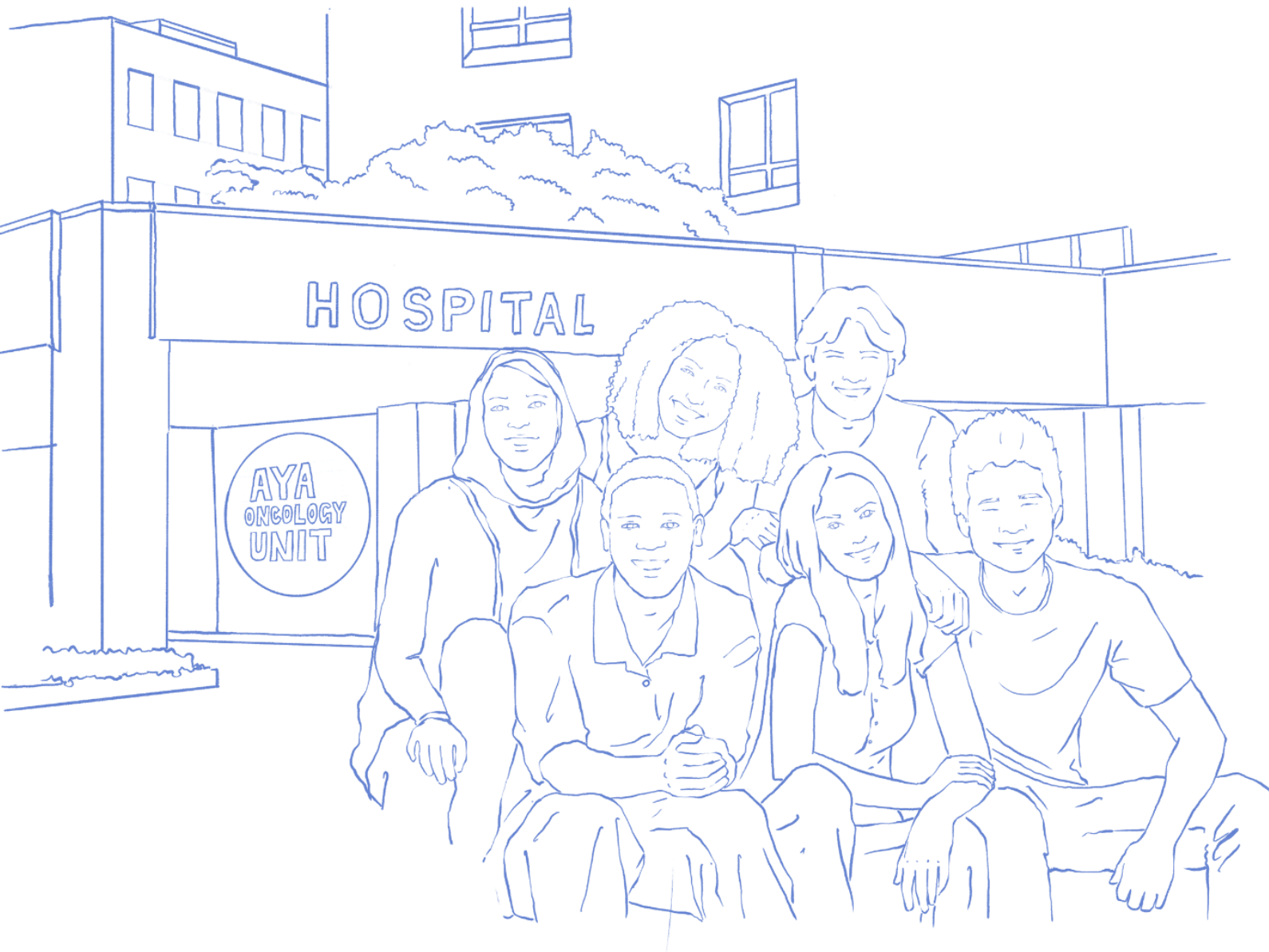


## Recommendations and Implementation Roadmap for

# Minimum Standards of Specialist Adolescent and Young Adult (AYA) Cancer Care Units



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## EXECUTIVE SUMMARY

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According to the data from the International Agency for Research on Cancer (IARC), in 2022, over 150,000 young individuals aged 15-39 were diagnosed with cancer across the European region. Despite being a critical demographic with unique biological and psychosocial needs, Adolescents and Young Adults often face limited access to specialised oncology services, particularly outside major urban centres in Western and Northern Europe. The present disparities in service provision and care outcomes highlight the necessity for uniform standards that ensure all young people facing cancer receive adequate and holistic care.

To address the objectives set out by Europe's Beating Cancer Plan<sup>1</sup>, which among others, highlights the needs of young people with cancer, the EU-CAYAS-NET consortium was funded by the European Union's EU4Health program (grant number 101056918). The project began in September 2022 and involves 9 Beneficiaries (& Affiliated Entities) and 28 Associated Partners from 18 countries. The overarching aim of EU-CAYAS-NET is to enhance care for children, adolescents, and young adults with cancer by facilitating meaningful connections between patients, survivors, healthcare professionals, and other stakeholders across the European Union. One of the project deliverables is the patient-led initiative to develop recommendations on how to achieve the minimum standards of care across cancer care centres in Europe for adolescents and young adults.

This position paper resulted from a mixed-method and interdisciplinary approach, integrating insights from Adolescents and Young Adults, healthcare providers, researchers, and other stakeholders. It calls on policymakers, healthcare professionals, and advocacy groups to prioritise the specific needs of Adolescents and Young Adults (AYAs), ensuring they have access to high-quality care that addresses all aspects of their health and well-being.

The recommendations are comprehensive, evidence-based, and actionable, described in two parts:

A. **A Checklist** for Minimum Standards of Care organised into three chapters

1. Age-Appropriate Built Environment
2. Clinical Care Organization and Patient Pathways
3. Support Services

B. **An Implementation Roadmap** with eight recommendations

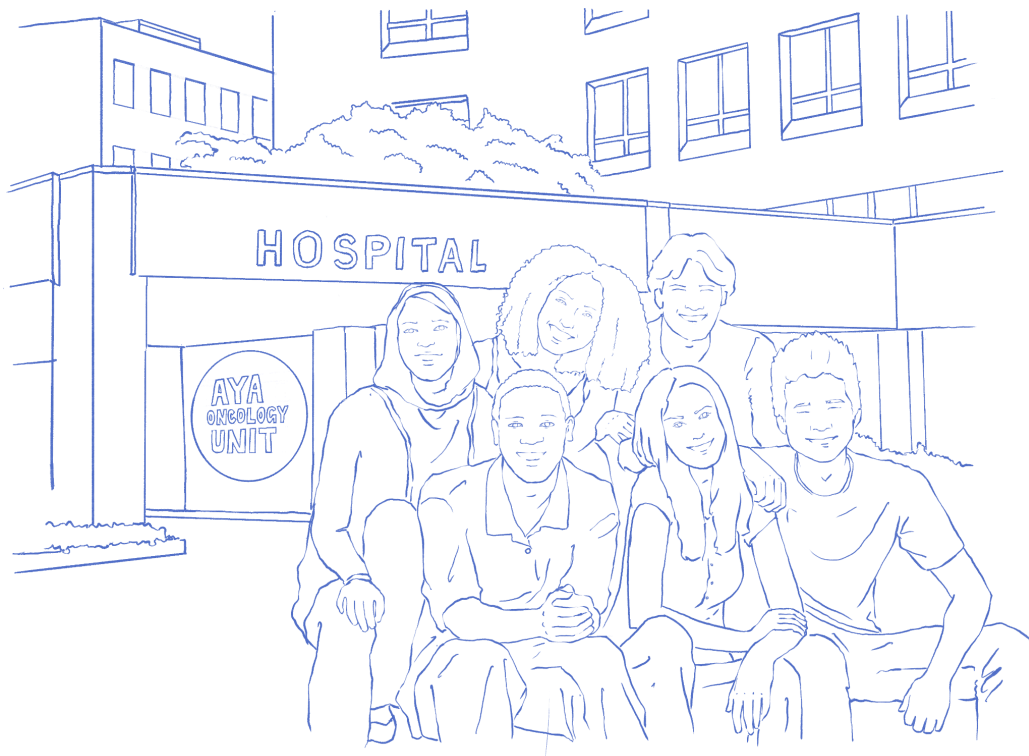
1. Develop a National Knowledge Hub
2. Invest in Training, Education, and Resource Optimization
3. Integrate Adolescent and Young Adult (AYA) - specific Care Across All Cancer Treatment Settings
4. Expand Access to Mental Health Services
5. Empower Adolescents and Young Adults (AYAs) Through Participation in Care Discussions
6. Enhance Integration and Interoperability of Healthcare Systems and Digital Health Platforms
7. Promote Research and Innovation
8. Advocate for Policy and Practice Changes

Supported through the EU-CAYAS-NET consortium, this position paper outlines a framework to address the unique needs of adolescents and young adults with cancer. By highlighting best practices and recommendations on how to standardise care, this initiative promises to improve the well-being of thousands of young Europeans, fulfilling, among others, the vision of Europe's Beating Cancer Plan.

