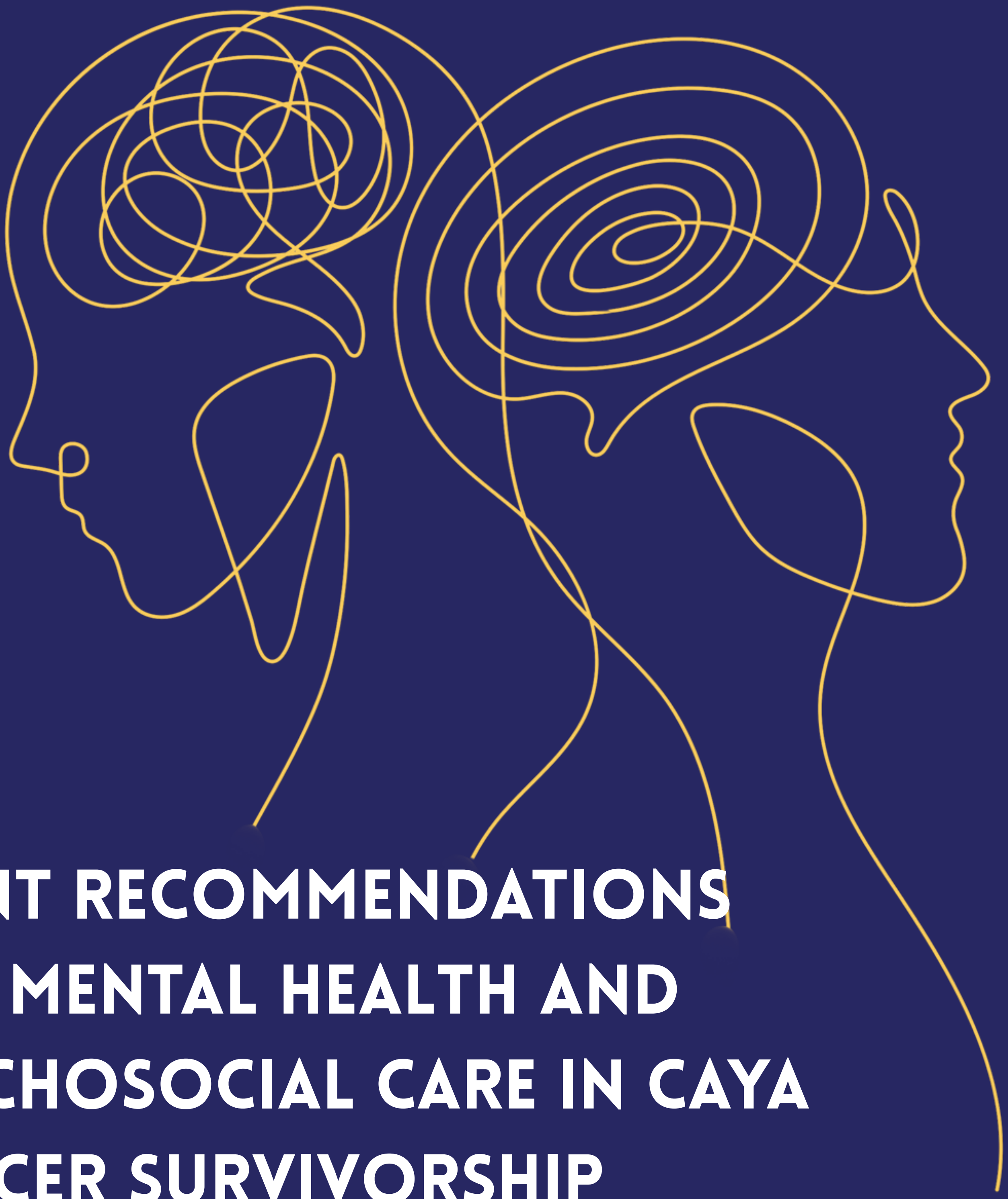
European Network of
YOUTH CANCER SURVIVORS



JOINT RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

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

INTRODUCTION

These joint recommendations of care have been developed within the framework of EU-CAYAS-NET, a patient advocate-driven project in which survivors, patient advocates, and professionals collaboratively co-created the content and structure from initial development through the implementation, in order to ensure that the perspectives and needs of young people and their families are meaningfully integrated at every stage.

Despite growing recognition of the importance of mental health and psychosocial well-being across all populations, the quality of life of Childhood, Adolescent, and Young Adult (CAYA) cancer survivors, defined as individuals aged 0 to 39 years at the time of diagnosis, remains an under-addressed aspect of comprehensive cancer care. While advancements in treatment have significantly increased survival rates, survivorship brings its own set of challenges that demand structured, multidisciplinary response.

The impact of cancer extends well beyond active treatment. Survivors frequently face long-term physical, emotional, cognitive, and social difficulties, ranging from mental health concerns and academic or vocational disruptions to challenges in transitioning to adult healthcare systems and maintaining overall well-being. These issues are especially critical for young survivors, whose development and life trajectories are often profoundly altered by a cancer diagnosis and its consequences.

Joint recommendations of care are essential to systematically address these complex needs. Within the framework of the EU-CAYAS-NET project, we advocate for collaborative, evidence-based approaches that bring together patient advocates, Health Care Professionals (HCP), researchers and other stakeholders across Europe. The goal is to ensure consistent, integrated follow-up care, strengthen mental health and psychosocial services, and bridge existing gaps.

By fostering coordination and cooperation across disciplines and systems, this standard of care supports not only survival but also thriving.

INTRODUCTION

These joint recommendations acknowledges already existing standards that have been developed for other continental and/or regional contexts and therefore consolidates and builds upon existing national and international recommendations related to mental health and psychosocial care in CAYA oncology and survivorship. Given the diverse healthcare landscapes across Europe, there is a pressing need for an accessible, harmonized resource that brings together essential guidance in one place. This document aims to serve as a practical, adaptable reference point for professionals and institutions, outlining core principles while also allowing for local adaptation. By compiling and contextualizing existing knowledge, we offer a flexible framework that can be implemented across varied healthcare settings, while recommending adaptations where necessary.

As the foundation of these recommendations, we initially reviewed existing international recommendations and guidelines. In several cases, only minor adaptations were suggested, for example, replacing terms like "paediatric" with "CAYA" to reflect a more inclusive age range and emphasize continuity across developmental stages. These seemingly small changes in wording are intentional and meaningful, as language shapes the way needs are perceived, addressed, and prioritized in care. The choice of terms can influence visibility, inclusivity, and responsiveness to the diverse realities of young people affected by cancer.

INTRODUCTION

Methods

First, a task force consisting of HCPs and survivors of CAYA cancer was established. Through the involvement of survivors in the preparation and realization of this task, we ensured that the recommendations would appropriately reflect the perspectives and real-life needs of young cancer survivors. On the other hand it was just as important to assess the perceptions and opinions of HCPs in order to see which guidelines are used and can be implemented in everyday clinical practice. The task force was coordinated by an HCP and a patient expert from the Medical University of Vienna, following a PPIE[1] approach.

[1] **PPIE** stands for **Patient and Public Involvement and Engagement**. It refers to the active and meaningful inclusion of patients, carers, and members of the public in the planning, conduct, and dissemination of healthcare services and research. The goal is to ensure that the needs, experiences, and perspectives of those directly affected by health conditions are integrated into decision-making processes.

In the context of PPIE, a distinction is often made between different roles:

- **Individual patients/carers**: People with lived experience of a disease, including family members or informal caregivers.
- **Patient advocates**: Individuals who speak or act on behalf of broader patient communities and promote patient-centered care or research agendas.
- **Patient organization representatives**: Members or delegates of formalized patient organizations who represent collective interests of specific patient groups
- **Patient experts**: Patients with lived experience and additional knowledge or training (e.g., in healthcare, research, policy), allowing them to contribute as peer professionals

PPIE emphasizes collaboration, co-creation, and mutual respect, recognizing that those affected by health issues bring valuable expertise to the table.

(Weiler-Wichtl et al., 2023)

INTRODUCTION

In order to capture the current state of research and practice, a systematic search of standards and guidelines in psychosocial follow-up care of cancer survivors was conducted. 43 standards and guidelines were identified based on Schröder et al., 2019 and an additional 8 guidelines were found in a recent update. All guidelines were tested for eligibility. After excluding guidelines because they either did not include psychosocial follow-up care and/or were not specific to oncology patients or survivors, 20 guidelines were included in this work.

In addition to the systematic search of guidelines, we identified further relevant topics. This was achieved through desktop research and meetings like focus group discussions and workshops that were carried out in the scope of the EU-CAYAS-NET project.

The topics identified through the systematic search of guidelines and the further search of relevant topics were prepared for the task force. To ensure that all participants understood the content and no ambiguities arose, the topics were described in lay language and illustrated with examples and figures.

General Considerations for the Care of CAYA Cancer Survivors and Their Families

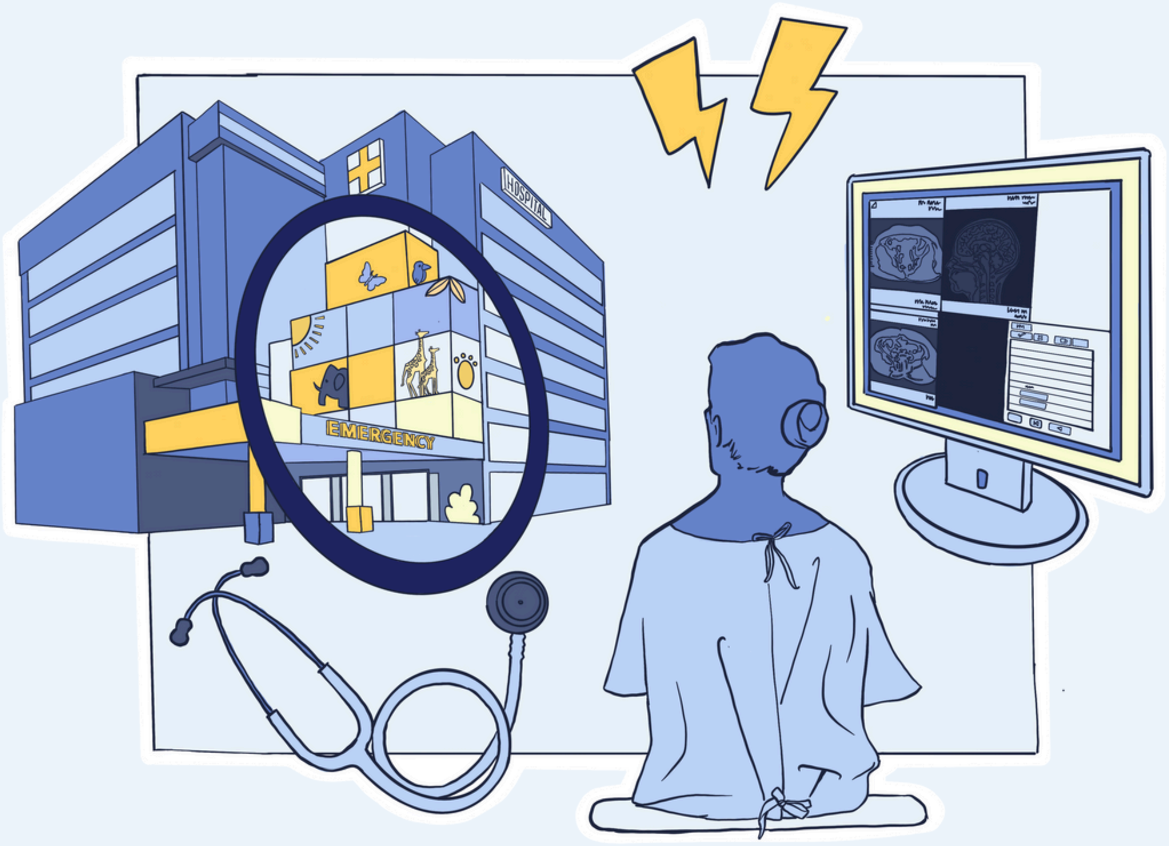
These overarching recommendations have been consolidated from repeated input and shared insights gathered across numerous consensus meetings, community events, project exchanges, and stakeholder meetings. They reflect recurring themes and priorities raised by patients, survivors, families, and professionals alike. This foundation ensures that the principles outlined are both practically grounded and broadly supported by those involved in the care of CAYA cancer patients and survivors.

When developing and delivering psychosocial and mental health care for CAYA cancer survivors, a number of overarching principles must be kept in mind to ensure care is developmentally appropriate, equitable, and responsive to the complexity of survivorship. These considerations apply across the care continuum and are relevant for all professionals involved in long-term follow-up (LTFU):

- **Care must always include the family/caregivers:** Survivorship care should be designed not only for the young person but also for their family/caregivers, who are essential partners in navigating late effects and long-term psychosocial outcomes.
- **Recognize and address stress and stigma:** Survivors often experience long-lasting psychological stress and societal stigma. These factors must be acknowledged and actively addressed within care structures and communication strategies.
- **Dedicated and competent professionals are essential:** The involvement of professionals with specific training, supervision, and expertise in paediatric psychooncology, adolescent development, and late effects is crucial. This includes medical-paedagogical caregivers and social service navigators who can guide survivors in accessing entitlements and support systems.

