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

# Optimizing Quality of Life after Youth Cancer*

Actionable recommendations from the EU-CAYAS-NET Project, addressing mental health, education & career support, transition and follow-up care gaps across Europe.

*Deliverable 3.5 of the EU-CAYAS-NET project: Position Paper on Mental Health & Psychosocial Care, Transition and Long-Term Follow-Up Needs during CAYA Cancer Survivorship – Standard, not luxury

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European Network of
YOUTH CANCER SURVIVORS

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Vienna, 2025

🂠 Pocket Cards
📄 Reading Material
📍 Interactive Maps
👁 Visual summary
▶ Videos

# Content

# 1. Foreword

**Despite increasing recognition of the importance of mental health and psychosocial wellbeing across ages and population over the past years, the quality of life of childhood, adolescent, and young adult cancer survivors remains an underappreciated aspect of cancer care across health care systems. Thanks to advancements in treatment, survival rates have significantly improved over the past decades. However, survivorship comes with its own set of challenges that require our urgent attention.**

**CARINA SCHNEIDER**
*Managing Director of CCI – Europe*
and patient advocate on behalf of the EU-CAYAS-NET Quality-of-Life Work Package Partners

Cancer's impact extends far beyond the period of active treatment. Survivors often face a lifetime of physical, emotional, and social challenges, ranging from mental health struggles and educational setbacks to difficulties transitioning into adult healthcare systems and achieving long-term physical and emotional/psychosocial wellbeing. These issues are particularly pressing for young survivors, whose developmental milestones are profoundly disrupted by cancer.

With the EU-CAYAS-NET Project we aim to close these gaps by fostering collaboration and co-creation between patient advocates, researchers and health care providers across Europe to implement evidence-based practices, improve follow-up care, and address unmet needs in mental health and education. Through collective effort and innovation, we strive to ensure that young cancer survivors not only live but thrive — equipped with the resources, care, and support they need to lead fulfilling lives.

I am deeply grateful to the project partners, researchers, healthcare professionals, and patient advocates who are uniting in this mission. Together, we are redefining survivorship, prioritizing quality of life, and building a future where every young cancer survivor can achieve their full potential.

# 2. Executive Summary

# Optimising Quality of Life After Youth Cancer

**The EU-CAYAS-NET project highlights the critical need for lifelong, person-centred support to address the physical, psychological, and social challenges faced by childhood, adolescent and young adult (CAYA) cancer survivors. Tailored approaches to mental health, education, career development, transition and long-term follow-up care are needed for survivors to thrive and reach the best possible quality of life after cancer.**

## Mental Health & Psychosocial Care

Receiving a cancer diagnosis at a young age is highly burdening and can cause a lot of distress for young people, as well as for their families and caregivers. It must be acknowledged that psychosocial well-being has a major impact on the health-related quality of life of survivors. Therefore, mental health and psychosocial support must be implemented for CAYA cancer survivors as routine, regardless of their background or income.

## Project Outcomes Addressing Mental Health & Psychosocial Care Gaps

- We developed a unified, European, evidence-based standard[1] for mental health and psychosocial follow-up care through collaborative efforts, ensuring survivors' needs will be met consistently across Europe.
- We produced a set of resources, like a **Pocket Card Set** and educational videos, providing practical tools to improve awareness, dialogue, and care delivery.

## The way forward

- Psychosocial follow-up care must be included in National Cancer Control Plans as a core component of person-centred, lifelong care.
- Treatment centres should integrate psychosocial care into lifelong follow-up programs for comprehensive cancer survivor support.
- All stakeholders involved (patient advocates, healthcare professionals, policy makers and regulatory bodies) need to advocate for national implementation of a European, evidence-based standard for psychosocial follow-up care.

## Education & Career Support

CAYA cancer survivors often face difficulties finding employment due to gaps in education or work history caused by their disease and treatment. These challenges can lead to frequent setbacks, career changes, and potential discrimination compared to individuals without a cancer history.

## Project Outcomes

### Strengthening Education & Career Opportunities

- We developed an **interactive map** and digital, specifically tailored training materials, to address barriers in education and employment.

- We created a **Train-the-Trainer curriculum** to equip educators and professionals to provide effective support and minimise the disruptive impact of cancer on education and vocation.

## The way forward

- National educational systems together with treatment centres should provide support during the entire course of education/training where needed. This requires a mention in national education plans.
- All involved stakeholders should enable easy access to information on all legal and practical support options.
- Treatment centres should provide and train dedicated professionals in long-term follow-up (LTFU) care, ensuring they have the required knowledge, skills and time to effectively coordinate communication between young person/family, school/workplace, healthcare team and support providers.

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[1] Standard published at the end of project (June 2025) and available for download under https://beatcancer.eu/resources/quality-of-life/article/quality-of-life-project-outputs/

## Transition

The transition process from child-oriented to adult-oriented care demands greater attention to ensure that CAYA cancer survivors receive comprehensive, long-term follow-up care.

