of standards, tools, and policy recommendations. The project aimed at improving not only survival, but quality of life, long-term health outcomes, and social participation for young people living with and beyond cancer. By actively involving survivors, HCPs, researchers, and policy makers, the project has highlighted the need for systemic change in key areas such as mental health and psychosocial care, education and career support, transition, LTFU care, AYA care, and EDI.

Despite these efforts, many challenges remain that require further action on the national and European levels. Disparities in access to specialised services persist, particularly in under-resourced regions. There is an ongoing need to strengthen LTFU systems, develop robust healthcare transition pathways, provide specialized AYA care, and embed mental health and psychosocial support into routine care.

### Implications for stakeholders

Moving forward, **healthcare providers** are encouraged to adopt and implement the developed care standards and guidelines, ensuring that all CAYA cancer patients and survivors receive developmentally appropriate, multidisciplinary, and continuous care. There is a need for more training and awareness among medical teams to support transition, identify late effects early, and provide culturally competent and inclusive care environments.

**Patient organisations** must continue to serve as key facilitators of peer support, advocacy, and co-creation. To advance the quality of cancer care, they play an essential role in amplifying the voices of survivors and ensuring that lived experience influences healthcare services and research priorities.

## CONCLUSIONS & GOING FORWARD

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**Researchers** are urged to design inclusive, survivor-informed studies that reflect the diversity of the young cancer community. Collaborative research frameworks that include patient and public involvement and engagement (PPIE) must become the norm rather than the exception.

For **policymakers and funders**, the EU-CAYAS-NET project has produced actionable policy tools such as declarations, recommendations, and implementation roadmaps that can directly inform national cancer plans. Inclusion of CAYA cancer patients and survivors in key decision-making processes is crucial to ensure that CAYA cancer patients and survivors receive the healthcare they need and deserve.



# ABOUT EU-CAYAS-NET

EU-CAYAS-NET is a project, co-funded by the European Commission, which unites leading organisations from 18 countries active in the childhood and youth cancer field to map the existing resources that are helpful to young cancer patients, survivors, and their caregivers, to create new European guidelines and empower cancer survivors to advocate for their rights and needs



[beatcancer.eu](https://beatcancer.eu)



@youthcancersurvivors



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