General Considerations for the Care of CAYA Cancer Survivors and Their Families

- **Developmentally-informed support:** Professionals involved in LTFU care should have a deep understanding of child and adolescent development, particularly how cancer and its late effects intersect with critical developmental milestones.
- **Tailored surveillance:** Neuropsychological and psychosocial surveillance should be individualized based on survivors' needs and risk factors. Flexible models of care should be adapted to the complexity and timing of late effects.
- **Increased need for complementary psychosocial support in LTFU care:** Psychosocial care must be more comprehensive and regular in the survivorship phase, recognizing that challenges often intensify or emerge over time.
- **Ongoing research is urgently needed:** Continued research into late effects, psychosocial outcomes, and effective interventions in CAYA survivorship is essential for the continuous improvement of care standards.



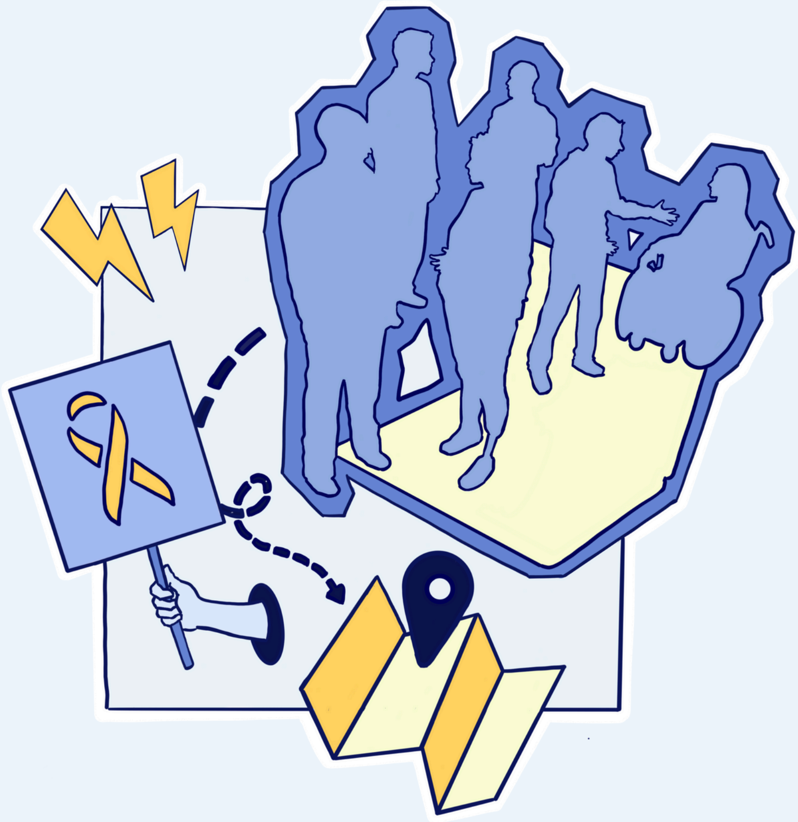
EU-CAYAS-NET JOINT RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

SOCIAL ASPECTS

Adapted after Pelletier & Bona (2015).

SOCIAL ASPECTS

Cancer in CAYA can lead to a variety of social challenges which should be tackled together with dedicated professionals. The social dimension is one of three aspects of CAYA care following the biopsychosocial model (Engel, 1977). The social dimension is especially addressed by social work. Social challenges can include different areas of the social dimension which should be addressed in follow-up care, e.g. socio-economic, socio-cultural, and socio-ecological factors as well as social relationships. A closer look on the social dimension shows that CAYA's have a considerable risk of becoming unemployed in adulthood (Mader et al., 2017) or having to claim social benefits (Font-Gonzalez et al., 2016). Furthermore, they have an increased risk of leading a dependent life, have difficulties establishing/maintaining social relationships, are less often married/in a couple, and are in a worse socio-economic situation compared to their peers (Brinkman et al., 2018; Font-Gonzalez et al., 2016). Cancer not only affects the social dimension of the CAYAs but also their family members and caregivers, e.g., difficulties in professional re-entry or financial burden. To record the social dimension in follow-up care, social diagnostics or social assessment can be used to take a comprehensive look on the social dimension and serve as the basis for social (work) counseling, intervention, and treatment.



SOCIAL ASPECTS

EU-CAYAS-NET JOINT RECOMMENDATIONS

Children, adolescents, and young adults affected by cancer, as well as their families are at high risk for financial burden, social isolation, and gaps in education and career support during and after cancer treatment with associated negative implications for quality of life and participation for CAYAS' and parental emotional health.

The social dimension should be addressed in follow-up care. This includes:

- Socioeconomic factors (material living conditions, education, employment),
- Sociocultural factors (language, country of origin),
- Socioecological factors (mobility, geographical/environmental factors),
- Social relationships (social network, social support)

1

Assessment of risk for financial hardship should be incorporated already at time of diagnosis for all young people and their families affected by cancer. Domains: risk factors for financial hardship during therapy including: pre-existing low-income or financial hardship, single parent status, distance from treating center, anticipated long/intense treatment protocol, and education and (parental) employment status.

2

Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) should be offered based on results of (family) assessment.

3

Longitudinal reassessment and intervention should continue throughout the cancer treatment trajectory and into survivorship and bereavement.

- Useful interventions are: support with educational and training paths, job search, reintegration into the job, and job maintenance for CAYA cancer survivors (especially when facing physical or psychosocial side or late effects) and caregivers.

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

PSYCHOLOGY - BASIC CARE

Adapted after: Kazak et al., (2015); Lown et al., (2015); Marchak et al., (2022); Schröder et al., (2019).

PSYCHOLOGY - BASIC CARE

Cancer in CAYAs can leave a profound and lasting impact, not only on physical health but also on mental health and psychosocial wellbeing. While advances in cancer treatment have significantly improved survival rates, the psychological effects of the disease and its treatment often remain underestimated and under-addressed, especially in the LTFU care of survivors (EU-CAYAS-NET, 2024b).

A significant proportion of CAYA cancer survivors experiences persistent challenges such as depression, anxiety, fatigue, cognitive and neuropsychological impairments, and even suicidal ideation. Beyond emotional distress, many survivors also face structural barriers and long-term consequences such as lower educational attainment and reduced participation in full-time employment. These issues are compounded by striking variations in the quality and availability of psychosocial care, both across and within countries, depending on local resources, infrastructure, and institutional practices. This emphasizes the high need to improve psychosocial support services that adequately address the mental health needs of CAYA cancer survivors. Access to optimal psychosocial care improves the quality of life for every child, adolescent, and young adult in Europe after their cancer treatment and supports them to thrive. Moreover, investing in effective long-term psychosocial care not only benefits the individual survivor but potentially will also reduce the burden on national healthcare systems and society as a whole by making more efficient use of resources and placing lower pressure on social funds (EU-CAYAS-NET, 2024a).

PSYCHOLOGY - BASIC CARE

EU-CAYAS-NET RECOMMENDATIONS

1

Youth with cancer and their family members should routinely receive systematic assessment of their psychosocial health care needs

2

Early psychosocial support should be aimed at the prevention of psychological sequelae and comorbidities in patients and family members. It should also serve to prevent social, emotional, and cognitive late effects/developmental disorders.

3

Mental health surveillance is recommended for all survivors at all ages to begin at their first follow-up and continue throughout the lifespan. It is recommended at every follow-up visit (at least once a year)

Surveillance is recommended for:

- Adverse educational and/or vocational progress
- social and relationship difficulties
- depression & mood disorder, anxiety
- psychological distress
- post-traumatic stress
- behavioral problems
- risky health behaviors
- suicidal ideation

Modality of surveillance: A medical history focused on survivor's mental health. If there is an indication for mental health problems:

- further testing with a validated parent- and/or self-report measure by a mental health professional

If abnormalities are identified:

- referral to a mental health professional for diagnostic and risk assessment
- Cognitive behavioral therapy for the treatment of anxiety, depression, and post-traumatic stress symptoms

4 Long-term survivors of childhood and adolescent cancers should receive yearly psychosocial screening for:

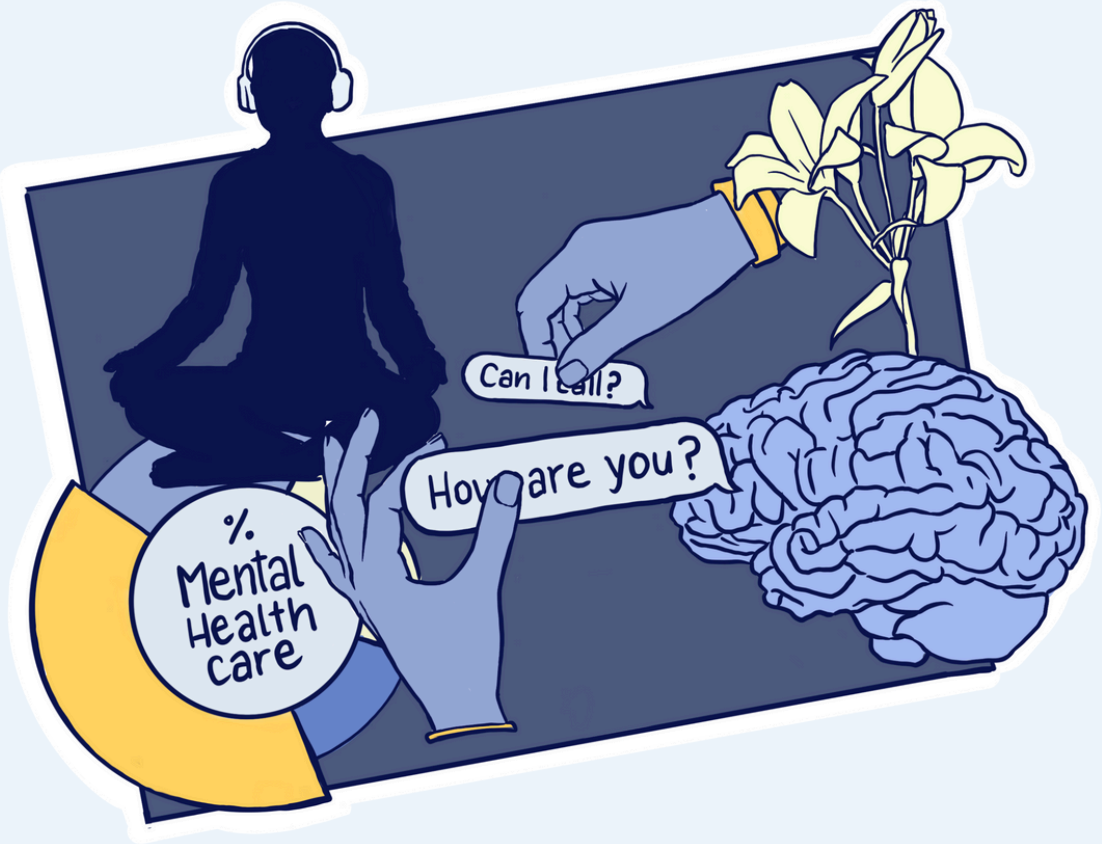
- adverse educational and/or vocational progress, social and relation-ship difficulties;
- distress, anxiety, and depression;
- risky health behaviors.

5 Adolescent and young adult cancer survivors and their family members should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends, and repeated at each follow-up visit.

6 It is essential to be aware of the distinction between appropriate emotional reactions to disease- or treatment-related stressors and emotional disorders of different (non-cancer-related) origin.

7 Psychosocial services should be accessible and covered by health insurances/national health care systems..

8 Youth with and beyond cancer and their family members should be informed about available services.



EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

SURVEILLANCE - NEUROPSYCHOLOGY

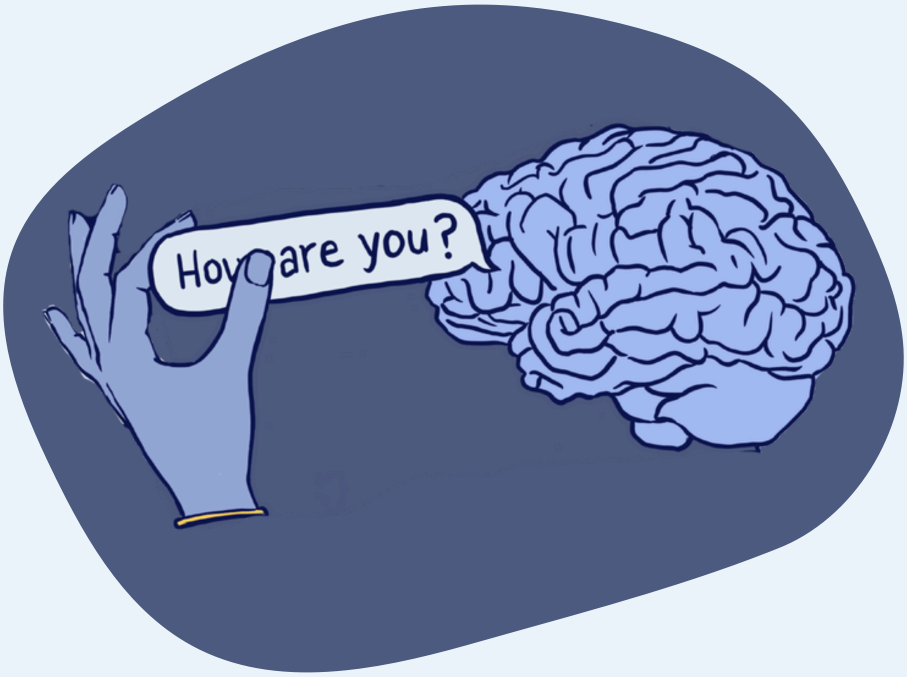
Adapted after Annett, Patel & Phipps (2015); Children’s Oncology Group (2022); Schröder et al., (2019); Scottish Intercollegiate Guidelines Network (2013).