## Project Outcomes Facilitating Seamless Healthcare Transitions

— We developed the first evidence-based transition guideline for young cancer survivors (**visual summary**). If implemented, it will ensure continuity of care from pediatric oncology to adult long-term follow-up services.

— We conducted several Peer Visits and workshops which identified best practices and provided valuable insights on how to improve transitional care systems.

## The way forward

— All involved stakeholders[2] should promote the inclusion of transition-related topics as a priority in national and EU health policies.

— Institutional leadership should ensure policy alignment and widespread support for the developed transition guideline.

— All involved stakeholders[2] should promote the development and use of transition materials for survivors and families, including a transition plan and easy-to-understand resources in various formats.

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[2] Patient advocates, healthcare professionals, policy makers and regulatory bodies

## Late Effects & Long-Term Follow-Up Care (LFTU)

Tailored LTFU care is crucial to mitigate the burden of late effects and their impact on survivors' quality of life. Guideline-based LTFU care enables early detection and management of late effects, reducing their long-term consequences.

## Project Outcomes on Follow-Up (LTFU) Care

- Surveys and workshops revealed critical gaps in LTFU care, emphasizing the need for accessible, multidisciplinary services.
- Specifically developed **recommendations** and a **visual summary** offer actionable steps for implementing effective LTFU care across Europe.
- **PLAIN** (**P**erson-Centred, **L**ay Language, **A**ccessible, **I**nternational, and **N**avigable) language summaries equip survivors with accessible information about late effects and recommended LTFU care.
- A **virtual map** of LTFU care facilities provides an up-to-date overview about available services across Europe and helps facilitate accessibility for survivors.

## The way forward

- All involved stakeholder groups need to continue advocating for the integration of evidence-based LTFU care into National Cancer Control plans.
- Treatment centres should provide survivorship care services to ensure personalised, proactive support covering all aspects of life of survivors and allow survivors to manage their own needs for care.
- University hospitals and professional societies should invest in specialist training and multidisciplinary care to ensure state-of-the art care for survivors.
- All involved stakeholders[3] should foster continuous international collaboration between healthcare, research, policy makers and survivors for ongoing improvements of LTFU care plans.

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[3] Patient advocates, healthcare professionals, policy makers and regulatory bodies

# 3. Introduction & Background

In recent decades, significant advancements in medical science have dramatically improved survival rates for children, adolescents, and young adults (CAYA) with cancer in Europe. Survival rates have risen from a mere 20% to approximately 80%, although these rates vary by cancer type and geographic location, with notable discrepancies between Western and Eastern European countries. It is estimated that more than 500,000 people with a history of childhood cancer are currently living in Europe (PMID: 24706509). Each individual faces unique challenges, including the potential long-term effects of cancer and its treatment.

EU-CAYAS-NET is a project led by patient organisations, supported by the European Union's EU4Health program (Grant Agreement number 101056918) that integrates the work of patient advocates, researchers and health care providers to establish a Europe-wide network, aiming to improve the quality of life of survivors and the care for AYA cancer patients.

## Factors impacting Quality of Life

Up to 75% of CAYA cancer survivors experience long-term effects related to cancer and its treatment, necessitating lifelong follow-up care (PMID: 34462344). Even those without apparent long-term effects require monitoring for early detection of late effects, and therefore should receive long-term follow-up (LTFU) care.

The quality of life for CAYA cancer survivors is multifaceted, encompassing physical, emotional, and social well-being. Despite the significant progress in survival rates, many survivors face enduring challenges, such as chronic health issues, psychological stress and difficulties in education and career development. The transition from paediatric to adult healthcare can also be daunting, requiring continuous support and tailored long-term follow-up care to address late effects and promote holistic recovery. Ensuring a high quality of life for CAYA cancer survivors involves addressing these diverse needs comprehensively.

As part of the EU-CAYAS-NET project, survivors and caregivers together identified the key themes in an unprecedented approach, which later formed the basis of EU-CAYAS-NET's work on quality of life:

- **Mental health and psychosocial care**
- the importance of **education and career support**
- the challenges of **transitioning** from child-centred to adult-oriented healthcare systems, and
- the critical role of **LTFU** in maintaining overall well-being.

This White Paper explores the various dimensions of the quality of life after cancer. Moreover, we underscore the need for targeted interventions on quality-of-life issues, aiming to inform policymakers, healthcare providers, and stakeholders about the multifaceted nature of survivorship and the essential measures needed to enhance the quality of life for CAYA survivors across Europe.

# 4. Approach & results

# 4.1 Impact Area 1: **Addressing Mental Health & Psychosocial Care Gaps**

Receiving a cancer diagnosis at a young age, whether as a child, adolescent or young adult, is highly burdening and can cause a lot of distress for young people, as well as for their families and caregivers. Various emotional and/or social problems can occur throughout the lifespan, arising from long-lasting and toxic treatments with many hospital stays, from being confronted with a life-threatening disease, disruptions to social life, education or professional life, and a high probability of developing physical late-effects. Cancer related anxiety, depression, fatigue or neuropsychological issues are only some of the psychosocial challenges that are commonly encountered by survivors and require specialised support.