## INTRODUCTION

Adolescents and young adults (AYAs) facing cancer represent a unique and often underserved population within Europe's healthcare landscape. Adolescent and Young Adult (AYA) cancer, while less rare than paediatric cancers, still constitutes a significant portion of Europe's cancer burden, affecting over 150,000 individuals annually, most of whom continue to live long beyond the illness.<sup>2</sup>

This demographic, aged between 15 and 39 years at the time of diagnosis, experiences distinct biological and psychosocial needs, but despite their increasing recognition, Adolescent and Young Adults (AYAs) still encounter inequitable access to age-appropriate oncology services. Specialised services often remain limited to major centres in Western and Northern Europe, large urban areas, or private settings. As a result, smaller centres, rural areas or non-specialist services contribute to disparities in Adolescents' and Young Adults' (AYAs') access, the care offered, and outcomes, underscoring the critical need for a concerted effort to advocate for and establish **Minimum Standards of Specialist Adolescent and Young Adult (AYA) Cancer Care Units.**



## The Need for Age-Appropriate Care

Adolescence and young adulthood are critical developmental stages marked by significant physiological, social, and emotional changes.<sup>3,4</sup> For young people with cancer, a diagnosis of cancer can disrupt key developmental milestones such as gaining independence, pursuing education, forming relationships, and planning for the future.<sup>5-7</sup> The direct or indirect interruption of Adolescents' and Young Adults' (AYAs') education and social engagements can lead to isolation from peers, only exacerbated by any physical changes like hair loss or surgical procedures, further impacting their self-esteem and body image.<sup>8,9</sup>



Furthermore, young cancer patients face distinct challenges that are often not addressed adequately in standard paediatric or adult oncology settings. These include unique psychological burdens, as well as practical concerns, such as fertility preservation and the management of late effects of cancer therapy.<sup>10</sup> The medical community's focus on survival often overshadows these crucial aspects of care, leaving young patients underprepared for the ongoing impact of their disease in their future lives.

Young people who have finished cancer treatment often face persistent anxiety and uncertainty about the possibility of their cancer returning. This constant worry can overshadow their lives, despite the progress medical advancements

have made in treating cancer. Many Adolescents and Young Adults (AYAs) have a promising future ahead, yet the fear of recurrence can still weigh heavily on them. Instead of being preoccupied with these fears, they should be focusing on enjoying their youth and looking forward to their future.

## The Need for Holistic Care

Providing age-appropriate care for Adolescents and Young Adults (AYAs) with cancer means embracing the principle: "Treat the patient, not just their cancer." This approach requires medical care that goes beyond targeting the disease itself to address the unique developmental and psychosocial needs of young patients. Holistic care extends beyond medical treatment to include psychological and social support, which is essential for managing the overall well-being. The existing literature highlights the importance of multidisciplinary approaches that integrates medical, nursing, psychological, and social services.<sup>11</sup> Regular, structured interactions with a diverse team of professionals that spans all phases of illness, including long-term follow-up will ensure a well-rounded care experience that acknowledges and supports the multifaceted challenges of young cancer patients. To achieve this, tailored training for healthcare professionals is crucial.



Our recommendations are based on the premise that equipping healthcare professionals with the necessary skills and knowledge to work effectively with Adolescent and Young Adult (AYA) patients, can foster an environment that encourages active patient involvement in care and decision-making.

A comprehensive and holistic care model is not just a preference, it is a necessity for ensuring that Adolescent and Young Adult (AYA) cancer patients receive the support

they need to 1) successfully navigate their treatment, and 2) continue living a life in which cancer does not determine their future.

## **The Need for Equitable, Accessible and Empowering Care**

Equitable access to cancer care means that all young people, regardless of their gender, ethnic background, beliefs, culture, sexual orientation, religion, or other status receive the best care they need. Compared to their healthy peers, Adolescents and Young Adults (AYAs) with cancer often endure significant disruptions in their lives, including chronic health conditions and higher levels of disability.<sup>12,13</sup> Moreover, even when in remission from cancer they might face more financial or other types of discrimination.<sup>14-18</sup>

This highlights the need for personalised and adaptable interventions tailored to Adolescents and Young Adults (AYAs) which goes beyond medical treatment to encompass health promotion and psychological well-being. Research has shown that interventions aimed at improving self-efficacy, coping mechanisms, and treatment preference communication are critical, yet high-quality intervention studies are few, and many focus only on in-treatment populations.<sup>19-21</sup> This can be problematic as the needs of Adolescents and Young Adults (AYAs) often extend well into the post-treatment phase, where psychosocial well-being becomes a priority.<sup>22</sup> Empowering Adolescents and Young Adults (AYAs) through equitable care means providing access to tailored interventions. By ensuring equitable access to such diverse and adaptive care options, we can better support holistic recovery.

The adage "one size does not fit all" aptly applies to both patients and healthcare systems. Our recommendations for minimum standards of care recognize and respect the substantial efforts and interventions already in place.

Rather than advocating for the introduction of entirely new initiatives, we emphasise the importance of aligning existing services more effectively with the specific needs of the right individuals. Similarly, we propose adaptable suggestions that can be customised to fit the diverse structures and demands of different healthcare systems.



## The Rationale

The concept of the **Minimum Standards of Specialist Adolescent and Young Adult (AYA) Cancer Care Units** is driven by a dual purpose: to highlight the unique needs of adolescents and young adults with cancer and to make a step towards age-appropriate and standardised care across the European Union.

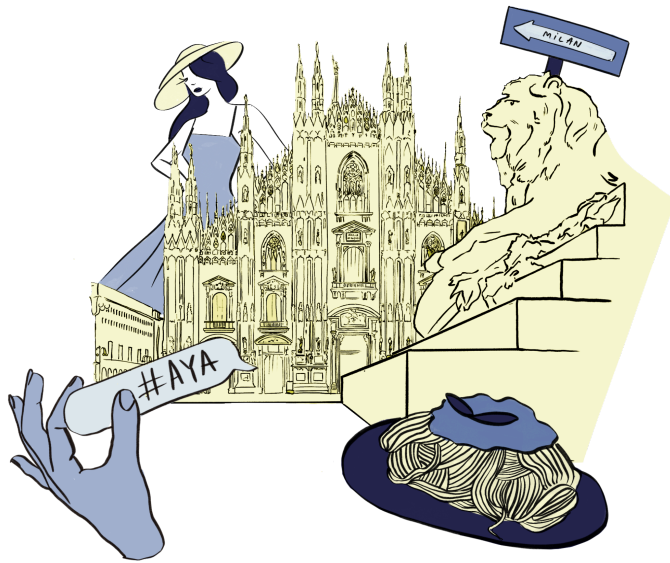
Let this position paper serve as a call to action for policymakers, healthcare professionals, and advocacy groups to prioritise the unique needs of Adolescents and Young Adults (AYAs) and ensure that all Adolescents and Young Adults (AYAs) with cancer have the minimum of their needs covered and equitable access to high-quality care across Europe.

Despite advancements in the field of Adolescent and Young Adult (AYA) oncology, disparities in care quality and availability persist. This document consolidates insights from first-hand experiences of young people, their healthcare providers, and researchers, gathered with the aim to outline essential criteria for Adolescent and Young Adult (AYA) cancer centres. The document sets a checklist and eight clear and actionable recommendations to ensure that all Adolescent and Young Adult (AYA) patients have access to age-appropriate, holistic, and equitable care.

## The Process

This position paper methodology employed a mixed-method and interdisciplinary approach, integrating Adolescents and Young Adults (AYAs) at its core. Each component was built upon the previous steps, literature reviews, and existing knowledge, ensuring a holistic and comprehensive approach to developing actionable and evidence-based recommendations for enhancing Adolescent and Young Adult (AYA) cancer care across Europe.