SURVEILLANCE – NEUROPSYCHOLOGY

Cancer at a young age presents not only a medical challenge but also a significant neuropsychological and psychosocial burden for young people and their families. Advances in cancer treatments have improved survival rates drastically; however, these gains have also brought increased awareness of the long-term cognitive, emotional, and behavioral consequences of both the disease and its treatment (Miller et al., 2020). CAYAs undergoing cancer therapy are at heightened risk for neurodevelopmental difficulties due to factors such as chemotherapy, radiation, surgery, and prolonged hospitalizations, all of which can disrupt critical periods of brain development (Annett, Patel & Phipps, 2015).

Neuropsychological surveillance refers to the systematic, longitudinal monitoring of cognitive and emotional functioning over the course of the cancer pathway and beyond. Early identification of neuropsychological changes allows for timely intervention, which can prevent worsening of late effects and support more adaptive developmental trajectories (Krull et al., 2013). Despite its importance, neuropsychological surveillance is often inconsistently applied and poorly integrated into routine oncological care.

Proper integration of neuropsychological surveillance requires interdisciplinary collaboration among oncologists, psychologists, neuropsychologists, social workers, educators, and families.



SURVEILLANCE - NEUROPSYCHOLOGY

EU-CAYAS-NET RECOMMENDATIONS

1 Regular review of neurological and neuropsychological function should be part of regular follow-up care. If a problem is suspected, the patient/survivor should be referred to a psychologist for a neuropsychological assessment

2 Children, adolescents and young adults with brain tumours and others are at high risk for neuropsychological deficits as a result of cancer treatment. Therefore, there should be monitoring for neuropsychological deficits during and after treatment.

- CAYAs with cancer who are due to receive cranial irradiation should undergo a neuropsychological assessment at the start of treatment. The assessment should be repeated annually, to monitor changes over time.
- In the case of certain risk factors such as brain tumours, ALL/AML, or following certain forms of medical treatment or surgery (e.g. neurosurgery, radiotherapy of the central nervous system, intrathecal therapy, stem cell transplants), neuropsychological diagnostics are recommended as a central element of psychosocial care (e.g. Boulet-Craig et al., 2018; Van Der Plas et al., 2018).

3 Healthcare and education professionals should be aware that the treatment of childhood cancer may have an impact on neurological function in later life, particularly if irradiation of the brain occurs at a young age.

4 Structured counseling and guidance should be provided for caregivers, as well as for educational institutions and employers, to support the young person's reintegration and ongoing development within these settings.

5 Ongoing monitoring and age-appropriate tools should be offered to support CAYAs in the self-management of cognitive and emotional challenges related to their disease and/or treatment.

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

PSYCHOEDUCATION, ANTICIPATORY GUIDANCE, & PROCEDURAL PREPARATION

Adapted after: Flowers & Birnie (2015); Lown et al., (2015); Schröder et al., (2019); Thompson & Young-Saleme (2015).

PSYCHOEDUCATION, ANTICIPATORY GUIDANCE, & PROCEDURAL PREPARATION

For CAYAS affected by cancer, understanding the psychological and social consequences of their illness and treatment is essential to long-term well-being. Easily accessible psychoeducation, which entails the provision of structured information about the condition, treatment options, and coping strategies, can significantly enhance understanding, improve adherence to care plans, and support better health management (Thompson & Young-Saleme, 2015; Flowers & Birnie, 2015).

Anticipatory guidance plays a complementary role by preparing young patients and their families for expected challenges along the care pathway, promoting proactive coping and reducing uncertainty (Schröder et al., 2019). Additionally, procedural preparation, which involves age-appropriate explanations and demonstrations of upcoming medical procedures, helps reduce fear and emotional distress through informed participation (Lown et al., 2019).

Together, these supportive approaches promote patient empowerment, reduce anxiety, and lead to improved healthcare experiences and outcomes for young people living with and beyond cancer.

PSYCHOEDUCATION, ANTICIPATORY GUIDANCE & PROCEDURAL PREPARATION

EU-CAYAS-NET RECOMMENDATIONS

1 Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care, from diagnosis into survivorship.

2 Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit.

3 Psychosocial interventions aimed at supporting the processing of complex information have proven to be effective information and orientation programmes.

4 Psychoeducation should continue after treatment and into survivorship regarding topics like transition, rehabilitation, fertility, sexual health, independent living, return to work/education, emotional burden, and information for psychosocial problems that could arise years later

5 All youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth with cancer should receive psychological intervention for invasive medical procedures.

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

INTERVENTIONS FOR EMOTIONAL AND SOCIAL SUPPORT - FOR PATIENTS

Adapted after: Christiansen et al., (2015); Steele et al., (2015); (also see Schröder et al., 2019).

INTERVENTIONS FOR EMOTIONAL AND SOCIAL SUPPORT - FOR PATIENTS

Social interaction and peer relationships play a critical role in the social development of children and adolescents. However, young people undergoing cancer treatment often face disruptions in these experiences due to prolonged hospital stays and the isolating nature of intensive therapies (Christiansen et al., 2015). While survival rates for pediatric cancer have improved significantly over the past four decades, the burden of treatment places both patients and their families at elevated risk for psychological and emotional challenges—not only during treatment, but also throughout survivorship and, when relevant, at the end of life (Christiansen et al., 2015).

Although many children and families show remarkable resilience, a substantial proportion experience clinically significant levels of psychological distress at multiple stages of the cancer journey—including at diagnosis, during treatment, and after treatment concludes (Steele et al., 2015). Access to psychosocial resources from the point of diagnosis has been shown to offer immediate and sustained benefits, with both patients and caregivers directly benefiting from early engagement with psychosocial professionals. These findings underscore the essential role of integrated psychosocial care throughout the entire cancer continuum—from diagnosis to survivorship (Steele et al., 2015).

INTERVENTIONS FOR EMOTIONAL AND SOCIAL SUPPORT - FOR PATIENTS

EU-CAYAS-NET RECOMMENDATIONS

1 All youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory, from diagnosis into survivorship and access to psychiatry as needed.

2 Dedicated support for adolescents and young adults is recommended and should include among other things topics such as body image, relationships, fertility, disability, and communication with friends/the social environment.

3 Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patient's unique characteristics, including developmental level, preferences for social interaction, and health status.

4 The patients, parent(s), and a psychosocial team member (e.g. designee from child life, psychology, social work, or nursing) should participate in this evaluation at time of diagnosis, throughout treatment, and when the patient enters survivorship; it may be helpful to include school personnel or additional providers.

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

EMOTIONAL SUPPORT - FOR FAMILY MEMBERS/ CAREGIVERS/SIBLINGS

Adapted after: Gerhardt et al., (2015); Kearney et al., (2015); (Also see Schröder et al., 2019).

EMOTIONAL SUPPORT – FOR FAMILY MEMBERS/CAREGIVERS/SIBLINGS

A cancer diagnosis in CAYAS profoundly affects the entire family system, particularly siblings and parents, who are often underserved in psychosocial care models. Siblings commonly experience heightened stress due to concern for the ill child, disrupted routines, diminished parental attention, and increased household responsibilities (Gerhardt et al., 2015). These stressors place them at risk for a range of psychosocial difficulties, including anxiety, depression, posttraumatic stress symptoms, lower quality of life, and challenges in academic and social functioning. Importantly, while some siblings demonstrate remarkable resilience and even posttraumatic growth, this variability underscores the need for systematic screening to identify both risk and protective factors and to provide appropriate, tailored support (Gerhardt et al., 2015).

This need is also urgent in the context of AYA patients, where siblings may face unique challenges. According to Vasegaard et al. (2024), siblings of AYA patients often struggle with ambiguous and shifting roles within the family, feelings of emotional isolation, and limited inclusion in communication and care processes. These factors can exacerbate emotional distress and lead to long-term disruptions in sibling relationships and individual psychosocial development. Yet, these siblings frequently remain invisible in the healthcare setting, with few opportunities to express their needs or access support (Vasegaard et al., 2024).

Parents are also deeply affected by their child's diagnosis. While many exhibit resilience and eventually adjust to a new "normal," those with pre-existing vulnerabilities may experience intense, sustained distress that can disrupt parenting, compromise treatment adherence, and negatively impact both the ill child and well siblings (Kearney et al., 2015). Collectively, these findings reinforce the importance of expanding psychosocial standards of care to include proactive, family-centered interventions ensuring that both siblings and parents are recognized, supported, and equipped to navigate the cancer pathway alongside the patient.

EMOTIONAL SUPPORT - FOR FAMILY MEMBERS/CAREGIVERS/SIBLINGS

EU-CAYAS-NET RECOMMENDATIONS

1 Siblings of children, adolescents, and young adults with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly

2 Parents and caregivers and siblings of children, adolescents, and young adults with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well being

3 Children of young adults with cancer, as well as parents of young adult patients, should also receive appropriate psychosocial support and mental health assessment, recognizing their unique emotional burdens and roles with the family system.

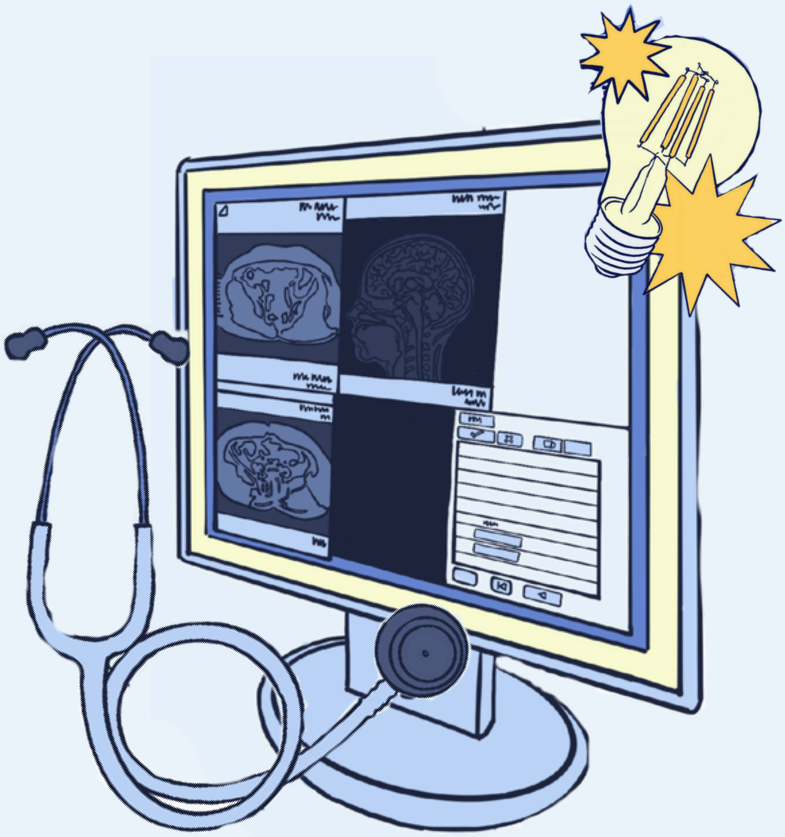
EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

FATIGUE

Adapted after: Children's Oncology Group (2022); Christen et al., (2020); Schröder et al., (2019).

FATIGUE

Cancer-related fatigue (CRF) is one of the most common and distressing symptoms experienced by CAYAs with cancer—not only during active treatment but often persisting years into survivorship. CRF is a distressing, ongoing, and subjective experience of physical, emotional and/or cognitive exhaustion that is not in proportion to recent activity and disrupts daily functioning. It can profoundly affect personal relationships, academic or work performance, and overall quality of life (Christen et al., 2020). It is essential to distinguish between fatigue and mood disorders such as depression, as both may present similarly but require different approaches. Due to its complex and multidimensional nature, CRF requires personalized, interdisciplinary management strategies to effectively support recovery and enhance long-term well-being (Berger et al., 2015).