For CAYA cancer survivors, mental health and psychosocial challenges are often inadequately addressed, either by being underestimated or overlooked, or by misinterpreting appropriate emotional responses as pathological.

A key factor contributing to the insufficient psychosocial support is the lack of specialised survivorship clinics that provide personalised psychosocial follow-up care.

Considering the biopsychosocial treatment model (PMID: 847460, PMID: 7369396, PMID: 20669419), it is essential to take into account the distinct mental health requirements of CAYA cancer survivors and how these affect their quality of life. Therefore, mental health and psychosocial support must be provided as routine care and adequately funded by health care systems.

## 4.1.1 How We Addressed the Challenges

### Development of awareness material

Through extensive collaboration with all stakeholders, a holistic approach was employed to identify best practices and understand the unique needs of young cancer survivors regarding mental health and psychosocial care. Common late effects were described based on current literature, awareness materials, and crucially, peer experiences. Multiple online consensus meetings with survivor representatives and healthcare professionals across Europe ensured the selected topics reflected real-life challenges. Insights from these discussions guided content development, which was then reviewed by the consensus group.

## Identification of gaps in psychosocial care for CAYA cancer survivors across Europe

An online survey of CAYA cancer survivors assessed the current state and gaps in LTFU care with a focus on mental health support and psychosocial care. Research objectives were shaped by survivor representatives in an online consensus meeting, supported by current literature and psychosocial care guidelines. Following a pilot phase, the finalized survey featured 41 questions addressing personal experiences, needs, and aspirations for psychosocial follow-up care across psychological, social, and physical dimensions. The survey was made available online in 13 languages.

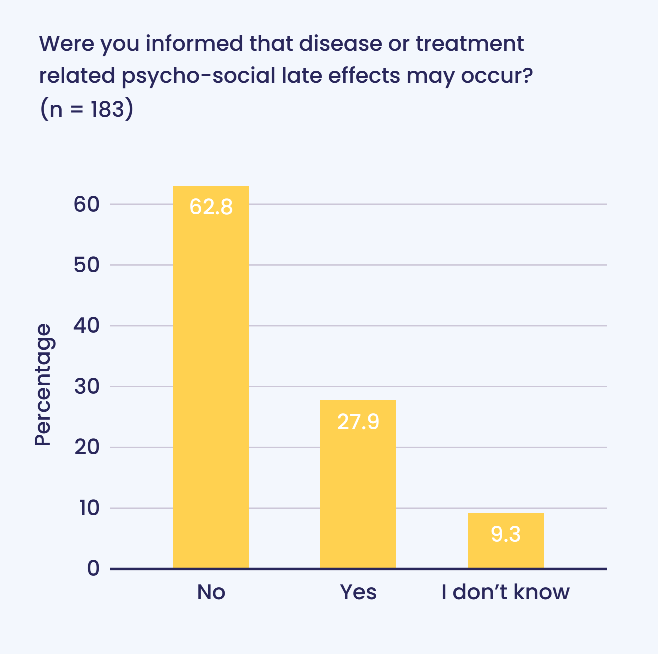
## Joint standard of mental health and psychosocial care

A workgroup of CAYA cancer survivor representatives and healthcare professionals reviewed existing psychosocial care guidelines and standards. During two consensus meetings, the relevance of each standard was evaluated, gaps were identified, and changes proposed. Drawing on these discussions, recent scientific literature and survey findings, the group developed a unified standard for psychosocial care in CAYA cancer survivorship.

## 4.1.2 Major Outcomes

### 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 (Figure 1).



Were you informed that disease or treatment related psycho-social late effects may occur? (n = 183)

Survivors highlighted unmet needs in areas like anxiety, fatigue, finances, relationships, and neuropsychological issues, alongside insufficient attention to psychosocial late effects in LTFU care and especially a lack of information about the risk of developing psychosocial late effects and about existing psychosocial support options. Common barriers included financial constraints and limited availability of follow-up care institutions 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

## Awareness Materials

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

The EU-CAYAS-NET Pocket Card set is aimed at young cancer survivors, carers, HCPs, educators, and peers. Teams of healthcare professionals and survivor representatives jointly authored and designed the final pocket cards, fostering inclusivity and relevance. Designed for psychoeducation, dialogue, and policy work, each card addresses a key topic, outlining the issue, needs, actions, and recommendations. Cards include key points, a contact field for specialist referrals, explanations of terms, and a link to the EU-CAYAS-NET Platform for further details.