The recommendations and writing of this paper were based on a literature review, Peer Visits, qualitative reports, and a Delphi process leading to a roundtable discussion. Initially, a literature review was conducted between October and December 2022 to explore the needs of Adolescents and Young Adults (AYAs), with a focus on psycho-social aspects. This was followed by Peer Visits where Adolescent and Young

Adults (AYAs) observed and engaged in healthcare settings to gather data to identify Adolescent and Young Adult (AYA) care strengths and weaknesses. Combined with qualitative reports the emerging themes fed into a Delphi process where stakeholders including Adolescents and Young Adults (AYAs) and healthcare professionals collaboratively identified priorities for Adolescent and Young Adult (AYA) cancer care across Europe. Finally, a roundtable discussion that focused on recommendations for improving clinical practices and policies was conducted.

A detailed methodology underpinning this position paper is available here:

[www.osf.io/vsujy](http://www.osf.io/vsujy)



Detailed methodology

## Who participated in creating these recommendations?



### Working Group

- 28 members, 14 countries,
- 16 AYAs,
  - 5 HCPs
  - 7 administrative, management & communication

### PEER VISITS

- 10 AYAs per Peer Visit  
From 16 countries  
5 major European institutions visited

### DELPHI SURVEY

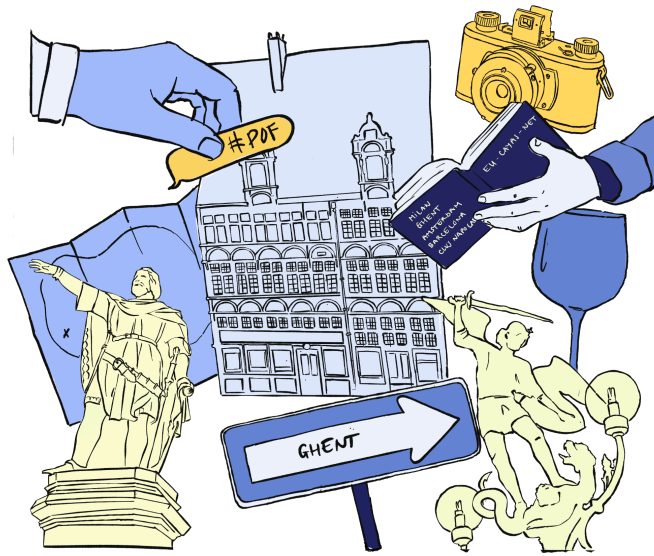
- Round 1:  
44 AYAs  
• 17 countries
- 90 HCPs  
• 18 countries

### ONLINE ROUNDTABLE

- 7 HCP Speakers  
7 AYA Speakers  
13 Countries



## RESEARCH INSIGHTS INFORMING OUR RECOMMENDATIONS



### Peer Visits

The Peer Visits were instrumental to gathering first-hand insights and knowledge about the operations and care of Adolescents and Young Adults (AYAs) across various European sites. Overall, the care environment at all locations was conducive to Adolescents' and Young Adults' (AYAs') well-being, featuring private rooms and areas for social

interaction, with facilities allowing patients to personalise their space and support for family stays.

All centres had well-established multidisciplinary approaches, which were effectively addressing patient needs, including psycho-social and language support, although palliative care was not as well-integrated. Genetic counselling was available but not standardised, and clinical trials communication varied by site, pointing to a need for better research and information strategies. Nutrition and exercise received strong support, with customised meal plans and physical programs. Fertility services were well-implemented, though sexual health discussions were less formalised. Mental health services were accessible, but there was a pronounced need for professionals trained specifically to address Adolescents and Young Adults (AYAs) concerns, **especially for patients with children**. Lastly, while educational support was available, more proactive support for employment and reintegration into work would be necessary to fully support Adolescents and Young Adult (AYA) patients.

## Qualitative Reports

### What are the components of cancer resources that young patients find most useful?

Young people with lived experience find that *multidisciplinary*, *psycho-socially oriented* support, and *clear, accessible* information are among the most relevant components that make cancer resources useful. **Multidisciplinary teams** provide a *one-stop-shop* when young people are navigating a difficult time.

Comprehensive approaches that include access to physiotherapy, rehabilitation, fertility consultations, psychological services, and guidance from nutritionists has been highlighted to be key **during**, as well as **after** treatment. Such approaches allow Adolescents and Young Adults (AYAs) to feel like they are being treated as a whole, and not just as their cancer. In order to **meet psycho-social needs**,

***What would best help is disease-specific and scientifically proven information on treatment options, their pros and cons, protocols, clinical trial results, in a clear and non-technical language. Secondly, peer support networks and multidisciplinary teams of different healthcare specialists would be crucial as well.***

*AYA, Female, 36 years at diagnosis,  
hematologic cancer*

peer-to-peer contact and testimonies from other young patients offer crucial emotional support and a sense of community, while access to mental health services helps manage more acute problems such as anxiety and depression. **Meeting informational and access needs is also critical**; patients benefit from disease-specific information that is clearly communicated, comprehensive resources on various aspects of their condition, and websites that provide a clear overview of cancer treatments

and trials, all **at the right time** in their illness trajectory (see below). Ensuring that young patients have access to scientifically accurate information in an understandable format, ideally matched for their level of health literacy, allows them to make informed decisions about their care and access necessary financial and practical support (**R1, R3, R6**).

## What specific resources and information do Adolescents and Young Adults (AYAs) need, and when do they need them?

***The useful thing about online resources is that they can be consulted at any time. That is why, for example, a folder with QR-codes could be the best way to share information with us.***

*AYA, Male, 18 at diagnosis,  
sarcoma*

***You need psychologists specialising in oncology, to treat AYA cancer patients, and generally speaking that staff need training in dealing with AYA's unique needs. Paediatrics isn't suitable, nor is the adult ward.***

*AYA, Male, 15 at diagnosis,  
haematologic cancer*

Resources to support young cancer patients should be thoughtfully timed and **continuously accessible** to address the unique challenges at different stages of illness. Psychological support, for example, is vital at every phase—including at diagnosis, during treatment, and post-treatment—helping patients manage emotional stress, pain, and the transition back to everyday life. From the moment of diagnosis, continuous education about the disease, treatment options, and long-term risks are also of vital importance. Resources like fertility preservation, genomic testing, and access to clinical trials should be introduced early, at diagnosis, but also remain accessible throughout the treatment process. Specific resources such as social workers and hotlines for treatment-related questions are especially helpful during the active treatment phase. Overall, **Adolescents and Young Adults (AYAs) need a holistic approach throughout their**

**illness and in particular, beyond** the active treatment is over. To promote accessibility and flexibility of resources, digital solutions like the online platform from EU-CAUAS-NET can be particularly effective (**R1, R4, R6**). Young people value

online resources at their fingertips, regardless of their physical location or the time of day.

***That national health systems are great for getting someone from the diagnosed with cancer stage to the survivor stage. Those same systems [that treat us] abandon people as soon as their lives are no longer in immediate danger and a cancer survivor is left to fend for themselves with this new body, new symptoms, and awful side effects.***

*AYA, Female, 32 at diagnosis,  
breast cancer*

***Holistic pathways are what I feel is most needed for cancer patients getting their treatment in some other places. When I was a cancer patient myself, along with getting my chemo, I had to research, seek info, and make decisions on literally all aspects of my cancer experience by myself – financing and nutrition, job and fertility, treatment options, physiology, finding medication, and everything else***

*AYA, Female, 36 at diagnosis,  
haematologic cancer*

## How do young people use technology in their cancer care?

Overall, many patients perceive technology positively, recognizing its **importance and benefits in cancer care.**

Adolescents and Young Adults (AYAs) agree that technology is crucial for advancing medical research, enhancing communication, and improving procedures such as surgical interventions that patients undergo. In addition, Adolescents and Young Adults (AYAs) note that, where available, digital and technological solutions offer **convenient and easy access to their medical records** and **appointment scheduling** through apps, and **support mental well-being** through resources for meditation and **continued education** while they are hospitalised. However, there exist challenges too; strict data protection laws and system incompatibilities can restrict technology's effectiveness, and result in disparities in access based

***Better and more technology is best, if well-balanced with the human touch we need.***

*AYA, Male, 17 years at diagnosis,  
hematologic cancer*

***I am followed at a private hospital and actually, they have an App where I can access my exams, my appointments, results,...all of which is really relevant.***

*AYA, Female, 22 at diagnosis,  
cervical cancer*

on geographic or systemic factors. Adolescents and Young Adults (AYAs) advocate for better connected digital systems that allow for seamless access to information and improved communication between patients and healthcare providers, which can be especially beneficial when young people move (e.g. study abroad) and need specialist help. The responses showed consensus on the potential for technology to further empower patients and streamline their care

experiences, however, not at the expense of having unrestricted access to a caring and specialist medical team (**R1, R6, R7**).