FATIGUE

EU-CAYAS-NET RECOMMENDATIONS

1 Healthcare providers and survivors of CAYA cancers should be aware that CAYA cancer survivors are at risk for cancer-related fatigue. Main risk factors for CRF are:

- Psychological distress
- Late effects or health problems, pain, relapse, older age at follow-up
- Radiotherapy

2 For all CAYA cancer survivors: a medical history on survivors' feelings of tiredness and exhaustion is recommended regularly (at every long-term follow-up visit, or at general medical checkups, at least once a year).

3 Psychosocial diagnostics on suspicion of fatigue is recommended at the conclusion of intensive oncologic therapy and in the course of follow-up care.

4 For CAYA cancer survivors with an indication for CRF from medical history/anamnesis:

- Further testing with a validated fatigue measurement is recommended.
- Screening for underlying medical conditions that may cause fatigue is recommended.

5 Screen for physical sources of fatigue, such as anemia, sleep disturbances, nutritional deficiencies, cardiomyopathy, pulmonary fibrosis, hypothyroidism, or other endocrinopathy.

6 Fatigue is considered as a significant disease- and treatment-related psychosocial stressor that can profoundly affect daily life and participation.

7 If fatigue is diagnosed with a validated fatigue measure and if no underlying medical condition is identified:

- Referral to a specialist in fatigue (or more generic specialist such as psychologist, physiotherapist, or other relevant specialist) is recommended.
- Interventions that are useful:
  - Physical activity
  - Education about CRF
  - Relaxation and mindfulness
  - Cognitive behavioral therapy
  - Adventure based training

FATIGUE

EU-CAYAS-NET RECOMMENDATIONS

8 Referral to specialties such as endocrinology, sleep lab/study, or nutrition as indicated.

9 Referral to psychology for behavioral intervention for emotional difficulties contributing to sleep and fatigue.

10 If appropriate, HCPs should provide information on possible pharmacological treatment approaches.

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

EDUCATION & CAREER SUPPORT

Sources: Devine et al., (2022); Thompson et al., (2015); Lown et al., (2015); Schröder et al., (2019).

EDUCATION & CAREER SUPPORT

CAYA cancer can significantly disrupt educational and professional trajectories — both during treatment and in the years that follow. During treatment, young people with cancer often face frequent, involuntary absences from school or work, ranging from primary school to university or from training to employment, depending on their age (Sisk et al., 2020). At the same time, schools and workplaces are often not fully aware of the specific challenges and needs associated with the disease and its treatment. In many cases, there is limited understanding of the types of additional support that can be offered to help manage these challenges (EU-CAYAS-NET, 2024b).

After treatment, returning to school, training, or work, or even starting them for the first time, can pose major difficulties. Reintegrating into everyday life can be socially and emotionally exhausting after a prolonged absence. Some survivors may experience exclusion or even discrimination due to differences between them and their peers who have not been affected by cancer. In addition, long-term physical, cognitive, emotional, or social effects of the disease or its treatment can make it hard to regain previous levels of performance, ability, or stress tolerance. It is important to note that these late effects may not emerge until years later and can result in setbacks that call for renewed support. As a result, survivors may need additional educational or vocational support—or may even have to reconsider and adjust their career or training goals altogether, as certain paths may no longer be feasible. The goal must always be to ensure that education aligns with the abilities, personality, and future plans of the CAYA cancer survivors (EU-CAYAS-NET, 2024a).

NOTE: This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.

EDUCATION & CAREER SUPPORT

RECOMMENDATIONS FOR EDUCATION

1

Who needs surveillance?

Healthcare providers, teachers, caregivers, and survivors of CAYA cancers, and survivors' schools should be aware that, on a group level, survivors of CAYA cancer are at risk for:

- lower educational achievement
- experiencing a delay in completing their education
- requiring educational accommodations

2

Particular attention is needed for survivors of CAYA cancer with the following risk factors for lower educational achievement: primary diagnosis of CNS tumor, CNS-directed therapies, impaired neurocognitive functioning, non-white race or immigration status, and parents' lower level of education (Devine et al., 2022).

3

At what age or time should surveillance be initiated?

Surveillance of educational outcomes is recommended for all ages to begin at diagnosis and continue through survivorship until young adulthood (Devine et al., 2022).

4

What surveillance modality should be used? At what frequency?

Regular assessment of educational outcomes via parent- or self-report is recommended at every long-term follow-up visit or general medical checkup at least annually until education is completed (Devine et al., 2022).

5

Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for:

- adverse educational and/or vocational progress, social and relationship difficulties;
- distress, anxiety, and depression; and
- risky health behaviours (Lown et al., 2015).

6

Assessment of support needs for reintegration in everyday life/ kindergarten/ school/ workplace at the conclusion of intensive oncological treatment and in the course of follow-up care is recommended (Schröder et al., 2019).

7

Documentation of educational problems in the survivor's medical record is recommended to facilitate sharing with all members of the care team (Devine et al., 2022).

EDUCATION & CAREER SUPPORT

RECOMMENDATIONS FOR EDUCATION

8 Referral to an educational specialist, psychologist, and/or social worker is recommended for assessment and implementation of relevant educational and/or disability services for survivors who report educational problems upon screening (Devine et al., 2022).

9 In collaboration with parents, school-aged youth diagnosed with cancer should receive school reentry support that focuses on providing information to school personnel about the patient's diagnosis, treatment and implications for the school environment and provides recommendations to support the child's school experience (Thompson et al., 2015).

10 Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the health care team (Thompson et al., 2015).

EDUCATION & CAREER SUPPORT

RECOMMENDATIONS FOR EMPLOYMENT

1

Who needs surveillance?

Healthcare providers, caregivers and survivors of CAYA cancers should be aware that, on a group level, survivors of CAYA cancer are at risk for unemployment. Particular attention is needed for survivors of CAYA cancer with the following risk factors for unemployment: female sex, lower educational achievement, primary diagnosis of CNS tumor, CNS-directed therapies, any adverse long-term side effects, impaired neurocognitive functioning, second malignancy or recurrence, psychological distress, and physical disability (Devine et al., 2022).

2

At what age or time should surveillance be initiated?

Vocational planning and employment surveillance is recommended beginning in adolescence to support survivors to transition from education to employment (Devine et al., 2022).

3

What surveillance modality should be used? At what frequency?

Regular assessment of vocational planning and employment status via parent- or self-report is recommended at every long-term follow-up visit or general medical checkup (Devine et al., 2022).

4

Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for:

- adverse educational and/or vocational progress, social and relationship difficulties;
- distress, anxiety, and depression; and
- risky health behaviours (Lown et al., 2015).

5

Assessment of support needs for reintegration in everyday life/ kindergarten/ school/ workplace at the conclusion of intensive oncological treatment and in the course of follow-up care (Schröder et al., 2019).

6

Referral to a vocational counsellor, psychologist, and/or social worker for assessment and implementation of relevant vocational and/or disability services is recommended for survivors who report vocational problems upon screening (Devine et al., 2022).

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

FERTILITY

Sources: Children's Oncology Group (2022); Mulder et al., (2021); Schröder et al., (2019).

FERTILITY

CAYA cancer patients and survivors are at increased risk for fertility problems and infertility if treatment adversely impacts reproductive function. For young patients, the risk of temporary or permanent infertility can have profound psychosocial implications that affect emotional well-being, identity development, intimate relationships, and future life planning. Fertility-related distress often begins at diagnosis, when patients and families must make urgent, complex decisions about fertility preservation under emotional duress and with limited time and information. This distress can persist throughout treatment and into survivorship, particularly if reproductive capacity is impaired or remains uncertain (Din et al., 2023). Given these emotional and social consequences of compromised fertility or potential loss, it is essential that fertility-related care is integrated as a standard component of oncological treatment and psychosocial support. This standard of care recognizes fertility as a key aspect of survivorship and affirms the need for early, consistent, and compassionate communication throughout the cancer care continuum.

This section on fertility focuses primarily on the psychosocial aspects and communication surrounding fertility preservation and reproductive health in the context of cancer. It emphasizes the emotional impact, decision making support, and the importance of timely age-appropriate conversations. For detailed guidance on medical procedures and clinical protocols, we refer to existing medical standards and specialist guidelines in the field.

NOTE: This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.

FERTILITY

RECOMMENDATIONS

1

Fertility preservation and the risk of infertility should be discussed as early as possible, before treatment starts to reduce distress and improve quality of life (COG, 2022).

2

General - HCP should:

- Be familiar with the latest evidence-based recommendations, institutional policies and professional educational resources on infertility risk and fertility preservation procedures (Mulder et al., 2020).
- Maintain currency with training where appropriate (Mulder et al., 2020).
- Refer patients to psychosocial providers when they are distressed about potential infertility (COG, 2022).

3

Provision of information about treatment-related infertility risk and fertility preservation - HCP should:

- HCP should deliver clear, comprehensive and age-appropriate information in a professional, neutral and empathic manner and consider the family's cultural/religious beliefs (Mulder et al., 2020).
- Provide up-to-date written and/or online educational resources to patients and their parents/caregivers/partner in appropriate languages and health literacy levels (Mulder et al., 2020).

4

Communicating treatment-related infertility risk and fertility preservation - HCP should:

- Involve patients and/or their parents/caregivers/partners (Mulder et al., 2020).
- Offer a private conversation with the patient depending on age (Mulder et al., 2020).
- Offer special counselling to adolescents (Schröder et al., 2019).
- Offer a separate conversation with parents/caregivers/partners after consent or assent of the patient (Mulder et al., 2020).
- Consider the patient's age, developmental status, and the family's cultural/religious beliefs (Mulder et al., 2020).
- Provide emotional support to patients and their parents/caregivers/partners during counselling about treatment-related infertility risk and fertility preservation and prompt psychosocial specialist referrals as appropriate (Mulder et al., 2020).
- Initiate counselling as early as possible after a cancer diagnosis and treatment plan are established and when a change in disease status occurs that requires treatment intensification with gonadal toxic agents/modalities (Mulder et al., 2020).
- Offer counselling on an ongoing basis during treatment and throughout survivorship because the infertility risk or patient's ideas may change (Mulder et al., 2020).

5

Hospitals should:

- Establish referral pathways for accessing fertility specialists or fertility specialist centres where appropriate (Mulder et al., 2020).

Ethical issues related to fertility preservation (Good practice statements) - HCP should:

- Foster the autonomy of the patient (Mulder et al., 2020).
- Assess the patient's emotional, psychological and intellectual status as part of the informed consent process (Mulder et al., 2020).
- Ensure that decisions about fertility preservation are driven by patient's best interest and not by own interest and/or interest of parents/caregivers/partners (Mulder et al., 2020).
- Encourage patients to consider the risks, and the medical, social, and ethical contingencies of fertility preservation procedures as well as future use of frozen tissue (Mulder et al., 2020).
- Address the uncertainty of future technologies during counselling about infertility risk and fertility preservation procedures (Mulder et al., 2020).
- Include societal and ethical values connected to social parenthood (adoption) and the potential discrimination when applying for adoption in the discussions with the patient and parents/caregivers/partners about adoption (Mulder et al., 2020).
- Include a two-stage consent process with patients and/or their families/caregivers/partners: 1) at diagnosis when the decision about harvesting and storing tissue is made and 2) after therapy at a developmentally appropriate age when the decision of whether and how to use the stored material is made (Mulder et al., 2020).
- Be aware of the importance to determine upfront with patients and their families/caregivers/partners the access of researchers to their stored gametes (Mulder et al., 2020).
- Be aware of the importance to determine upfront with patients and their families/caregivers/partners the disposition of gametes and/or preserved tissue in the event of patients death (Mulder et al., 2020).
- Be aware of possible conflicts of interest between the needs of patients/parents/caregivers and the potential short- and long-term financial costs involved in fertility preservation procedures and storage, as well as post-treatment costs associated with pursuing family-building (Mulder et al., 2020).

FERTILITY

RECOMMENDATIONS

7

HCP should:

- Be familiar with the latest evidence-based recommendations, institutional policies and professional educational resources on infertility risk and fertility preservation procedures (Mulder et al., 2020).
- Maintain currency with training where appropriate (Mulder et al., 2020).
- Establish referral pathways for accessing fertility specialists (Mulder et al., 2020)
- Provide up-to-date written and/or online educational resources to patients and their parents/caregivers/partner in appropriate languages and health literacy levels (Mulder et al., 2020).

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

CHRONIC PAIN

ADAPTED AFTER: CHILDREN’S ONCOLOGY GROUP (2022).

CHRONIC PAIN

Chronic pain is a prevalent and often under-recognized consequence of cancer and its treatment in CAYAs. Unlike acute pain, which can serve a protective function, chronic pain can persist beyond the expected period of healing and significantly impact a young persons physical, emotional, cognitive, and social functioning. It is closely linked to psychological distress, reduced quality of life, and disruptions in school attendance, peer relationships, and family dynamics. In CAYA oncology, a comprehensive approach to pain management must extend beyond pharmacological interventions to include psychosocial, behavioural, and rehabilitative strategies (Schulte et al., 2020). Early identification and continuous assessment of pain, combined with individualized, developmentally appropriate interventions, are essential.

Chronic pain should be addressed within a joint standard of care that integrates physical health, mental health, and psychosocial support, ensuring coordinated efforts between oncologists, psychologists, pain specialists, physiotherapists, social workers, and educators.