The Pocket Card set currently comprises nine cards with the flexibility to expand as needed:

- 10 Key Points on Mental Health
- Talking about serious matters
- Do's and Don'ts in communication
- Social dimension
- Education support
- Career support
- Neuropsychology
- Fear and Hope
- Grief and Depression
- My right to grieve

### Educational Video on Mental Health in Survivorship

To enhance awareness, an educational video was created, emphasizing the importance of prioritising mental and physical health during and after cancer treatment. Featuring tips from psychology and social work experts, the video offers strategies for mental well-being, highlights the value of professional help, and underscores the role of education and supportive social networks in recovery.

### Webinar on Mental Health & Psychosocial Care

The webinar explores healthy processing strategies, risks to mental health, and communication with CAYA cancer survivors. Topics include the balance between hope and fear, grief vs. depression, psychosocial support options, care gaps, and sensitive communication, for example with a talk about What (Not) to Say to CAYA Cancer Survivors. The session also features a panel discussion involving patient representatives and HCPs. Open to survivors, families, HCPs, and anyone interested in the topic, the webinar recording is available on YouTube.

### Joint standard of mental health and psychosocial care

A diverse workgroup of CAYA cancer survivors, mental health experts, and healthcare professionals thoroughly reviewed existing psychosocial care guidelines. During two consensus meetings, they evaluated the relevance of current standards, identified gaps, and proposed necessary changes. By going through existing standards and guidelines for psychosocial care together with discussions in the consensus group it was recognised that most guidelines are focused on paediatric patients and survivors and do not take adolescent and young adult patients and survivors into account. Additionally, there were also important topics for the CAYA cancer population missing, for example: **communication, peer support, fertility preservation** and **communication about fertility**. Incorporating recent scientific literature and survey results, the group developed a unified standard for psychosocial care in CAYA cancer survivorship. This European standard will be published on www.beatcancer.eu upon project completion (June 2025).

### Vienna Declaration on mental 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:

## 4.1.3 The way forward

Through EU-CAYAS-NET, we identified key challenges, barriers, and facilitators affecting psychosocial care access and delivery. Using a collaborative, multi-stakeholder approach co-led by patient advocates and healthcare professionals, we created practical, accessible resources tailored to young cancer survivors, to be shared via the network platform.

Building on our findings, we call for implementation of the following policy actions set to address critical gaps in psychosocial care, ensuring equitable, tailored support for young cancer survivors across Europe:

- Psychosocial follow-up care must be included in National Cancer Control Plans as a core component of person-centred, lifelong care.
- Treatment centres should integrate psychosocial care into lifelong follow-up programs for comprehensive cancer survivor support.
- All involved stakeholders[4] need to advocate for national implementation of a European, evidence-based standard for psychosocial follow-up care.

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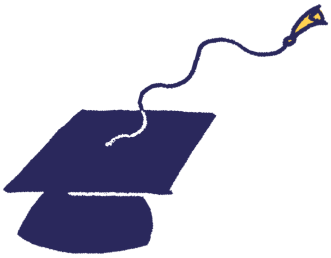
[4] Patient advocates, healthcare professionals, policy makers and regulatory bodies

# 4.2 Impact Area 2: **Strengthening Education & Career Opportunities**



Cancer and its treatment can significantly impact education and career opportunities, often leading to prolonged absences and institutions that are ill-prepared to offer the necessary support.

When homeschooling, remote learning, or hospital-based education are not provided, young cancer patients often struggle to stay motivated and may lose vital social connections with friends, teachers, and peers. Cancer and its treatment can also cause physical, cognitive, and emotional changes that make learning and working more difficult. After treatment, CAYA cancer survivors may find it hard to catch up on missed schoolwork if they return to the same class or face social difficulties if they repeat a year in a new class. They may feel pressured to keep up with their peers and prove their recovery. Disease- and treatment-related impairments may also lead to unmet support needs, a need to switch to a different educational track, or a realisation that certain career paths are no longer viable.

Eventual gaps in education or work history can make it difficult for CAYA cancer survivors to secure employment. Even years after treatment, late effects may require additional time away from work or school or result in reduced capacity due to fatigue, low energy, and other challenges. These ongoing setbacks can require survivors to change careers and may lead to job discrimination due to the differences between cancer survivors and those without such experiences.

On the side of educational and employment institutions, oftentimes there is a lack of awareness and information about what still can be feasible during treatment or what extra support might be required and could be offered to help the young patients to thrive and succeed in their educational and career paths.

## 4.2.1 How We Addressed the Challenges

### Digital Training Materials on Education & Career Support

Tailored support and resources can effectively support survivors to overcome these barriers and thrive. To address these unique challenges and highlight opportunities for growth, digital training materials were developed under this project, including an educational video and a recorded webinar, to provide guidance and promote personalised education and career support for young cancer survivors.

### Collecting best practice/ guidance materials for education and career support

Via desktop research and through reaching out to consortium members, including Associated Partners and extended networks across Europe, existing best practice materials for education and career support in various European languages were collected and categorised, thus could be made available to the public.