## Delphi Method

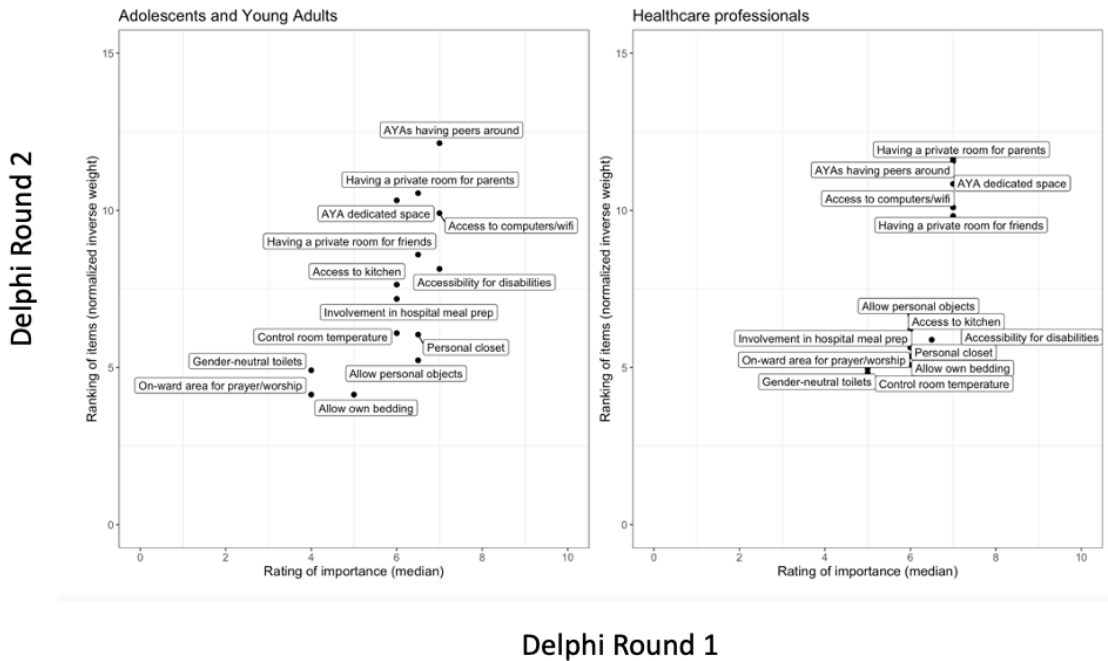
The modified online Delphi process presented the topics that emerged from the literature review, Peer Visits, and qualitative responses. Two subsequent rounds outlined services and topics, which were rated on the scale of importance (Round 1) and ranked for priority (Round 2). The survey was distributed via consortium channels and mailing lists to the major stakeholders: Adolescent and Young Adults (AYAs) and healthcare professionals (HCPs). The goal was to reach a consensus on what the priorities should be when implementing Adolescent and Young Adult (AYA) cancer care across different settings across Europe. This iterative process sought to highlight what patients, survivors, and healthcare professionals deem most important and relevant for their care, and observe where their respective expert opinions diverged.

## Cancer Care

Adolescent and Young Adults (AYAs) and healthcare professionals (HCPs) agreed on the relative importance of having the ability to allow personal objects at the hospital, adequate access for individuals with disabilities, and access to the



kitchen on site, however, while Adolescents and Young Adults (AYAs) emphasised the need to have peers around, healthcare professionals (HCPs) prioritised having a private room for the parents on site.



**Figure 1: Two-dimensional plot showing the results from Round 1 (rating of importance) and Round 2 (Ranking of items) for Adolescent and Young Adults (AYAs) (left) and healthcare professionals (HCPs) (Right).**

The items were rated in terms of importance in Round 1 and ranked in terms of priority in Round 2 of the Delphi. Each item is thus situated within a two-dimensional space, where the axis from bottom left to top right presents increasing priority. We see that Adolescent and Young Adults (AYAs) prioritised having Adolescent and Young Adult (AYA) peers around, while healthcare professionals (HCPs) prioritised having a private room for parents.

### What Adolescents and Young Adults (AYAs) say:

*"I think that having peers around for AYA is a key need, while the difference we observe in the rating such that HCPs are prioritising "having a room dedicated to the parents" is because HCPs are still thinking in terms of child [paediatric] care and adult care rather than AYAs as independent"*

Another interesting divergence between Adolescent and Young Adults (AYAs) and healthcare professionals (HCPs) occurred in the rating of the importance of unrestricted access to digital health records; Adolescent and Young Adults (AYAs) felt it was very important to have digital access while healthcare professionals (HCPs) assigned it lower importance. This view reflects the qualitative responses from the Peer Visits and supports the recommendations (**R1, R6, R7**).

### Adolescent and Young Adult (AYA) Services Available During and After Cancer Care

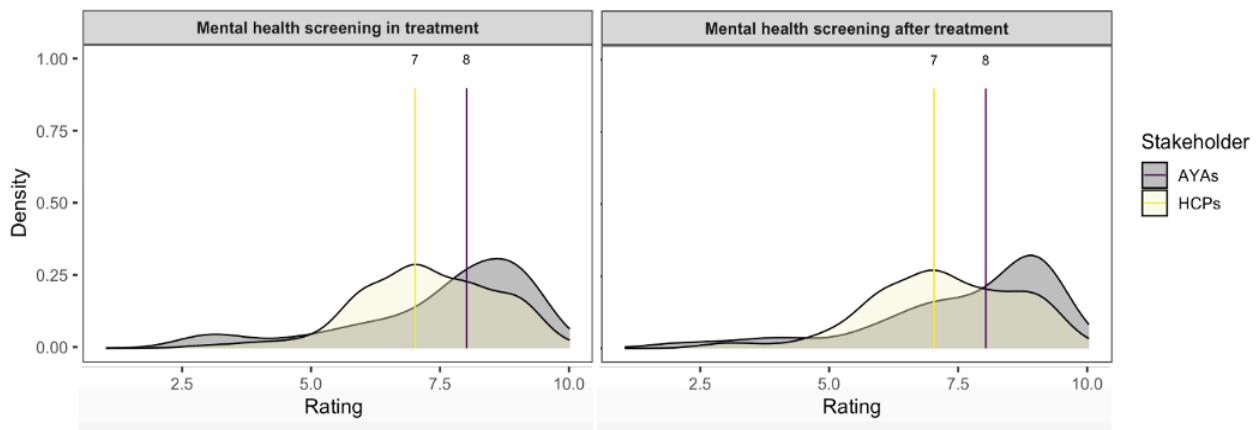
Additionally, when considering services all Adolescents and Young Adults (AYAs) should have on offer, having a dedicated care coordinator was a priority for Adolescent and Young Adults (AYAs) and healthcare professionals (HCPs) alike. Such coordinators could offer support across different services even in places where various specialities are less integrated. Dedicated care coordinators can play an important role for individuals with lower levels of health literacy and could promote successful integration of patients in critical decision-making processes (**R2, R5**). An area that warrants further exploration is palliative care which was ranked as more important among the healthcare professionals (HCPs).



### What Adolescents and Young Adults (AYAs) say:

*“When I think of palliative care I think of death. My guardian during the treatment who was a specialist in public health took the time to tell me that I should request palliative care services because they are meant to alleviate suffering and promote quality of life in all patients, not just those with terminal illness. I think many young people don't know this, maybe even some doctors.”*

Furthermore, mental health continues to be a key challenge for Adolescents and Young Adults (AYAs) with lived experience. Young people emphasised the need to be screened for mental health during as well as after treatment (see Figure 2). Mental health services should also be distinct from other social services (R4) that can help young people with other challenges such as education, vocational support, or logistical help in care access.



**Figure 2: Density plot showing median rating of importance on items from Delphi Round 1.**

The line represents the median rating of importance from 0-10 for Adolescent and Young Adults (AYAs) and healthcare professionals (HCPs), respectively. We observe that, on average, the importance of mental health screening was rated higher among Adolescents and Young Adults (AYAs).