Such an integrated model promotes resilience and improves functional outcomes. By embedding pain management into the broader framework of psychosocial care, CAYAs can be supported more effectively in the recovery, suffering can be reduced, and their overall well-being enhanced.

CHRONIC PAIN

EU-CAYAS-NET RECOMMENDATIONS

1 In CAYAS with chronic pain, physical therapies may be used, either alone or in combination with other treatments

2 a) In CAYAS with chronic pain, psychological management through cognitive behavioral therapy and related interventions (acceptance and commitment therapy, behavioral therapy and relaxation therapy) may be used. b) Psychological therapy may be delivered either face-to-face or remotely, or using a combined approach. c) This may include alternative therapies like music, art or play therapy especially in children dealing with chronic pain

3 In CAYAS with chronic pain, appropriate pharmacological management tailored to specific indications and conditions may be used

4 a) Appropriate pharmacological management tailored to specific indications may include the use of morphine under the principles of opioid stewardship, for end-of-life-care. b) In children with chronic pain associated with life-limiting conditions, morphine may be given by appropriately trained healthcare providers, under the principles of opioid stewardship.

CHRONIC PAIN
EU-CAYAS-NET RECOMMENDATIONS

Best practices for the clinical management of chronic pain in CAYA cancer patients and survivors:

1. CAYAS with chronic pain and their families and caregivers must be cared for from a biopsychosocial perspective; pain should not be treated simply as a biomedical problem

2. A comprehensive biopsychosocial assessment is essential to inform pain management and planning. As a component of this assessment, healthcare providers should use age-, context- and culturally appropriate tools to screen for, and monitor, pain intensity and its impact on the quality of life of the child and family

3. CAYAS with chronic pain must have a thorough evaluation of any underlying conditions and access to appropriate treatment for those conditions, in addition to appropriate interventions for the management of pain. Chronic pain in childhood, adolescence, or young adulthood often exists with comorbid conditions affecting the child's health, and social and emotional well-being, which require concurrent management.

4. CAYAS presenting with chronic pain should be assessed by healthcare providers who are skilled and experienced in the evaluation, diagnosis, and management of chronic pain.

5. Management, whether with physical therapies, psychological or pharmacological interventions, or combinations thereof, should be tailored to the child's, adolescent's or young adult's health; underlying condition; developmental age; physical, language and cognitive abilities; and social and emotional needs

6. Care of young people with chronic pain should be patient/survivor- and family-centred. That is, the young person's care should:
    - focus on, and be organized around, the health needs, preferences and expectations of the young person, and their families and communities;
    - be tailored to the family's values, culture, preferences and resources; and
    - promote engagement and support young people and their families to play an active role in care through informed and shared decision-making

CHRONIC PAIN

EU-CAYAS-NET RECOMMENDATIONS

7 Families and caregivers must receive timely and accurate information. Shared decision-making and clear communication are essential to good clinical care. Communication with patients should correspond to their cognitive, developmental, and language abilities. There must be adequate time in a comfortable space for discussions and questions regarding care management plans and progress.

8 The young person and their family and caregivers should be treated in a comprehensive and integrated manner: all aspects of the young person's development and well-being must be attended to, including their cognitive, emotional, and physical health. Moreover, the young person's educational, culture, and social needs and goals must be addressed as part of the care management plan.

9 In CAYAS with chronic pain, an interdisciplinary, multimodal approach should be adopted which is tailored to the needs and desires of the child, family, and caregivers, and to available resources. The biopsychosocial model of pain supports the use of multiple modalities to address the management of chronic pain.

10 Policy-makers, programme managers, and healthcare providers, as well as families and caregivers must attend to opioid stewardship to ensure the rational and cautious use of opioids. The essential practices of opioid stewardship in CAYAS include:

- Opioids must only be used for appropriate indications and prescribed by trained providers, with careful assessment of the benefits and risks. The use of opioids by individuals, their impact on pain and their adverse effects must be continuously monitored and evaluated by trained providers.
- The prescribing provider must have a clear plan for the continuation, tapering or discontinuation of opioids according to the child's condition. The young person and family must be apprised of the plan and its rationale.
- There must be due attention to procurement, storage, and the disposal of unused opioids.

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

TRAINING AND COMMUNICATION FOR PSYCHOSOCIAL HCP

ADAPTED AFTER: PATENAUDE, PELLETIER & BINGEN (2015); (ALSO SEE SCHRÖDER ET AL., 2019).

TRAINING AND COMMUNICATION FOR PSYCHOSOCIAL HCP

High-quality psychosocial care in paediatric oncology relies on well-trained, effectively integrated professionals who can communicate openly and collaboratively with medical teams, patients, and families. Young people living with and beyond cancer, as well as their caregivers and families, face complex emotional, developmental, and practical challenges that require coordinated, developmentally appropriate support from healthcare providers. Psychosocial HCPs play a key role in addressing these needs and must be recognized as essential members of the interdisciplinary care team.

Clear standards for communication, documentation, and training are necessary to ensure consistent, ethical, and effective psychosocial care. As outlined by Patenaude, Pelletier, and Bingen (2015), and supported by later recommendations (Schröder et al., 2019), psychosocial providers should have full access to relevant medical information, participate in care planning meetings, and contribute expert interpretation of psychological findings to inform clinical decisions. Adherence to institutional and legal documentation standards, along with ethical guidelines, further safeguards the quality of care.

Crucially, psychosocial providers must possess specialized training and credentials in their discipline and receive ongoing supervision or peer support. This ensures their ability to deliver sensitive, developmentally appropriate interventions for CAYAs coping with serious and chronic illness. By establishing shared standards for communication, documentation, and professional competency, oncology teams can deliver truly patient- and family centred care that meets the psychological as well as medical needs of every child.

TRAINING AND COMMUNICATION FOR PSYCHOSOCIAL HCP

EU-CAYAS-NET RECOMMENDATIONS

1 Open, respectful communication and collaboration among medical and psychosocial providers, patients, and families is essential for effective patient- and family-centred care. Psychosocial professionals should be integrated into CAYA oncology care settings as integral team members and be participants in patient care rounds/meetings.

2 Psychosocial providers for CAYA cancer patients and survivors should have access to medical records and relevant reports should be shared among care team professionals, with psychological report interpretation provided by psychosocial providers to staff and patients/families for patient care planning. Psychosocial providers should follow documentation policies of the health system where they practise in accordance with ethical requirements of their profession and state/ laws.

3 Psychosocial providers for CAYA cancer patients and survivors must have special training and education and be credentialed in their discipline to provide developmentally appropriate assessment and treatment for children with serious, chronic illness is crucial as well as ongoing relevant supervision/peer support.

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

PEER SUPPORT

The content presented in this chapter draws from ongoing interdisciplinary discussions and collaborative exchanges within the EU-CAYAS-NET project.

PEER SUPPORT

Peer support plays a vital role in the psychosocial wellbeing of CAYA cancer survivors. The shared lived experience of having faced cancer at a young age, provides a unique foundation for mutual understanding, validation, and trust which differs greatly from professional therapeutic relationships. Many CAYA survivors report feeling isolated from their peers during and after treatment, especially when developmental milestones such as education, relationships, and independence are disrupted. Engaging with others who have experienced something similar can reduce feelings of alienation, normalize complex emotions, and promote resilience. Peer support can take many forms, including informal connections, structured programs, online communities, and organized survivors networks. Evidence suggests that such engagement not only improves emotional well-being but also fosters empowerment, advocacy, and long-term adaptation. As such, peer support should be considered a key component of survivorship care, and systems should be in place to facilitate safe, accessible and age-appropriate opportunities for CAYAs to connect with others.

Disclaimer: Even though peer support is not yet universally recognized as a stand-alone standard in survivorship care, we believe it should be established and upheld as its own standard of care within psychosocial follow-up, given its well-documented value in fostering emotional resilience, reducing isolation, and promoting long-term well-being. The importance of this topic to the survivor community, and its relevance across all phases of the care continuum, warrants dedicated attention and structured integration into standard practice. The content presented in this chapter draws from ongoing interdisciplinary discussions and collaborative exchanges within the EU-CAYAS-NET project, reflecting the lived experiences and perspectives of survivors, peer supporters, patient advocates, and healthcare professionals. While it incorporates elements of existing practices, it does not yet represent a formally established or evidence-graded clinical guideline. Development of a comprehensive, evidence-based standard for peer support will require future steps including systematic review, consensus-building, and validation across diverse healthcare settings.

PEER SUPPORT

EU-CAYAS-NET RECOMMENDATIONS

1

Access and Inclusion

- Survivorship care plans should ensure that all CAYA patients are informed about available peer support opportunities
- Programs must be inclusive, culturally responsive, and accessible to diverse populations including marginalized or underrepresented communities

2

Integration into Care

- Peer support should be offered as a standard component of survivorship care alongside medical and psychosocial follow-up care
- Clinicians and care teams should collaborate with certified peer mentors, survivor networks, and youth organizations to refer and co-develop appropriate support structures

3

Training and Quality

- Peer supporters should receive training in active listening, boundaries, confidentiality, trauma-informed care, and mental health awareness
- Programs should be regularly evaluated for safety, effectiveness, and survivor satisfaction

4

Transition and Continuity

- Peer support services should be adaptable across the care continuum - from treatment to post-treatment and long-term survivorship
- Special attention should be given to transitional phases, such as re-entry to school or work, or transition to adult care systems

5

Responsibilities of Care Providers and Institutions

- Recognize peer support as a vital element of psychosocial care
- Include survivor voices in service planning, program delivery, and policy development

EU-CAYAS-NET RECOMMENDATIONS FOR MENTAL HEALTH AND PSYCHOSOCIAL CARE IN CAYA CANCER SURVIVORSHIP

GRIEVING & LOSS IN SURVIVORSHIP

The content presented in this chapter draws from ongoing interdisciplinary discussions and collaborative exchanges within the EU-CAYAS-NET project.

GRIEVING & LOSS IN SURVIVORSHIP

Grief is a common but often under-recognized aspect in cancer survivorship. Many individuals carry deep and complex feelings of loss that persist long after treatment ends. These losses may include changes in physical function, body image, fertility, independence, social roles, and future plans. For young survivors in particular, the disruption to developmental milestones, like education, career progression, or family-building can lead to a sense of disconnection from the social environment and a mourning of a “lost” version of their expected life path. Grief in this context is not always linked to death, but to the intangible losses that accompany survival itself. These experiences may surface gradually, and can be complicated by a lack of societal or clinical acknowledgment.

Another aspect of grieving and loss in survivorship is survivor’s guilt. Survivor’s guilt refers to the psychological burden that can arise when an individual survives a life-threatening illness while others do not. Among cancer survivors, this phenomenon may manifest in feelings of unworthiness, self-blame, or emotional conflict related to surviving when peers, fellow patients, or friends have died. These emotions can be especially pronounced in AYA survivors, who often form strong bonds with others undergoing similar experiences. Survivor’s guilt may lead individuals to minimize their own struggles, suppress feelings of joy or achievement, or question their right to a future others were denied. While survivor’s guilt is a natural emotional response, it can contribute to symptoms of depression, anxiety, and social withdrawal if left unaddressed.

Disclaimer: Even though addressing Grieving and Loss in survivorship care is not a stand-alone-standard, but should be a standard element in providing emotional and psychological support, given the importance of this topic to the survivor community and its relevance across the care continuum, we felt it essential to include it in this joint standard as a foundational reference point for further development. The content presented in this chapter is based on ongoing interdisciplinary discussions and collaborative exchanges within the EU-CAYAS-NET project, reflecting the shared experiences and perspectives of survivors, patient advocates, and professionals. While it draws on existing practices and expert consensus, it does not yet represent a formally established or evidence-graded clinical guideline. A comprehensive, evidence-based practice will need to be developed in future steps through systematic review and broader validation across diverse healthcare settings.

GRIEFING & LOSS IN SURVIVORSHIP

EU-CAYAS-NET RECOMMENDATIONS

1

Acknowledgement and Validation

- Survivorship care plans must include formal recognition of grief and loss as part of survivorship
- Survivors should be given language and space to articulate the emotional impact of what has been lost, beyond physical health

2

Routine Psychosocial Screening

- Grief-related distress should be routinely screened using age-appropriate tools during survivorship follow-up visits
- Particular attention should be paid to transitional life stages (e.g., end of treatment, returning to work school or work, peer reintegration) when grief may intensify

3

Access to Grief-Informed Support

- Survivors should have timely access to trained mental health professionals offering grief counseling, narrative therapy, and trauma-informed care
- Programs should provide developmentally tailored grief support, including play-based interventions for children, group therapy for teens, and identity-based support for young adults

4

Peer and Expressive Pathways

- Survivors must be offered opportunities to process grief through peer discussion groups, creative arts, journaling, and digital story telling
- Grief support should be adaptable to individual preferences, cultural contexts, and levels of openness

5

Provider Education and System Integration

- Multidisciplinary care teams should receive training on recognizing grief responses and responding with empathy, appropriate language, and referral pathways
- Grief support should be integrated into survivorship protocols, not treated as ancillary or reactive

Grieving is a normal, healthy, and often necessary part of adapting to life after cancer. Recognizing and supporting diverse forms of loss experienced by CAYA survivors is a critical component of compassionate, comprehensive survivorship care.