## Development of a Train-the-Trainer Curriculum

The EU-CAYAS-NET Train-the-Trainer concept is tailored to the needs of CAYA cancer survivors and aims to equip participants with the necessary knowledge, attitude and skills to deepen their knowledge and be able to disseminate information or build educational and career support in their national/local structures.

## Focus group discussions to collect insight and inform our materials/tools

Two focus groups were organised with CAYA cancer survivors who have received career support (Vienna, Utrecht). The two conversations provided first hand experiences and exchange about best- and bad practices, which further informed the developed materials.

## 4.2.2 Major Outcomes

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

**Educational Video**

The video sheds light on the unique challenges faced by survivors, while also highlighting their capabilities and potential opportunities for education and career advancement.

**Webinar**

The webinar explores barriers to education and career support, showcases best practices, and shares insights from survivors and healthcare professionals. Preliminary findings from focus group discussions in Vienna and Utrecht are presented, offering valuable insights for developing enhanced career support concepts for CAYA cancer survivors.

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

The wheel does not always need to be reinvented: an interactive map on the EU-CAYAS-NET Platform offers country-specific education and career support materials in local languages which were systematically collected within the scope of the project. These resources include brochures, website links, and support programs tailored for young cancer survivors, parents, and teachers.

### Train-the-Trainer Curriculum

The Train-the-Trainer curriculum is a manual that includes nine modules, covering topics such as personal strengths and weaknesses, environmental factors, and workplace conditions. Each module outlines its objectives, methods, and required materials. The manual also provides theoretical insights into Train-the-Trainer concepts, developmental psychology, and examples of group work and input.

Designed for those with prior Train-the-Trainer experience, the manual enables participants to lead future sessions, ideally co-facilitated by patient advocates and healthcare professionals. The program targets individuals working in education and career support, those looking to establish initiatives in the field, and anyone eager to collaborate and raise awareness.

## 4.2.3 The way forward

To effectively support CAYA cancer survivors, a multi-level approach is needed - one that addresses both individual needs and broader systemic gaps in education and employment, including the following key actions:

- National educational systems together with treatment centres should provide support during the entire course of education/training where needed. This requires a mention in national education plans.
- All involved stakeholders[5] should enable easy access to information on all legal and practical support options.
- Treatment centres should provide and train dedicated professionals in long-term follow-up (LTFU) care, ensuring they have the required knowledge, skills and time to effectively coordinate communication between young person/family, school/workplace, healthcare team and support providers.

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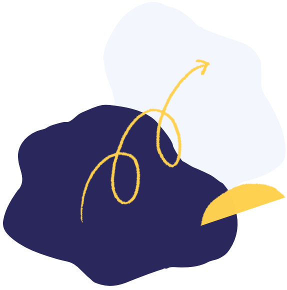
[5] Patient advocates, healthcare professionals, policy makers and regulatory bodies

# 4.3 Impact Area 3:
# **Facilitating Seamless Healthcare Transitions**



Transition 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).

This process is essential for ensuring continuity of care as CAYA cancer survivors often require LTFU care due to the potential late effects of cancer treatment. These late effects may include chronic health issues, secondary cancers, psychological challenges, or socio-economic difficulties that can emerge years after treatment.

However, the lack of formalised transition programs leaves many survivors to navigate complex healthcare systems without adequate support. This gap disrupts continuity of care and poses significant challenges, profoundly affecting the quality of life for survivors. The absence of a structured transition framework underscores the need for targeted solutions to address these issues.

The issue is not limited to specific regions but is also prevalent across the European Union, where many young cancer survivors face similar obstacles. Without structured transition programs, survivors often encounter fragmented care, a lack of coordinated services, or even a contact point to transition to. In many cases, there is no dedicated service or system available to receive them, making transition itself unattainable. This results in inadequate support to address their evolving medical, psychological, and social needs. These challenges underscore the urgent need for comprehensive strategies to support young survivors through this critical period.

A seamless transition process empowers young survivors to thrive and achieve their full potential. It also facilitates the development of self-management skills, which are essential for maintaining health and well-being in adulthood. By investing in robust transition programs, healthcare systems can ensure that survivors receive the continuity of care they require, ultimately benefiting both: individuals and society as a whole.

## 4.3.1 How We Addressed the Challenges

### Clinical Practice Guideline

We developed an **evidence-based clinical practice guideline** to standardise transition care across Europe.

Following the methodology of the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG), a group of 33 international stakeholders with expertise in paediatric oncology, survivorship, psychology, nursing, radiation oncology, epidemiology, and guideline methodology was involved in the whole process. The group included three patient representatives who actively participated in all steps.

In the guideline development process, we used three data sources for development of the recommendations:

- Scientific evidence,
- Recommendations from existing guidelines for chronic disease populations, and
- Experiences and values of patients, parents, and clinicians.

The aim of the guideline is to provide European harmonised recommendations to enhance healthcare transitions for childhood and adolescent cancer survivors as they move from short-term follow-up care to long-term survivorship care and from paediatric to adult care services.