### What Adolescents and Young Adults (AYAs) say:

*"You need psychologists specialized in oncology to treat AYA cancer patients, and generally speaking that staff need training in dealing with AYA's unique needs. Paediatrics isn't suitable, nor is the adult ward."*

A complete set of results from the Delphi is available here: [www.osf.io/k4vdj/](http://www.osf.io/k4vdj/)



Delphi Recommendations

# DEVELOPING COMPREHENSIVE AYA SERVICES IN CLINICAL SETTINGS

## Part A | A Checklist for Minimum Standards of Care

Developing comprehensive Adolescent and Young Adult (AYA) services in clinical settings is essential to meet the unique needs of young cancer patients. This checklist provides a beginner's guide to establishing minimum standards of care, ensuring a supportive and inclusive environment for Adolescents and Young Adults (AYAs).

### Age-Appropriate Built Environment

- Environment:** Adolescent and Young Adult (AYA) patients should be treated in departments with other patients of similar age.
- Social Spaces:** Provide dedicated social spaces for Adolescents and Young Adults (AYAs) to spend time with peers and friends.
- Connectivity:** Ensure access to computers and Wi-Fi.
- Control and Comfort:** Allow Adolescents and Young Adults (AYAs) to control and personalise their hospital environment (e.g., bringing their own objects, clothing, and bedding, and controlling the room temperature). Ensure a private closet is available for each patient.

### Clinical Care Organization and Patient Pathways

- Adolescent and Young Adult (AYA) Multidisciplinary Team:** Establish a team comprising medical, radiation and surgical oncologists, haematologists, nurses, social workers, psychologists, and other specialists trained in Adolescent and Young Adult (AYA) care. This team should include experts in palliative care, reproductive and sexual health, nutrition, physical therapy, occupational therapy, and mental well-being.
- Trained Professionals:** Ensure healthcare professionals are specifically trained and have access to ongoing education to address the unique needs of Adolescent and Young Adult (AYA) patients.
- Case Management:** Include a dedicated Adolescent and Young Adult (AYA) coordinator to oversee patient care and transitions.
- Clinical Trials:** Encourage participation in clinical trials and research. Provide accessible, easily understood information about clinical trials and facilitate Adolescent and Young Adult (AYA) participation in clinical and translational research.
- Genetic Counselling:** Integrate genetic testing and counselling into patient care.
- Digital Records Access:** Provide unrestricted digital access to patient records.
- Second Opinions:** Facilitate access to second opinions for treatment options.

- Supportive Care:** Ensure access to palliative care, pain management, and symptom control.
- Sexual Health:** Provide access to professionals who offer therapy and support for sexual health concerns, changes in sexual function, and intimacy issues.
- Mental Wellbeing:** Include specially trained mental health counsellors, psychologists, psychotherapists, and psychiatrists in the multidisciplinary team to provide mental health assessments, psychological support, therapy for patients and their families, and management of psychiatric symptoms during and after cancer treatment.
- Late Effects Surveillance and Long-Term Follow-Up Care:** Provide each patient with a survivorship care plan that addresses long-term follow-up, late effects, and ongoing health needs. Ensure a seamless transition to long-term follow-up care.
- Reproductive Health:** Include fertility specialists in the multidisciplinary team to offer counselling and treatment options for fertility preservation and reproductive planning before, during, and after cancer treatment. Utilise decision-aid tools for fertility preservation and family planning.
- Nutrition:** Provide access to a certified nutritionist and offer either kitchen facilities or involve patients in hospital menu planning and meal options if a kitchen is unavailable.
- Facilitated Care Pathways:** Facilitate smooth transitions from paediatric to adult care services. Use technology to enhance communication and coordination of care.
- Exercise Training and Physical Rehabilitation:** Promote access to physical activity and sport-related activities. Include exercise specialists and physiotherapists or physical therapists who specialise in oncology rehabilitation in the multidisciplinary team.

## Support Services

- Education and Career Support:** Provide support for patients to continue or return to education during and after treatment. Offer career counselling and resources to help patients plan and pursue their professional goals.
- Family and Social Support:** Offer support services for families, including counselling and support groups.
- Housing Support:** Offer free or low-cost housing on-site or near the hospital.
- Transportation Support:** Assist patients with getting reimbursed or free transportation to the treatment site.
- Family and Social Support:** Offer support services for families, including counselling and support groups.
- Insurance, Finances, and Legal Assistance:** Ensure a dedicated social worker is available to assist with financial and legal issues and provide access to legal assistance.

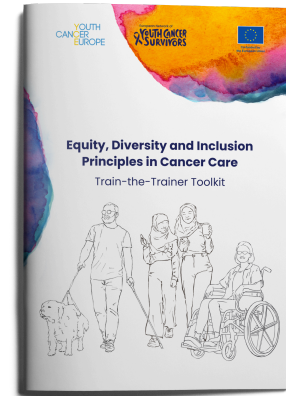
## Make all services and care settings inclusive and accessible

Ensure that all services and care settings prioritise inclusivity and accessibility. This involves offering interpretation and translation services, utilising pictograms, and providing easily understandable information for neurodiverse patients, among other supports. These resources must be readily available without patients needing to request them. Facilities should be designed to accommodate those with limited mobility and consider neurodiversity by including calm and quiet areas. Moreover, inclusive amenities like gender-neutral toilets should be provided, along with a multi-faith prayer or worship area to meet the diverse spiritual needs of all patients. These are just a few examples of how services and care settings can ensure inclusivity and accessibility for everyone they serve.

For more information on improving equity, diversity and inclusion (EDI) in cancer services and providing culturally sensitive care please see the position paper Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe.<sup>23</sup>

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This checklist highlights essential items to consider when developing Adolescent and Young Adult (AYA) services in clinical settings. Our recommendations provide a roadmap to achieving fully operational and improved care for all Adolescent and Young Adult (AYA) units across Europe, ensuring a supportive and inclusive environment for young cancer patients.

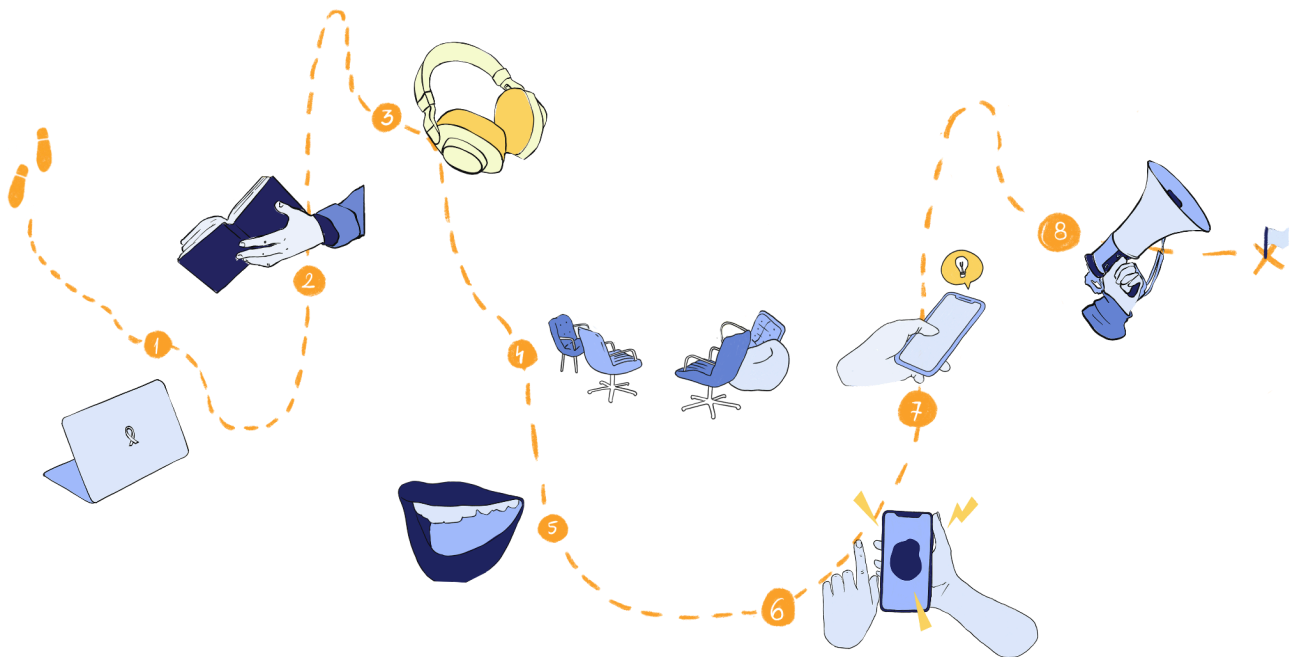


Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe

# DEVELOPING COMPREHENSIVE AYA SERVICES IN CLINICAL SETTINGS

## Part B | Implementation Roadmap

The below Implementation Roadmap consists of **eight targeted Recommendations** aimed at enhancing cancer care for Adolescents and Young Adults (AYAs) across Europe. These Recommendations are grounded in principles of age-appropriate care, holistic support, and equity, addressing the unique challenges and needs of Adolescents and Young Adults (AYAs) throughout their cancer journey. From establishing national knowledge hubs to advocating for policy changes and integrating digital health solutions, this roadmap empowers stakeholders to foster a supportive healthcare environment. By mobilising efforts at both European and national levels, we strive to improve treatment outcomes and quality of life for Adolescents and Young Adults (AYAs), ensuring equitable access and personalised care.