SIDE-BY-SIDE COMPARISON

The following section presents a side-by-side comparison of the original standards and our adapted versions. All modifications are highlighted in bold to ensure transparency and traceability of changes.

SOCIAL ASPECTS

Sources: Pelletier & Bona (2015).

Existing Standards	Our Recommendations
1. Pediatric oncology families are at high risk for financial burden during cancer treatment with associated negative implications for quality of life and parental emotional health. 2. Assessment of risk for financial hardship should be incorporated at time of diagnosis for all pediatric oncology families. Domains: risk factors for financial hardship during therapy including: pre-existing low-income or financial hardship, single parent status, distance from treating center, anticipated long/intense treatment protocol, and parental employment status (Pelletier & Bona, 2015). 3. Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) should be offered based on results of family assessment (Pelletier & Bona, 2015). 4. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship and bereavement (Pelletier & Bona, 2015).	**Children, adolescents, and young adults affected by cancer, as well as their families** are at high risk for financial burden, **social isolation and gaps in education and career support** during and after cancer treatment with associated negative implications for quality of life **and participation for CAYAS'** and parental emotional health. **The social dimension should be addressed in follow-up care. This includes:** - **Socioeconomic factors (material living conditions, education, employment),** - **Sociocultural factors (language, country of origin),** - **Socioecological factors (mobility, geographical/environmental factors),** - **Social relationships (social network, social support)**

SOCIAL ASPECTS

Sources: Pelletier & Bona (2015).

Existing Standards	Our Recommendations
	1. Assessment of risk for financial hardship should be incorporated already at time of diagnosis for all young people and their families affected by cancer. Domains: risk factors for financial hardship during therapy including: pre-existing low-income or financial hardship, single parent status, distance from treating center, anticipated long/intense treatment protocol, and **education and (parental)** employment status. 2. Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) should be offered based on results of **(family)** assessment. 3. Longitudinal reassessment and intervention should continue throughout the cancer treatment trajectory and into survivorship and bereavement. 4. **Useful interventions are: support with educational and training paths, job search, reintegration into the job, and job maintenance for CAYA cancer survivors (especially when facing physical or psychosocial side or late effects) and caregivers.**

PSYCHOLOGY – BASIC CARE

Sources: Kazak et al., (2015); Lown et al., (2015); Marchak et al., (2022); Schröder et al., (2019).

Existing Standards	Our Recommendations
1. Youth with cancer and their family members should routinely receive systematic assessment of their psychosocial health care needs. (Kazak et al., 2015).	1. Youth with cancer and their family members should routinely receive systematic assessment of their psychosocial health care needs
2. Early psychosocial support should be aimed at the prevention of psychological sequelae and comorbidities in patients and relatives. It should also serve to prevent social, emotional and cognitive late effects/developmental disorders. Psychosocial care should make the prevention of social isolation, social difficulties, and excessive familial stress possible (Schröder et al., 2019).	2. Early psychosocial support should be aimed at the prevention of psychological sequelae and comorbidities in patients and family members. It should also serve to prevent social, emotional, and cognitive late effects/developmental disorders. Psychosocial care should make the prevention of social isolation, social difficulties and excessive familial stress possible
3. Healthcare providers should be aware that mental disorders and symptoms can be present at diagnosis or arise during treatment for CAYA cancer. Mental health surveillance is important for patients throughout treatment for CAYA cancer. Mental health surveillance is recommended for all survivors at all ages to begin at their first follow-up and continue throughout the lifespan. It is recommended at every follow-up visit (at least once a year) (Marchak et al., 2022).	3. Healthcare providers should be aware that mental disorders and symptoms can be present at diagnosis or arise during treatment for CAYA cancer. Mental health surveillance is important for patients throughout treatment for CAYA cancer. Mental health surveillance is recommended for all survivors at all ages to begin at their first follow-up and continue throughout the lifespan. It is recommended at every follow-up visit (at least once a year)

PSYCHOLOGY - BASIC CARE

Sources: Kazak et al., (2015); Lown et al., (2015); Marchak et al., (2022); Schröder et al., (2019).

Existing Standards	Our Recommendations
a. Surveillance is recommended for: Adverse educational and/or vocational progress, social and relationship difficulties, depression & mood disorder, anxiety, psychological distress, post-traumatic stress, behavioral problems, risky health behaviors, suicidal ideation (The main risk factors for mental disorders and symptoms in survivors of CAYA cancer are unemployment, lower educational achievement, late effects, experiencing pain, and female sex) (Marchak et al., 2022)	a. Surveillance is recommended for: Adverse educational and/or vocational progress, social and relationship difficulties, depression & mood disorder, anxiety, psychological distress, post-traumatic stress, behavioral problems, risky health behaviors, suicidal ideation. (The main risk factors for mental disorders and symptoms in survivors of CAYA cancer are unemployment, lower educational achievement, late effects, experiencing pain, and female sex)
b. Modality of surveillance: A medical history focused on survivor's mental health. If there is an indication for mental health problems: further testing with a validated parent- and/or self-report measure by a mental health professional (Marchak et al., 2022)	b. Modality of surveillance: A medical history focused on survivor's mental health. If there is an indication for mental health problems: further testing with a validated parent- and/or self-report measure by a mental health professional
c. If abnormalities are identified: Healthcare providers and survivors of CAYA cancer should be aware of standardly recommended care	c. If abnormalities are identified: Healthcare providers and survivors of CAYA cancer should be aware of standardly recommended care

PSYCHOLOGY - BASIC CARE

Sources: Kazak et al., (2015); Lown et al., (2015); Marchak et al., (2022); Schröder et al., (2019).

Existing Standards	Our Recommendations
i. Prompt referral of survivors reporting mental health symptoms to a mental health professional for diagnostic and risk assessment (Marchak et al., 2022)	i. Prompt referral of survivors reporting mental health symptoms to a mental health professional for diagnostic and risk assessment
ii. Immediate referral of survivors with severe mental health problems that may significantly interfere with their safety (e.g. psychosis, severe depression, suicidal ideation, self-harming behaviors or impulses) to a mental health professional (e.g. psychiatrist, psychologist, or local mental health crisis services) (Marchak et al., 2022).	ii. Immediate referral of survivors with severe mental health problems that may significantly interfere with their safety (e.g. psychosis, severe depression, suicidal ideation, self-harming behaviors or impulses) to a mental health professional (e.g. psychiatrist, psychologist, or local mental health crisis services)
iii. Cognitive behavioral therapy for the treatment of anxiety, depression and post-traumatic stress symptoms (Marchak et al., 2022).	iii. Cognitive behavioral therapy for the treatment of anxiety, depression and post-traumatic stress symptoms
4. Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for: (1a) adverse educational and/or vocational progress, social and relation-ship difficulties; (1b) distress, anxiety, and depression; and(1c) risky health behaviors. (Lown et al., 2015).	4. Long-term survivors of childhood and adolescent cancers should receive yearly psychosocial screening for: (1a) adverse educational and/or vocational progress, social and relation-ship difficulties; (1b) distress, anxiety, and depression; and (1c) risky health behaviors.
	5. **Adolescent and young adult cancer survivors and their family members should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends, and repeated at each follow-up visit.**

PSYCHOLOGY – BASIC CARE

Sources: Kazak et al., (2015); Lown et al., (2015); Marchak et al., (2022); Schröder et al., (2019).

Existing Standards	Our Recommendations
	6. **It is essential to be aware of the distinction between appropriate emotional reactions to disease- or treatment-related stressors and emotional disorders of different (non-cancer-related) origin.** 7. **Psychosocial services should be accessible and covered by health insurances/national health care systems.** 8. **Youth with and beyond cancer and their family members should be informed about available services.**

SURVEILLANCE - NEUROPSYCHOLOGY

Sources: Annett, Patel & Phipps (2015); Children's Oncology Group (2022); Schröder et al., (2019); Scottish Intercollegiate Guidelines Network (2013).

Existing Standards	Our Recommendations
1. Regular review of neurological function should be part of normal follow-up. If a problem is suspected, the patient should be referred to a psychologist for a neuropsychological assessment (SIGN, 2013)	1. Regular review of neurological and neuropsychological function should be part of regular follow-up care. If a problem is suspected, the patient/**survivor** should be referred to a psychologist for a neuropsychological assessment
2. Children with brain tumors and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment (Annett et al., 2015; Schröder et al., 2019)	2. Children, **adolescents and young adults** with brain tumors and others are at high risk for neuropsychological deficits as a result of cancer treatment. **Therefore, there should be monitoring for neuropsychological deficits during and after treatment.**
a. Children with cancer who are due to receive cranial irradiation should undergo a neuropsychological assessment at the start of treatment. The assessment should be repeated annually, to monitor changes over time (SIGN, 2013)	a. **CAYAs** with cancer who are due to receive cranial irradiation should undergo a neuropsychological assessment at the start of treatment. The assessment should be repeated annually, to monitor changes over time.
b. In the case of certain risk factors such as brain tumours, ALL/AML, or following certain forms of medical treatment or surgery (e.g. neurosurgery, radiotherapy of the central nervous system, intrathecal therapy, stem cell transplants), neuropsychological diagnostics are recommended as a central element of psychosocial care (e.g. Boulet-Craig et al., 2018; Van Der Plas et al., 2018). (Schröder et al., 2019)	b. In the case of certain risk factors such as brain tumours, ALL/AML, or following certain forms of medical treatment or surgery (e.g. neurosurgery, radiotherapy of the central nervous system, intrathecal therapy, stem cell transplants), neuropsychological diagnostics are recommended as a central element of psychosocial care (e.g. Boulet-Craig et al., 2018; Van Der Plas et al., 2018).
3. Healthcare and education professionals should be aware that the treatment of childhood cancer may have an impact on neurological function in later life, particularly if irradiation of the brain occurs at a young age (SIGN, 2013)	3. Healthcare and education professionals should be aware that the treatment of childhood cancer may have an impact on neurological function in later life, particularly if irradiation of the brain occurs at a young age.

SURVEILLANCE – NEUROPSYCHOLOGY

Sources: Annett, Patel & Phipps (2015); Children's Oncology Group (2022); Schröder et al., (2019); Scottish Intercollegiate Guidelines Network (2013).

Existing Standards	Our Recommendations
	4. **Structured counseling and guidance should be provided for caregivers, as well as for educational institutions and employers, to support the young persons reintegration and ongoing development within these settings.** 5. **Ongoing monitoring and age-appropriate tools should be offered to support CAYAs in the self-management of cognitive and emotional challenges related to their disease and/or treatment**

PSYCHOEDUCATION, ANTICIPATORY GUIDANCE, & PROCEDURAL PREPARATION

Sources: Flowers & Birnie (2015); Lown et al., (2015); Schröder et al., (2019); Thompson & Young-Saleme (2015).

Existing Standards	Our Recommendations
1. Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care (Thompson & Young-Saleme, 2015).	1. Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care, **from diagnosis into survivorship.**
2. Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit (Lown et al., 2015).	2. Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit.
3. Psychosocial interventions aimed at supporting the processing of complex information have proven to be effective information and orientation programmes. (materials also for transition to follow-up care/rehabilitation)[...] there is expert-based consensus that psychosocial interventions aimed at giving support in processing complex issues have proved to be effective means of information and orientation (Schröder et al., 2019).	3. Psychosocial interventions aimed at supporting the processing of complex information have proven to be effective information and orientation programmes. [...] there is expert-based consensus that psychosocial interventions aimed at giving support in processing complex issues have proved to be effective means of information and orientation.
4. All youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth with cancer should receive psychological intervention for invasive medical procedures (Flowers & Birnie, 2015).	4. **Psychoeducation should continue after treatment and into survivorship regarding topics like transition, rehabilitation, fertility, sexual health, independent living, return to work/education, emotional burden, and information for psychosocial problems that could arise years later .**

PSYCHOEDUCATION, ANTICIPATORY GUIDANCE, & PROCEDURAL PREPARATION

Sources: Flowers & Birnie (2015); Lown et al., (2015); Schröder et al., (2019); Thompson & Young-Saleme (2015).

Existing Standards	Our Recommendations
	4. All youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth with cancer should receive psychological intervention for invasive medical procedures.

INTERVENTIONS FOR EMOTIONAL & SOCIAL SUPPORT – FOR PATIENTS

Sources: Christiansen et al., (2015); Steele et al., (2015); (also see Schröder et al., 2019).