A total of 44 recommendations were formulated, divided into three sections: *1. General principles, 2. Transition process,* and *3. Other conditions for a successful transition process and transfer moment.*

### Needs and preferences workshops

Organisation of **multiple workshops** with CAYA cancer survivors, healthcare professionals, and caregivers to identify the needs and preferences for an optimal transition from child-centred to adult-oriented care.

One workshop was held online, including 10 survivors and 2 parents from 7 EU countries. Using the Open Space methodology, participants proposed and led discussions on key topics. Action points and conclusions were documented in real time by a designated note-taker. Discussions provided valuable insights into the challenges and opportunities in improving transitional care. The other workshops were held in-person, as part of Peer Visits.

### Peer Visits to Best Practice Centres

2-day peer site visits brought together 30 peer visitors, including survivors, parents, and healthcare providers, from 15 EU countries.

Such Peer Visits are a form of innovative learning and research. We visited three renowned cancer care centres across Europe:

- Princess Máxima Center for Pediatric Oncology (Netherlands)
- Sant Joan de Déu Pediatric Cancer Center (Spain)
- Medical University of Vienna (Austria)

The visits focused on two key aspects: *Long-Term Follow-Up (LTFU) care* and *transition practices.* Participants observed current best practices, identified gaps, and shared experiences to enhance transitional care models.

## 4.3.2 Major Outcomes

### Transition Guideline

**The first evidence-based transition guideline for young cancer survivors was developed,** which will ensure continuity of care from paediatric oncology to adult long-term follow-up services.

**This guideline covers the following core components:**
In general, the transition process must prioritise the needs of patients, ensuring their voices and preferences are at the forefront. Essential components of the transition plan should include:

- A formalised transition policy to guide the process.
- A well-defined and structured transition coordination.
- Gradual and purposeful transition planning, tailored to each individual.
- An individualised transition plan that reflects the specific needs and goals of the survivor.
- Ensuring that the transfer occurs only when the individual demonstrates transition readiness, assessed through established criteria.

**Conditions for a successful transition are:**

- Education and involvement of survivors and their families/caregivers to equip them with the skills and knowledge needed to navigate the adult care system.
- Training for healthcare providers to enhance their understanding of survivors' unique needs and their competence in delivering transition support.
- Leveraging e-health information systems to enable seamless, efficient communication and data sharing during the transition.
- Conducting regular evaluation of the transition process using key performance metrics to ensure ongoing improvement and success.
- Promote the inclusion of transition-related topics as a priority in national and EU health policies.
- Engage institutional leadership and stakeholders to ensure policy alignment and widespread support for the transition guideline.
- Promote the development and use of transition materials for survivors and families, including a transition plan and easy-to-understand resources in various formats.
- Encourage and support more visits to best-practice centres to facilitate knowledge sharing and improve transition strategies.

## Awareness Materials

**Educational video about transition**
This video for young people affected by cancer explains what the transition from pediatric to adult medical care looks like and what needs to be considered to make the transition as smooth as possible and how to continue with long-term-follow-up care.

**Webinar to disseminate findings and recommendations to stakeholders**
The webinar has the same aim as the educational video, namely to bring the topic of transition closer to all stakeholders and to discuss where there are still shortcomings and what can be done about them.

**Vilnius declaration on transition needs:**
A health policy symposium was also held in Vilnius, Lithuania, on the subject of transition, at which a declaration was presented and signed by all participating stakeholders, proposing a series of measures to improve the transition of children and adolescents with or beyond cancer into adult care:

## 4.3.3 The way forward

To ensure continuity of care and long-term well-being for CAYA cancer survivors, structured and multidisciplinary transition programs are essential. Achieving this requires coordinated efforts from all stakeholders, including policymakers, healthcare institutions, and advocacy groups. Key actions include:

- All involved stakeholders[6] should promote the inclusion of transition-related topics as a priority in national and EU health policies.
- Institutional leadership should ensure policy alignment and widespread support for the developed transition guideline.
- All involved stakeholders[6] should promote the development and use of transition materials for survivors and families, including a transition plan and easy-to-understand resources in various formats.

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[6] Patient advocates, healthcare professionals, policy makers and regulatory bodies

# 4.4 Impact Area 4: **Late Effects & Long-Term Follow-Up Care**

Approximately 75% of CAYA cancer survivors develop late health problems that need LTFU care. These late effects vary widely depending on the type and stage of cancer, as well as the treatment received, impacting not only physical health but also psychosocial well-being, neurocognitive function, and participation in daily life and society.

Tailored LTFU care is crucial to mitigate the burden of late effects and their impact on survivors' quality of life. Guideline-based LTFU care enables early detection and management of late effects, reducing their long-term consequences. However, many survivors across Europe lack access to adequate LTFU care, with significant disparities between countries. As a result, numerous survivors become "lost to follow-up," missing critical opportunities for monitoring and intervention.