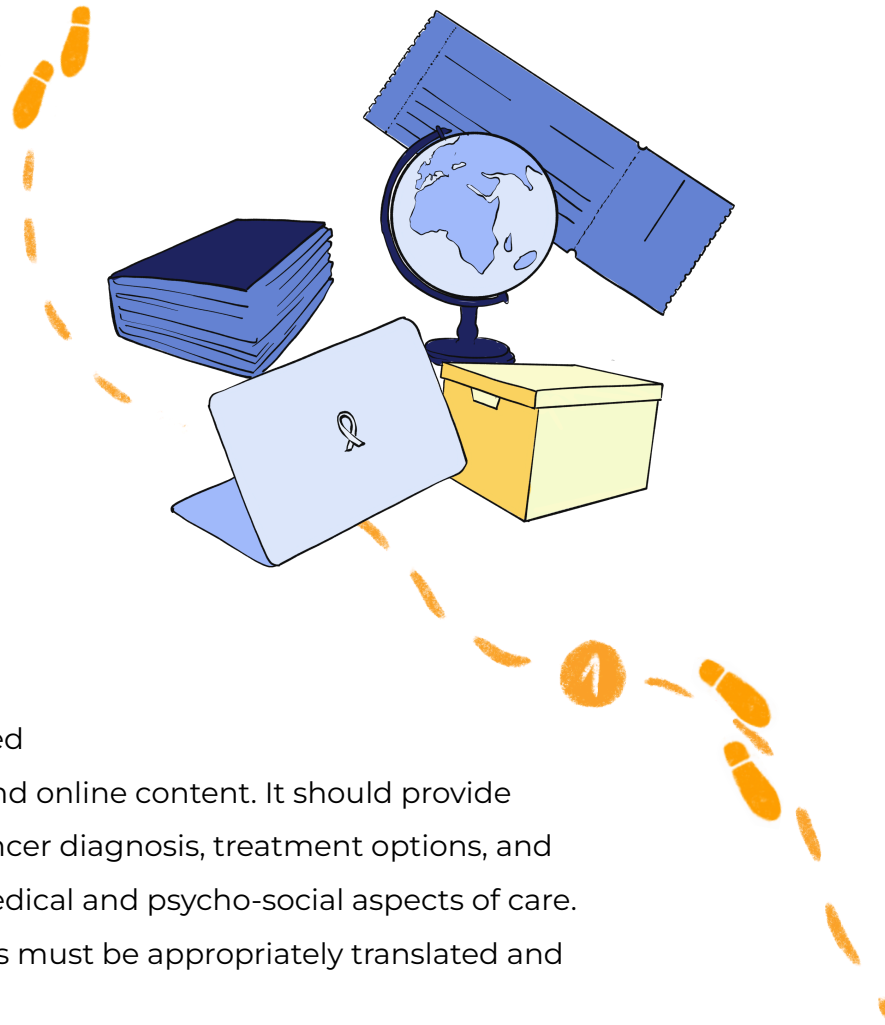
## Recommendation 1

### Develop a National Knowledge Hub for reliable Adolescent and Young Adult (AYA) - related information and resources

To address the unique needs of Adolescents and Young Adults (AYAs) with cancer, it is recommended to establish nationwide centralised knowledge hubs, to serve as a dependable source for Adolescent and Young Adult (AYA) - related information and resources, offering standardised and verified education materials and online content. It should provide comprehensive information on cancer diagnosis, treatment options, and support services, covering both medical and psycho-social aspects of care. To ensure accessibility, all resources must be appropriately translated and culturally appropriate.

The knowledge hub should link to various Adolescent and Young Adult (AYA) initiatives, including EU-funded projects and their outcomes, to enhance awareness of ongoing work among researchers, healthcare professionals, and Adolescents and Young Adults (AYAs). To aid Adolescents and Young Adults (AYAs) in navigating this wealth of information, the integration of AI-driven language learning models could be considered, tailored to individual health literacy and learning needs.

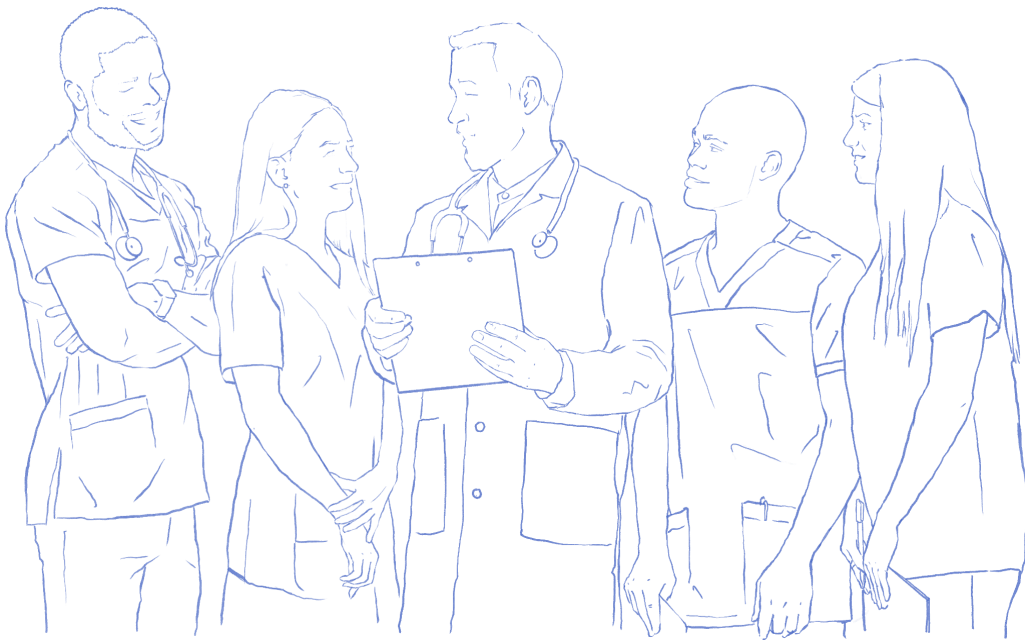
The European Commission could support national knowledge hubs through regular updates and annual reviews of guidelines. Furthermore, a mechanism should be established for Adolescents and Young Adults (AYAs), caregivers, healthcare professionals, or researchers to request the inclusion of missing or inaccessible information. This approach will help the hub remain comprehensive, responsive, and aligned with the evolving needs of its users.



## Recommendation 2

### Invest in Training, Education, and Resource Optimization for Healthcare Professionals

Investing in training and education programs for healthcare professionals is essential to enhance their cultural competence and communication skills, especially when interacting with young cancer patients from diverse backgrounds. To achieve this, the establishment of private-public partnerships