Existing Standards	Our Recommendations
1. All youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed (Steele et al., 2015). 2. Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patient's unique characteristics, including developmental level, preferences for social interaction, and health status (Christiansen et al., 2015). 3. The patients, parent(s), and a psychosocial team member (e.g. designee from child life, psychology, social work, or nursing) should participate in this evaluation at time of diagnosis, throughout treatment, and when the patient enters survivorship; it may be helpful to include school personnel or additional providers (Christiansen et al., 2015).	1. All youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory, **from diagnosis into survivorship** and access to psychiatry as needed. 2. **Dedicated support for adolescents and young adults is recommended and should include, among other things, topics such as body image, relationships, fertility, disability, and communication with friends/the social environment.** 3. Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patient's unique characteristics, including developmental level, preferences for social interaction, and health status 4. The patients, parent(s), and a psychosocial team member (e.g. designee from child life, psychology, social work, or nursing) should participate in this evaluation at time of diagnosis, throughout treatment, and when the patient enters survivorship; it may be helpful to include school personnel or additional providers

EMOTIONAL SUPPORT – FOR FAMILY MEMBERS/CAREGIVERS/SIBLINGS

Sources: Gerhardt et al., (2015); Kearney et al., (2015).

Existing Standards	**Our Recommendations**
1. Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly (Gerhardt et al., 2015).	1. Siblings of children, **adolescents and young adults** with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly
2. Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well being (Kearney et al., 2015).	2. Parents and caregivers and siblings of children, **adolescents and young adults** with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, **CAYA**, and family well being
	3. **Children of young adults with cancer, as well as parents of young adult patients, should also receive appropriate psychosocial support and mental health assessment, recognizing their unique emotional burdens and roles with the family system.**

FATIGUE

Sources: Children's Oncology Group (2022); Christen et al., (2020); Schröder et al., (2019).

Existing Standards	Our Recommendations
1. Healthcare providers and survivors of CAYA cancers should be aware that CAYA cancer survivors are at risk for cancer-related fatigue. Main risk factors for CRF are: a. Psychological distress b. Late effects or health problems, pain, relapse, older age at follow-up c. Radiotherapy (Christen et al., 2020)	1. Healthcare providers and survivors of CAYA cancers should be aware that CAYA cancer survivors are at risk for cancer-related fatigue. Main risk factors for CRF are: a. Psychological distress b. Late effects or health problems, pain, relapse, older age at follow-up c. Radiotherapy.
2. For all CAYA cancer survivors: a medical history/anamnesis on survivors' feelings of tiredness and exhaustion is recommended regularly (at every long-term follow-up visit, or at general medical checkups, at least once a year) (Christen et al., 2020).	2. For all CAYA cancer survivors: a medical history/anamnesis on survivors' feelings of tiredness and exhaustion is recommended regularly (at every long-term follow-up visit, or at general medical checkups, at least once a year).
3. Psychosocial diagnostics on suspicion of fatigue is recommended at the conclusion of intensive oncologic therapy and in the course of follow-up care (Schröder et al., 2019).	3. Psychosocial diagnostics on suspicion of fatigue is recommended at the conclusion of intensive oncologic therapy and in the course of follow-up care.
4. For CAYA cancer survivors with an indication for CRF from medical history/anamnesis: a. Further testing with a validated fatigue measurement is recommended. b. Screening for underlying medical condition that may cause fatigue is recommended (Christen et al., 2020).	4. For CAYA cancer survivors with an indication for CRF from medical history/anamnesis: a. Further testing with a validated fatigue measurement is recommended. b. Screening for underlying medical condition that may cause fatigue is recommended.
5. Screen for physical sources of fatigue, such as anemia, sleep disturbances, nutritional deficiencies, cardiomyopathy, pulmonary fibrosis, hypothyroidism, or other endocrinopathy (COG, 2022).	5. Screen for physical sources of fatigue, such as anemia, sleep disturbances, nutritional deficiencies, cardiomyopathy, pulmonary fibrosis, hypothyroidism, or other endocrinopathy.

FATIGUE

Sources: Children's Oncology Group (2022); Christen et al., (2020); Schröder et al., (2019).

Existing Standards	Our Recommendations
6. Fatigue is considered as a significant disease- and treatment-related psychosocial stressor (Schröder et al., 2019).	6. Fatigue is considered as a significant disease- and treatment-related psychosocial stressor **that can profoundly affect daily life and participation.**
7. If fatigue is diagnosed with a validated fatigue measure and if no underlying medical condition is identified: a. Referral to a specialist in fatigue (or more generic specialist such as psychologist, physiotherapist, or other relevant specialist) is recommended (Christen et al., 2020). b. Interventions that are useful: i. Physical activity ii. Education about CRF iii. Relaxation and mindfulness iv. Cognitive behavioral therapy v. Adventure based training (Christen et al., 2020).	7. If fatigue is diagnosed with a validated fatigue measure and if no underlying medical condition is identified: a. Referral to a specialist in fatigue (or more generic specialist such as psychologist, physiotherapist, or other relevant specialist) is recommended. b. Interventions that are useful: i. Physical activity ii. Education about CRF iii. Relaxation and mindfulness iv. Cognitive behavioral therapy v. Adventure based training.
8. Referral to specialties such as endocrinology, sleep lab/study, or nutrition as indicated (COG, 2022).	8. Referral to specialties such as endocrinology, sleep lab/study, or nutrition as indicated.
9. Referral to psychology for behavioral intervention for emotional difficulties contributing to sleep and fatigue (COG, 2022).	9. Referral to psychology for behavioral intervention for emotional difficulties contributing to sleep and fatigue.
	10. **If appropriate, HCPs should provide information on possible pharmacological treatment approaches.**

EDUCATION & CAREER SUPPORT

Sources: Devine et al., (2022); Thompson et al., (2015); Lown et al., (2015); Schröder et al., (2019).

Existing Standards

Education:

- Who needs surveillance?

Healthcare providers, teachers, caregivers, and survivors of CAYA cancers, and survivors' schools should be aware that, on a group level, survivors of CAYA cancer are at risk for:

   a. lower educational achievement
   b. experiencing a delay in completing their education
   c. requiring educational accommodations (Devine et al., 2022).

Particular attention is needed for survivors of CAYA cancer with the following risk factors for lower educational achievement: primary diagnosis of CNS tumor, CNS-directed therapies, impaired neurocognitive functioning, non-white race or immigration status, and parents' lower level of education (Devine et al., 2022).

- At what age or time should surveillance be initiated?

Surveillance of educational outcomes is recommended for all ages to begin at diagnosis and continue through survivorship until young adulthood (Devine et al., 2022).

- What surveillance modality should be used? At what frequency?

Regular assessment of educational outcomes via parent- or self-report is recommended at every long-term follow-up visit or general medical checkup at least annually until education is completed (Devine et al., 2022).

This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.

EDUCATION & CAREER SUPPORT

Sources: Devine et al., (2022); Thompson et al., (2015); Lown et al., (2015); Schröder et al., (2019).

Existing Standards

- Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for:
    a. adverse educational and/or vocational progress, social and relationship difficulties;
    b. distress, anxiety, and depression; and
    c. risky health behaviours (Lown et al., 2015).
- Assessment of support needs for reintegration in everyday life/ kindergarten/ school/ workplace at the conclusion of intensive oncological treatment and in the course of follow-up care is recommended (Schröder et al., 2019).
- Documentation of educational problems in the survivor's medical record is recommended to facilitate sharing with all members of the care team (Devine et al., 2022).
- Referral to an educational specialist, psychologist, and/or social worker is recommended for assessment and implementation of relevant educational and/or disability services for survivors who report educational problems upon screening (Devine et al., 2022).

This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.

EDUCATION & CAREER SUPPORT

Sources: Devine et al., (2022); Thompson et al., (2015); Lown et al., (2015); Schröder et al., (2019).

Existing Standards	
• In collaboration with parents, school-aged youth diagnosed with cancer should receive school reentry support that focuses on providing information to school personnel about the patient’s diagnosis, treatment, and implications for the school environment and provides recommendations to support the child’s school experience (Thompson et al., 2015). • Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the health care team (Thompson et al., 2015).	*This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.*

EDUCATION & CAREER SUPPORT

Sources: Devine et al., (2022); Thompson et al., (2015); Lown et al., (2015); Schröder et al., (2019).

Existing Standards	
Employment: • Who needs surveillance? Healthcare providers, caregivers, and survivors of CAYA cancers should be aware that, on a group level, survivors of CAYA cancer are at risk for unemployment. Particular attention is needed for survivors of CAYA cancer with the following risk factors for unemployment: female sex, lower educational achievement, primary diagnosis of CNS tumor, CNS-directed therapies, any adverse long-term side effects, impaired neurocognitive functioning, second malignancy or recurrence, psychological distress, and physical disability (Devine et al., 2022). • At what age or time should surveillance be initiated? Vocational planning and employment surveillance is recommended beginning in adolescence to support survivors to transition from education to employment (Devine et al., 2022). • What surveillance modality should be used? At what frequency? Regular assessment of vocational planning and employment status via parent- or self-report is recommended at every long-term follow-up visit or general medical checkup (Devine et al., 2022).	*This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.*

EDUCATION & CAREER SUPPORT

Sources: Devine et al., (2022); Thompson et al., (2015); Lown et al., (2015); Schröder et al., (2019).

Existing Standards

- Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for:
    a. adverse educational and/or vocational progress, social and relationship difficulties;
    b. distress, anxiety, and depression; and
    c. risky health behaviours (Lown et al., 2015).

- Assessment of support needs for reintegration in everyday life/ kindergarten/ school/ workplace at the conclusion of intensive oncological treatment and in the course of follow-up care (Schröder et al., 2019).

- Referral to a vocational counsellor, psychologist, and/or social worker for assessment and implementation of relevant vocational and/or disability services is recommended for survivors who report vocational problems upon screening (Devine et al., 2022).

This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.

FERTILITY

Sources: Children's Oncology Group (2022); Mulder et al., (2021); Schröder et al., (2019).

Existing Standards

- Fertility preservation and the risk of infertility should be discussed as early as possible, before treatment starts to reduce distress and improve quality of life (COG, 2022).

General - HCP should:

1. Be familiar with the latest evidence-based recommendations, institutional policies, and professional educational resources on infertility risk and fertility preservation procedures (Mulder et al., 2020)
2. Maintain currency with training where appropriate (Mulder et al., 2020).
3. Refer patients to psychosocial providers when they are distressed about potential infertility (COG, 2022).

Provision of information about treatment-related infertility risk and fertility preservation - HCP should:

1. HCP should deliver clear, comprehensive, and age-appropriate information in a professional, neutral, and empathic manner and consider the family's cultural/religious beliefs (Mulder et al., 2020)
2. Provide up-to-date written and/or online educational resources to patients and their parents/caregivers/partner in appropriate languages and health literacy levels (Mulder et al., 2020).

This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.

FERTILITY

Sources: Children's Oncology Group (2022); Mulder et al., (2021); Schröder et al., (2019).

Existing Standards	
Communicating treatment-related infertility risk and fertility preservation - HCP should: 1. Involve patients and/or their parents/caregivers/partners (Mulder et al., 2020). 2. Offer a private conversation with the patient depending on age (Mulder et al.., 2020). 3. Offer special counselling to adolescents (Schröder et al., 2019). 4. Offer a separate conversation with parents/caregivers/partners after consent or assent of the patient (Mulder et al., 2020). 5. Consider the patient's age, developmental status, and the family's cultural/religious beliefs (Mulder et al., 2020). 6. Provide emotional support to patients and their parents/caregivers/partners during counselling about treatment-related infertility risk and fertility preservation and prompt psychosocial specialist referrals as appropriate (Mulder et al., 2020). 7. Initiate counselling as early as possible after a cancer diagnosis and treatment plan are established and when a change in diseases status occurs that requires treatment intensification with gonadal toxic agents/modalities (Mulder et al., 2020). 8. Offer counselling on an ongoing basis during treatment and throughout survivorship because the infertility risk or patient's ideas may change (Mulder et al., 2020).	*This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.*

FERTILITY

Sources: Children's Oncology Group (2022); Mulder et al., (2021); Schröder et al., (2019).

Existing Standards

Hospitals should:

1. Establish referral pathways for accessing fertility specialists or fertility specialist centres where appropriate (Mulder et al., 2020).

Ethical issues related to fertility preservation (Good practice statements) - HCP should:

1. Foster the autonomy of the patient (Mulder et al., 2020).
2. Assess the patient's emotional, psychological and intellectual status as part of the informed consent process (Mulder et al., 2020).
3. Ensure that decisions about fertility preservation are driven by patient's best interest and not by own interest and/or interest of parents/caregivers/partners (Mulder et al., 2020).
4. Encourage patients to consider the risks, and the medical, social, and ethical contingencies of fertility preservation procedures as well as future use of frozen tissue (Mulder et al., 2020).
5. Address the uncertainty of future technologies during counselling about infertility risk and fertility preservation procedures (Mulder et al., 2020).
6. Include societal and ethical values connected to social parenthood (adoption) and the potential discrimination when applying for adoption in the discussions with the patient and parents/caregivers/partners about adoption (Mulder et al., 2020).

This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.