Addressing these gaps requires coordinated efforts to implement LTFU care across Europe. Providing consistent, comprehensive care ensures improved health outcomes and enhances the overall quality of life for CAYA cancer survivors.

## 4.4.1 How We Addressed the Challenges

### Surveys to Identify Best Practices and Gaps in LTFU Care

A survey, designed in different versions for CAYA cancer survivors and healthcare professionals, was conducted across Europe to understand the state of LTFU care.

The survey explored:
- How LTFU care is organized and delivered in various countries.
- Barriers and gaps in implementing effective LTFU care.
- Survivor experiences, including satisfaction levels and unmet needs.
- Healthcare professionals' perspectives on their role, resources, and challenges in delivering care.

Survivors provided insights into the care they received or missed, while professionals detailed the care they delivered, highlighting systemic issues such as access, consistency, and resources.

## Workshops: "Getting Long-Term Survivorship Care on Track"

Four workshops were conducted with survivors, healthcare professionals, and caregivers, using a unique train-track metaphor:

1. Participants imagined a starting point (current LTFU care status) and an ideal destination (optimal care).
2. They collaboratively mapped the "track," identifying the elements, barriers, and facilitators needed to reach the ideal care model.

Key themes included: i) Ensuring accessible and appropriate LTFU care for all survivors, ii) providing holistic support, covering medical, psychological, and social aspects, iii) strengthening caregiver support and healthcare professional training.

## Peer Visits to Best Practice Centres

As mentioned before, three renowned European cancer centres hosted Peer Visits:

1. Princess Máxima Center for Pediatric Oncology (Netherlands)
2. Sant Joan de Déu Pediatric Cancer Center (Spain)
3. Medical University of Vienna (Austria)

Thirty participants, including survivors, parents, and professionals from 15 EU countries, observed: i) how LTFU care is organized and personalised, ii) the training and expertise required for LTFU care providers, iii) integration of multidisciplinary approaches and shared decision-making, and iv) tools like survivorship care plans and digital tracking of treatment histories.

## Webinars addressing Long-Term Survivorship Challenges

Two webinars were held to educate and engage stakeholders.

## PLAIN language summaries

To bridge gaps in access to specialized care, appealing PLAIN language (**P**erson-Centred, **L**ay Language, **A**ccessible, **I**nternational, and **N**avigable) summaries based on IGHG and PanCare guidelines were developed and extended. These user-friendly materials empower survivors to:

- Understand late effects and the recommendations for surveillance of late effects.
- Advocate for their care needs with non-specialist providers.

## Workshops for Recommendations for Communication with Survivors to Prepare Them for Late Effects and Provide Support

Survivors wish for clear, honest information about their health, care options, and the long-term effects to live confidently and independently. Unfortunately, many survivors remain unaware of late effects, leading to anxiety, isolation, or depression. Poor communication can worsen mental health, hinder treatment adherence, and strain relationships. In order to be able to take charge of their health management, survivors need to be well informed about the potential and factual consequences of their cancer and its treatment.

Therefore, open discussions between survivors and HCPs about such difficult topics are essential; the approach and attitude greatly influence outcomes.

The workshop participants discussed the need for clear, honest information regarding late effects and shared their preferences for effective patient - health care provider communication.

## 4.4.2 Major Outcomes

### Recommendations

**LTFU Care Recommendations**
Drawing on the activities outlined above, insights from the IGHG, previous PanCare projects,[7] and models of care guidelines, recommendations were developed to optimise long-term follow-up (LTFU) care for CAYA cancer survivors in Europe. Organised into key thematic areas, these recommendations form a clear and comprehensive framework for establishing and delivering LTFU care that enhances survivors' quality of life.
The key thematic areas are:

- **Access to care,** describing the need for proper access to care for all CAYA cancer survivors
- **Organisation of care,** describing requirements for the organisation of optimal care
- **Personalised care,** highlighting the importance of personalised care
- **Collaboration, representation and improvement,** advocating for (international) collaboration and professional training of HCPs
- **Support system for CAYA cancer survivors CS and their families,** addressing the importance of a proper support system.

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[7] PanCareSurFup, https://www.pancare.eu/projects/project-pancaresurfup/, PanCareLIFE, www.pancarelife.eu, PanCareFollowUp, www.pancarefollowup.eu and PanCareSurPass, www.pancaresurpass.eu

A **visual summary of LTFU care recommendations,** highlighting the final step of successful cancer treatment, is available on the Project Platform in eight EU languages. This summary provides an accessible overview of the roadmap and key guidelines for supporting young cancer survivors.