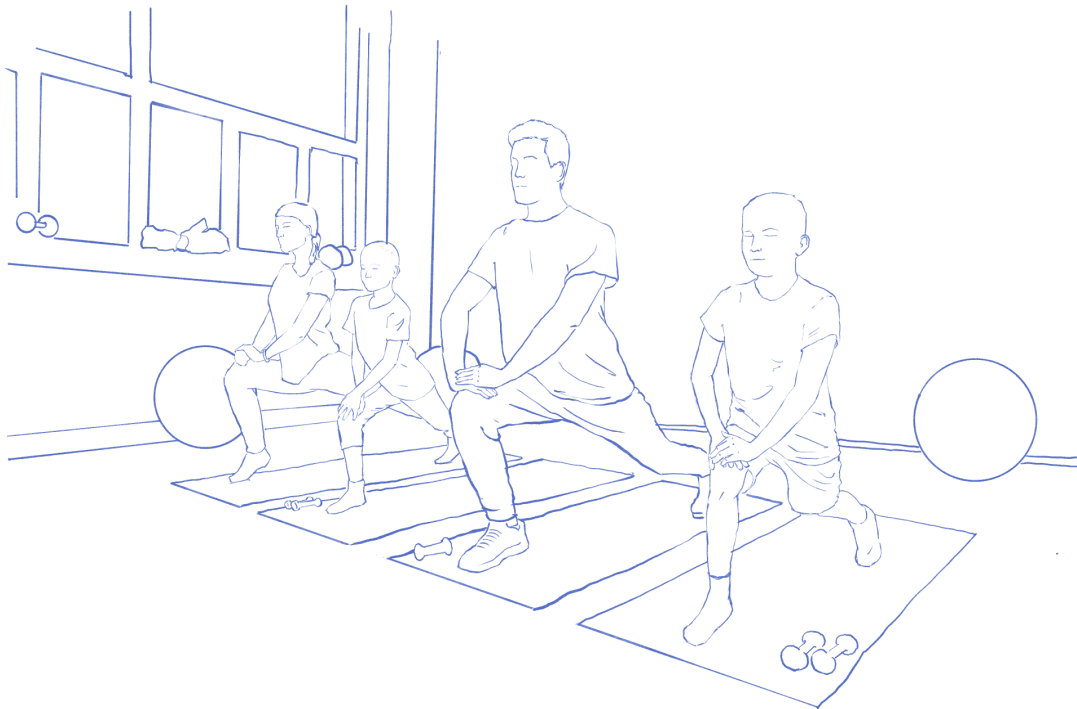
can be instrumental in developing and delivering these training modules. Additionally, the **creation of a matchmaking platform for services** can further optimise patient care. This platform would help healthcare providers identify and utilise existing interventions that are proven effective for specific scenarios, such as cognitive-behavioural therapy (CBT) for Adolescents and Young Adults (AYAs) experiencing anxiety related to fear of cancer recurrence. By aligning interventions with the individual needs and evidence-based interventions, healthcare professionals can ensure that their approaches are not only culturally sensitive, but also tailored to the unique challenges faced by each patient. This strategic investment in both training and resource allocation will enhance the overall quality of care provided to young cancer patients, respecting their diverse needs and improving their treatment experiences.



### Recommendation 3

#### Integrate Adolescent and Young Adult (AYA) - specific care across all cancer treatment settings

Acknowledging Adolescents and Young Adults (AYAs) as a unique group within all cancer care settings is essential, despite the practical limitations that prevent many clinics from establishing dedicated Adolescent and Young Adult (AYA) wards. Adolescents and Young Adults (AYAs) are often grouped with either paediatric or adult patients based on the age cut-off or available expertise in



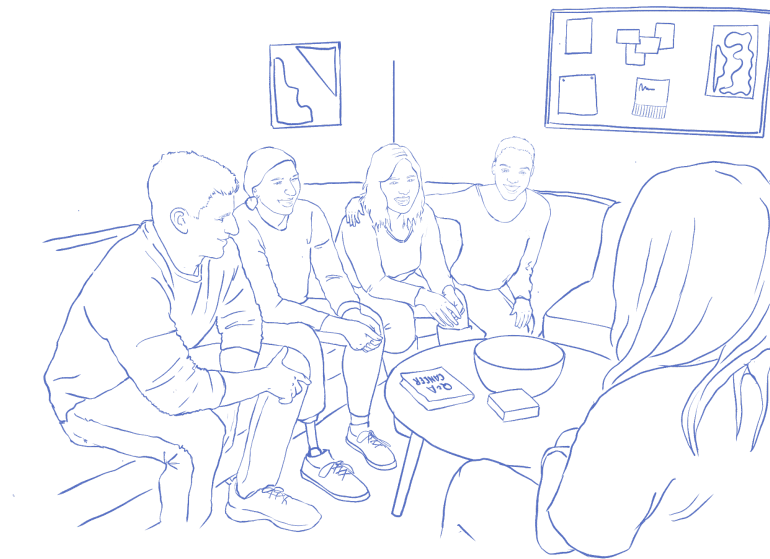
a specific setting. To address this challenge, specific strategies should be implemented to integrate Adolescent and Young Adult (AYA) care into existing treatment environments, such as educational resources that are age-appropriate and relevant to Adolescent and Young Adults (AYAs) available in both adult and paediatric settings, ensuring that Adolescent and Young Adults (AYAs) have access to information that resonates with their stage of life and experience with cancer, or designate areas within clinics that cater to the needs and preferences of young patients, tailoring them with amenities and environments that enhance

comfort and engagement, thereby fostering a sense of connection and reducing isolation for Adolescent and Young Adults (AYAs). In addition to these integration strategies, it is vital that these settings are linked to the centralised knowledge hub proposed in recommendation **R1** serving as a valuable resource, offering comprehensive and standardised information on cancer diagnosis, treatment options, and support services tailored for Adolescents and Young Adults (AYAs), for instance, facilitating the development of patient pathways that promote timely referrals, such as for fertility preservation prior to treatment initiation. Additionally, where multidisciplinary teams cannot be seamlessly integrated, the introduction of a care coordinator is recommended to ensure that Adolescent and Young Adult (AYA) - specific needs are adequately managed, reinforcing the commitment to tailored and empathetic care across all treatment environments.

## Recommendation 4

### Expand Access to Mental Health Services, Including On-Demand Counselling and Support Groups During and After Treatment

Expanding access to mental health services for Adolescent and Young Adults (AYAs) living with and beyond cancer is vital to address their psychosocial needs from diagnosis through post-treatment recovery. This expansion should include on-demand counselling and support groups to assist Adolescents and Young Adults (AYAs) as they navigate the challenges of treatment and its long-term effects, particularly focusing on the period after active treatment when patients often struggle with lingering side effects and the adjustment to life after illness. To ensure these services effectively meet the needs of Adolescents and Young Adults (AYAs), **the development of Key Performance Indicators (KPIs) for psychosocial support is recommended**. These KPIs should be **integrated into National Cancer Control Plans** to encourage local governments to prioritise and standardise mental health and social services, ensuring they are distinct and tailored to the specific challenges faced by young cancer patients. Additionally, a care coordinator, as discussed in recommendation **R3**, can facilitate the seamless integration of these services into the patient's overall care plan, enhancing the accessibility and effectiveness of psychosocial support throughout cancer treatment and recovery.



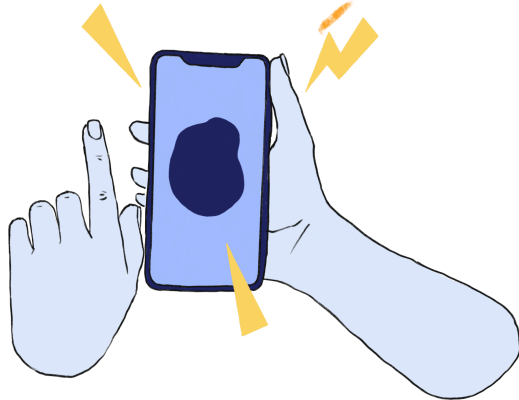
## Recommendation 5

### Empowering Adolescents and Young Adults (AYAs) Through Participation in Care Discussions and Shared Decision-Making

While it is important that physicians and medical teams first discuss individual cases, incorporating Adolescent and Young Adults (AYAs) into subsequent interdisciplinary tumour boards or case review meetings where their care is discussed is a critical step toward empowering patients and enhancing collaborative treatment planning and shared decision-making. *Whenever desired, possible, and in line with privacy and ethical considerations*, Adolescents and Young Adults (AYAs) should have a chance to sit at the table with their medical teams. Such inclusive approaches allow Adolescents and Young Adults (AYAs) to have a voice in their care pathway, irrespective of geographical location or access to multidisciplinary teams. To support this initiative, the **development of decision-making aids that improve health literacy** will be essential. This effort should be included in the upcoming research projects to ensure that all stakeholders are equipped to facilitate effective communication and shared decision-making. By actively involving Adolescents and Young Adults (AYAs) in care discussions and **equipping them with adequate tools for meaningful engagement**, we can ensure that their unique needs and perspectives are considered, ultimately leading to more personalised and effective cancer care.

## Recommendation 6

### Enhance integration and interoperability of healthcare systems and digital health platforms to enable Adolescent and Young Adult (AYA) patients and survivors



Enhancing the integration and interoperability of healthcare systems and digital health platforms is crucial to enable Adolescents and Young Adults (AYAs) with cancer to better navigate their care effectively. Given that young people today often relocate for educational or vocational opportunities and value mobility, it is essential that digital solutions like those supported by the European Union research programmes such as

SmartCARE, MyHealth@EU, as well as STRONG-AYA that allows cross-border data comparisons, are developed and integrated into existing healthcare frameworks. These platforms should be **designed to facilitate seamless care coordination and information sharing across different healthcare settings**, ensuring that Adolescents and Young Adults (AYAs) can access their medical information and support services **irrespective of their location and while safeguarding their privacy**. In addition to technical improvements, there should be a concerted effort to enhance health literacy and develop resources and tools within these digital platforms that are specifically tailored to help Adolescents and Young Adults (AYAs) understand and manage their health and treatment options more effectively. By focusing on both technological advancement and educational support, we can create a more cohesive and supportive healthcare environment for Adolescent and Young Adult (AYA) patients and survivors, empowering them to take an active role in their treatment and care.