FERTILITY

Sources: Children's Oncology Group (2022); Mulder et al., (2021); Schröder et al., (2019)

Existing Standards

7. Include a two-stage consent process with patients and/or their families/caregivers/partners: 1) at diagnosis when the decision about harvesting and storing tissue is made and 2) after therapy at a developmentally appropriate age when the decision of whether and how to use the stored material is made (Mulder et al., 2020).
8. Be aware of the importance to determine upfront with patients and their families/caregivers/partners the access of researchers to their stored gametes (Mulder et al., 2020).
9. Be aware of the importance to determine upfront with patients and their families/caregivers/partners the disposition of gametes and/or preserved tissue in the event of patient's death (Mulder et al., 2020).
10. Be aware of possible conflicts of interest between the needs of patients/parents/caregivers and the potential short- and long-term financial costs involved in fertility preservation procedures and storage, as well as post-treatment costs associated with pursuing family-building (Mulder et al., 2020).

This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.

FERTILITY

Sources: Children’s Oncology Group (2022); Mulder et al., (2021); Schröder et al., (2019).

Existing Standards	
HCP should: 1. Be familiar with the latest evidence-based recommendations, institutional policies, and professional educational resources on infertility risk and fertility preservation procedures (Mulder et al., 2020). 2. Maintain currency with training where appropriate (Mulder et al., 2020). 3. Establish referral pathways for accessing fertility specialists (Mulder et al., 2020). 4. Provide up-to-date written and/or online educational resources to patients and their parents/caregivers/partner in appropriate languages and health literacy levels (Mulder et al., 2020).	*This section presents existing guidelines in their original wording, as the EU-CAYAS-NET consensus group had no additional recommendations related to the European context. They have been included here to consolidate key guidance in one accessible place, ensuring consistency and ease of reference within the broader standard of care.*

CHRONIC PAIN

Sources: Children's Oncology Group (2022).

Existing Standards	**Our Recommendations**
1. In children with chronic pain, physical therapies may be used, either alone or in combination with other treatments (COG, 2022)	1. In CAYAS with chronic pain, physical therapies may be used, either alone or in combination with other treatments (COG)
2. a) In children with chronic pain, psychological management through cognitive behavioral therapy and related interventions (acceptance and commitment therapy, behavioral therapy and relaxation therapy) may be used. b) Psychological therapy may be delivered either face-to-face or remotely, or using a combined approach (COG, 2022).	2. a) In CAYAS with chronic pain, psychological management through cognitive behavioral therapy and related interventions (acceptance and commitment therapy, behavioral therapy and relaxation therapy) may be used. b) Psychological therapy may be delivered either face-to-face or remotely, or using a combined approach. c) this may include alternative therapies like music, art, or play therapy especially in children dealing with chronic pain
3. In children with chronic pain, appropriate pharmacological management tailored to specific indications and conditions may be used (COG, 2022).	3. In CAYAS with chronic pain, appropriate pharmacological management tailored to specific indications and conditions may be used
4. a) Appropriate pharmacological management tailored to specific indications may include the use of morphine under the principles of opiod stewardship, for end-of-life-care. b) In children with chronic pain associated with life-limiting conditions, morphine may be given by appropriately trained healthcare providers, under the principles of opioid stewardship (COG, 2022).	4. a) Appropriate pharmacological management tailored to specific indications may include the use of morphine under the principles of opiod stewardship, for end-of-life-care. b) In children with chronic pain associated with life-limiting conditions, morphine may be given by appropriately trained healthcare providers, under the principles of opioid stewardship.

CHRONIC PAIN

Sources: Children's Oncology Group (2022).

Existing Standards	Our Recommendations
Best practices for the clinical management of chronic pain in children:	**Best practices for the clinical management of chronic pain in CAYA cancer patients and survivors:**
1. Children with chronic pain and their families and caregivers must be cared for from a biopsychosocial perspective; pain should not be treated simply as a biomedical problem (COG, 2022).	1. **CAYAS** with chronic pain and their families and caregivers must be cared for from a biopsychosocial perspective; pain should not be treated simply as a biomedical problem
2. A comprehensive biopsychosocial assessment is essential to inform pain management and planning. As a component of this assessment, healthcare providers should use age-, context- and culturally appropriate tools to screen for, and monitor, pain intensity and its impact on the quality of life of the child and family (COG, 2022).	2. A comprehensive biopsychosocial assessment is essential to inform pain management and planning. As a component of this assessment, healthcare providers should use age-, context- and culturally appropriate tools to screen for, and monitor, pain intensity and its impact on the quality of life of the child and family.
3. Children with chronic pain must have a thorough evaluation of any underlying conditions and access to appropriate treatment for those conditions, in addition to appropriate interventions for the management of pain. Chronic pain in childhood often exists with comorbid conditions affecting the child's health, and social and emotional well-being, which require concurrent management (COG, 2022).	3. **CAYAS** with chronic pain must have a thorough evaluation of any underlying conditions and access to appropriate treatment for those conditions, in addition to appropriate interventions for the management of pain. Chronic pain in **childhood, adolescence, or young adulthood** often exists with comorbid conditions affecting the child's health, and social and emotional well-being, which require concurrent management.
4. Children presenting with chronic pain should be assessed by healthcare providers who are skilled and experienced in the evaluation, diagnosis, and management of chronic pain (COG, 2022).	4. **CAYAS** presenting with chronic pain should be assessed by healthcare providers who are skilled and experienced in the evaluation, diagnosis, and management of chronic pain.

CHRONIC PAIN

Sources: Children's Oncology Group (2022).

Existing Standards	Our Recommendations
5. Management, whether with physical therapies, psychological or pharmacological interventions, or combinations thereof, should be tailored to the child's health; underlying condition; developmental age; physical, language and cognitive abilities; and social and emotional needs (COG, 2022).	5. Management, whether with physical therapies, psychological or pharmacological interventions, or combinations thereof, should be tailored to the **child's, adolescent's, or young adult's** health; underlying condition; developmental age; physical, language and cognitive abilities; and social and emotional needs
6. Care of children with chronic pain should be child- and family-centred. That is, the child's care should: a. focus on, and be organized around, the health needs, preferences and expectations of the child, and their families and communities; b. be tailored to the family's values, culture, preferences and resources; and c. promote engagement and support children and their families to play an active role in care through informed and shared decision-making (COG, 2022).	6. Care of **young people** with chronic pain should be **patient/survivor**- and family-centred. That is, the young person's care should: a. focus on, and be organized around, the health needs, preferences and expectations of the **young person**, and their families and communities; b. be tailored to the family's values, culture, preferences, and resources; and c. promote engagement and support **young people** and their families to play an active role in care through informed and shared decision-making
7. Families and caregivers must receive timely and accurate information. Shared decision-making and clear communication are essential to good clinical care. Communication with patients should correspond to their cognitive, developmental, and language abilities. There must be adequate time in a comfortable space for discussions and questions regarding care management plans and progress (COG, 2022).	7. Families and caregivers must receive timely and accurate information. Shared decision-making and clear communication are essential to good clinical care. Communication with patients should correspond to their cognitive, developmental, and language abilities. There must be adequate time in a comfortable space for discussions and questions regarding care management plans and progress.

CHRONIC PAIN

Sources: Children's Oncology Group (2022).

Existing Standards	Our Recommendations
8. The child and their family and caregivers should be treated in a comprehensive and integrated manner: all aspects of the child's development and well-being must be attended to, including their cognitive, emotional and physical health. Moreover, the child's educational, culture, and social needs and goals must be addressed as part of the care management plan (COG, 2022).	8. The **young person** and their family and caregivers should be treated in a comprehensive and integrated manner: all aspects of the **young person's** development and well-being must be attended to, including their cognitive, emotional, and physical health. Moreover, the young person's educational, culture, and social needs and goals must be addressed as part of the care management plan.
9. In children with chronic pain, an interdisciplinary, multimodal approach should be adopted which is tailored to the needs and desires of the child, family, and caregivers, and to available resources. The biopsychosocial model of pain supports the use of multiple modalities to address the management of chronic pain (COG, 2022).	9. In **CAYAS** with chronic pain, an interdisciplinary, multimodal approach should be adopted which is tailored to the needs and desires of the child, family, and caregivers, and to available resources. The biopsychosocial model of pain supports the use of multiple modalities to address the management of chronic pain.

CHRONIC PAIN

Sources: Children’s Oncology Group (2022).

Existing Standards	Our Recommendations
10. Policy-makers, programme managers, and healthcare providers, as well as families and caregivers must attend to opioid stewardship to ensure the rational and cautious use of opioids. The essential practices of opioid stewardship in children include: a. Opioids must only be used for appropriate indications and prescribed by trained providers, with careful assessment of the benefits and risks. The use of opioids by individuals, their impact on pain and their adverse effects must be continuously monitored and evaluated by trained providers. b. The prescribing provider must have a clear plan for the continuation, tapering, or discontinuation of opioids according to the child’s condition. The child and family must be apprised of the plan and its rationale. c. There must be due attention to procurement, storage, and the disposal of unused opioids (COG, 2022).	10. Policy-makers, programme managers, and healthcare providers, as well as families and caregivers must attend to opioid stewardship to ensure the rational and cautious use of opioids. The essential practices of opioid stewardship in **CAYAS** include: a. Opioids must only be used for appropriate indications and prescribed by trained providers, with careful assessment of the benefits and risks. The use of opioids by individuals, their impact on pain and their adverse effects must be continuously monitored and evaluated by trained providers. b. The prescribing provider must have a clear plan for the continuation, tapering, or discontinuation of opioids according to the child’s condition. The **young person** and family must be apprised of the plan and its rationale. c. There must be due attention to procurement, storage, and the disposal of unused opioids.

TRAINING & COMMUNICATION FOR PSYCHOSOCIAL HCP

Sources: Patenaude, Pelletier & Bingen (2015); (also see Schröder et al., 2019)

Existing Standards	**Our Recommendations**
1. Open, respectful communication and collaboration among medical and psychosocial providers, patients, and families is essential for effective patient- and family-centred care. Psychosocial professionals should be integrated into paediatric oncology care settings as integral team members and be participants in patient care rounds/meetings (Patenaude, Pelletier & Bingen, 2015).	1. Open, respectful communication and collaboration among medical and psychosocial providers, patients, and families is essential for effective patient- and family-centred care. Psychosocial professionals should be integrated into **CAYA** oncology care settings as integral team members and be participants in patient care rounds/meetings
2. Paediatric psychosocial providers should have access to medical records and relevant reports should be shared among care team professionals, with psychological report interpretation provided by psychosocial providers to staff and patients/families for patient care planning. Psychosocial providers should follow documentation policies of the health system where they practise in accordance with ethical requirements of their profession and state/federal laws (Patenaude, Pelletier & Bingen, 2015)	2. **Psychosocial providers for CAYA cancer patients and survivors** should have access to medical records and relevant reports should be shared among care team professionals, with psychological report interpretation provided by psychosocial providers to staff and patients/families for patient care planning. Psychosocial providers should follow documentation policies of the health system where they practise in accordance with ethical requirements of their profession and state/ laws.
3. Paediatric psychosocial providers must have special training and education and be credentialed in their discipline to provide developmentally appropriate assessment and treatment for children with serious, chronic illness is crucial as well as ongoing relevant supervision/peer support (Patenaude, Pelletier & Bingen, 2015)	3. **Psychosocial providers for CAYA cancer patients and survivors** must have special training and education and be credentialed in their discipline to provide developmentally appropriate assessment and treatment for children with serious, chronic illness is crucial as well as ongoing relevant supervision/peer support.

ADDITIONAL HELPFUL MATIERALS AND RESOURCES

White paper on Quality of Life:
Optimizing Quality of Life after Youth Cancer

EU-CAYAS-NET Pocket Cards for Mental Health Awareness and Guidance: Pocket Cards for Mental Health Awareness and Guidance for Cancer Patients and Beyond

Educational Video on Mental Health in Survivorship: Educational video: Mental Health in Survivorship

Educational Video on Education and Career Support: Webinar: Education and Career Support

Map of Best Practices for Education and Career Support: Explore EU-CAYAS-NET Project Outcomes & Resources

Train-the-Trainer Curriculum for Education & Career Support: Supporting Educational and Career Pathways for AYA Cancer Survivors

Report on Career Support for Young People Living With and Beyond Cancer: Career Support Report

Recommendations on Effective Communication about Late Effects: From Experience to Action: A Guide to Talking with Survivors About Late Effects

PLAIN Language Summaries of Late Effects: PLAIN language summaries – PanCare

As part of the **EU-CAYAS-NET project,** numerous resources have been developed to **identify and better address the needs of CAYA** (Children, Adolescents, and Young Adults) cancer patients and survivors. The project focused on key areas such as the **quality of life of CAYA** cancer survivors—including mental health and psychological support, education and career guidance, transition to adult care, and long-term follow-up (LTFU). It also **emphasized tailored care for AYA (Adolescents and Young Adults)** patients and the importance of **equity, diversity, and inclusion (EDI) in cancer care.** All findings and resources have been compiled in a **comprehensive outcome brochure, that can be found on beatcancer.eu.**

- For more information on **Transition and LTFU**.
- For more insights into **AYA Care**.
- To learn more about **EDI in Cancer Care**.

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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

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