**Recommendations on effective communication about late effects (in preparation)**
Survivors have shared their preferences for effective communication about late effects in an open discussion, resulting in recommendations for health care providers across four key areas:
— Survivor-centred care
— Communication and information-sharing from the start
— Emotional and psychosocial support
— Respect and empowerment

## Virtual map of LTFU care across Europe

Updated during the EU-CAYAS-NET project as one of the key outcomes of the LTFU survey conducted, a virtual map of LTFU care facilities provides an up-to-date overview about available services across Europe and helps facilitate accessibility for survivors:

## Awareness Materials

**Webinars**
1. **“Long-Term Survivorship Care”:** Highlighting tools, solutions, and steps to improve survivorship care and shared insights from experts and survivors.

2. **“Navigating Fertility and Intimacy Challenges”:** Addressing the impact of cancer treatment on fertility plans and intimacy in relationships, providing actionable guidance and encouraging open dialogue with survivors.

**PLAIN summaries**
Enhanced during the EU-CAYAS-NET project, the summaries now include graphics and info boxes with additional information. For more details and access to these PLAIN language summaries, visit PanCare’s dedicated resource page:

**Barcelona declaration on LTFU needs**
Following the approach for other themes, a health policy symposium was also held in Barcelona, this time on the topic of long-term follow-up care. Here, too, a declaration was issued proposing a series of measures to improve long-term follow-up care and is to be signed by the participating stakeholders.

## 4.4.3 The way forward

Optimal LTFU care enhances the quality of life for young cancer survivors in Europe, empowering them to reach their full potential while easing the burden on national healthcare systems through efficient resource utilisation.

To achieve this, LTFU care must be integrated into National Cancer Control Plans and aligned with evidence-based European guidelines, such as those from PanCare and IGHG, which offer clear recommendations for monitoring and managing late effects. Tailored programs should address diverse survivor needs, including psychosocial support, education on long-term health management, and seamless transitions between paediatric and adult care. Survivorship care plans should serve as the foundation, enabling personalised, proactive support.

Collaboration between the European Commission and national governments is crucial to establish comprehensive LTFU care with sustainable public funding. Investing in provider training and accessible, multidisciplinary systems will ensure lasting benefits for survivors and society alike.

— All involved stakeholder[8] groups need to continue advocating for the integration of evidence-based LTFU care into National Cancer Control plans.

— Treatment centres should provide survivorship care services to ensure personalized, proactive support covering all aspects of life of survivors and allow survivors to manage their own needs for care.

— University hospitals and professional societies should invest in specialist training and multidisciplinary care to ensure state-of-the art care for survivors.

— All involved stakeholders[8] should foster continuous international collaboration between healthcare, research, policy makers and survivors for ongoing improvements of LTFU care plans.

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[8] Patient advocates, healthcare professionals, policy makers and regulatory bodies

Tailored approaches to **mental health, education, career development, transition and long-term follow-up care** empower CAYA cancer survivors to reach the best possible quality of life.

# 5. Conclusion

**Survival rates for CAYA cancer patients in Europe have improved significantly, but long-term survivorship comes with persistent challenges. Up to 75% of survivors face late effects impacting their physical, mental, and social well-being, yet follow-up care remains inconsistent across Europe. The EU-CAYAS-NET project highlights the urgent need for comprehensive, standardised support systems to ensure a high quality of life for survivors.**

## Key Policy Recommendations

1. **Mental Health & Psychosocial Care**
   - Integrate psychosocial follow-up care into National Cancer Control Plans (NCCPs) with dedicated funding and implementation strategies.
   - Mandate the adoption of European evidence-based guidelines for psychosocial care.
   - Establish mental health support as a core component of cancer care, ensuring access to psychological services as a universal standard of care.
2. **Education & Career Support**
   - Develop national policies ensuring tailored educational and vocational support for childhood cancer survivors.
   - Adopt and implement anti-discrimination legislation to protect survivors from education and workplace bias, ensuring equal career opportunities.
   - Train dedicated professionals to coordinate survivor needs across education, employment, and healthcare sectors.
3. **Healthcare Transition Support**
   - Implement structured transition programs in national health policies to ensure seamless transition from pediatric to adult oncology care.
   - Ensure continuity of care for survivors through the formal integration of developmentally appropriate, survivor-centred healthcare pathways.
   - Align national policies with the EU-CAYAS-NET evidence-based transition framework to ensure consistency across Member States.
4. **Long-Term Follow-Up (LTFU) Care**
   - Include LTFU care in National Cancer Control Plans with sustainable public funding mechanisms.
   - Ensure access to specialised LTFU clinics staffed with multidisciplinary teams trained in survivorship care.
   - Improve awareness and accessibility of LTFU services through digital tools and survivor-centred communication strategies.

## Call to Action

**We call on all stakeholders, including policy makers on the national and EU levels, to act now and:**

- Prioritise young cancer survivors' well-being in national health strategies.
- Legislate comprehensive, standardised follow-up care across Europe.
- Allocate funding and resources to professional training, cross-sector collaboration, and innovative care models

CAYA cancer survivors need **lifelong, person-centred care**—not just to survive, but to thrive.

# About the EU-CAYAS-NET project

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.

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Join us!

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