## Recommendation 7

### **Promote research and innovation in digital health technologies, age-related medical treatment, and survivorship care to further enhance the quality and effectiveness of cancer care for Adolescents and Young Adults (AYAs) across Europe**

To further enhance the quality and effectiveness of cancer care for Adolescents and Young Adults (AYAs) across Europe, there is a critical need to promote research and innovation in areas such as digital health technologies, personalised medicine, and survivorship care. Initiatives should focus on integrating national registries and novel patient-reported outcome measures and patient-reported experience measures (PROM/PREMs) data, as exemplified by the STRONG-AYA project. This integration will provide a more comprehensive understanding of patient needs and outcomes, informing better care strategies. Additionally, **co-designing and validating culturally adapted patient tools is essential to effectively use patient-reported outcomes (PROs) for Adolescent and Young Adults' (AYAs') own care management.** These tools should be tailored to meet the diverse cultural and individual needs of young patients, enhancing their ability to engage with and influence their treatment plans actively. Lastly, developing an Adolescent and Young Adult (AYA)-specific curricula for new graduate or medical students can bridge the gap between clinical practice and research, particularly in data-related aspects. Integrating such specialised training into existing educational frameworks will prepare the next generation of researchers and clinicians to implement cutting-edge, data-informed practices that cater specifically to the unique challenges faced by Adolescent and Young Adult (AYA) cancer patients.

## Recommendation 8

### Advocate for Policy and Practice Changes in Healthcare Systems to Address Adolescent and Young Adult (AYA) - related Challenges and Inequities in Cancer Care Delivery Across Europe

To effectively address the specific challenges and inequities faced by Adolescent and Young Adults (AYAs) in cancer care delivery across Europe, it is crucial to implement targeted system-level policies and practices. Examples of such policies could include initiatives like the "right to be forgotten," which allows cancer survivors the option to exclude their cancer history from records to mitigate potential discrimination. Another critical area for policy focus is ensuring equitable reimbursement for fertility preservation treatments. These examples



highlight specific areas where policy changes can significantly impact Adolescents' and Young Adults' (AYAs') healthcare experiences.

These policy implementations should be advanced through initiatives led by the European Commission (EC) and other pertinent European bodies, such as the European Parliament and the European Council. These bodies play pivotal roles in recognizing equity and health literacy as fundamental human rights, thereby influencing healthcare policies across member states.

At the national level, advocacy and lobbying efforts by healthcare providers, national medical societies, patient representations, and other stakeholders are instrumental in driving policy changes. These groups can effectively advocate for Adolescent and Young Adult (AYA) - specific policies, leveraging their expertise and influence to spearhead initiatives that adapt and implement European

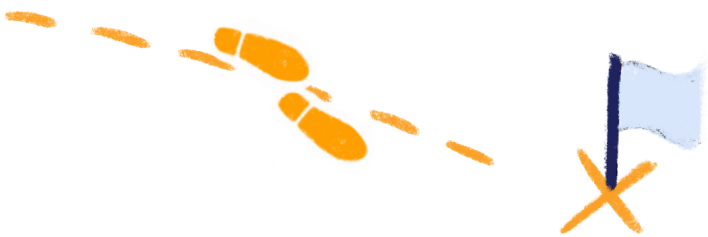


guidelines within local healthcare systems. By mobilising at both the European and national levels, stakeholders can ensure that policy improvements are comprehensive, aligned with European standards, and responsive to local challenges and priorities.

## CONCLUSIONS

The **Minimum Standards of Specialist Adolescent and Young Adult (AYA) Cancer Care Units** Recommendations and Implementation Roadmap underscores a critical initiative aimed at enhancing cancer care for Adolescents and Young Adults (AYAs) across Europe. Grounded in principles of age-appropriate, holistic, and equitable care, these recommendations offer a strategic framework to address the unique needs of young people.

In moving forward with these recommendations, stakeholders are encouraged to collaborate across borders and disciplines, ensuring implementation aligns with local healthcare contexts while upholding European standards. By prioritising the needs and voices of Adolescents and Young Adults (AYAs), we aim to foster a healthcare environment that supports their physical, emotional, and social well-being, ultimately improving treatment outcomes and quality of life for all young people living with and beyond cancer.



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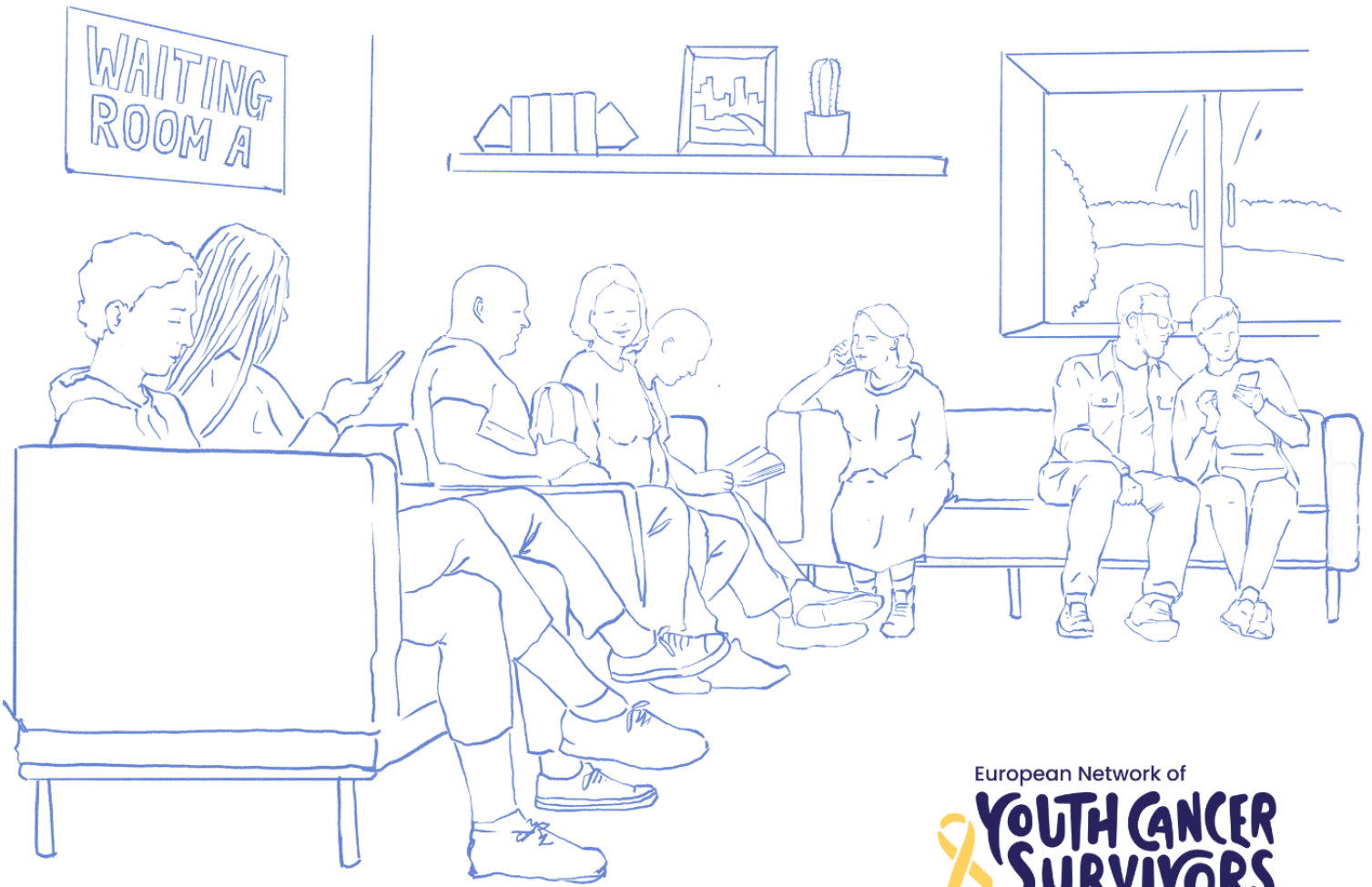
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