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REVIEW

Minimum standards of specialist adolescent and young adult (AYA) cancer care units: recommendations and implementation roadmap

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In 2022, according to the Global Cancer Observatory, >115 000 adolescents and young adults (AYAs; aged 15-39 years) were diagnosed with cancer across Europe. Despite their unique biological and psychosocial needs, AYAs face disparity of access to specialised oncology services, particularly outside major urban centres in the east and south of Europe. Addressing these inequalities is essential to ensuring comprehensive and equitable cancer care. As part of EU4Health, the European Union Network of Youth Cancer Survivors (EU-CAYAS-NET) consortium was established to advance Europe's Beating Cancer Plan. The project aimed to develop—with patient organisations at the helm—evidence-based recommendations to standardise and improve care across Europe, ultimately enhancing outcomes and quality of life for all young people.

Key words: adolescents and young adults, AYA oncology, multidisciplinary cancer care, cancer care health policy, health equity

INTRODUCTION

Adolescents and young adults (AYAs) facing cancer represent a unique and often underserved population within the European, as well as global, health care landscape. This demographic, aged between 15 and 39 years at the time of diagnosis, constitutes a significant portion of the burden of morbidity and mortality. The incidence of AYA cancers is rising, with an estimated 1.3 million new AYA cancer cases worldwide in 2022,[1] while in Europe, AYA-onset cancer affects >115 000 individuals annually.[2] Due to continued medical and technological advancements, the majority of AYAs now live long beyond their illness, with >85% surviving beyond 5 years globally; however, survival varies significantly by cancer type and region. Recent data from EUROCARE-6, the most comprehensive study of AYA cancer survival across 29 European countries, reported an overall 5-year relative survival of 84%, with rates ranging from 70% to 90% across 12 tumour types.[3] Notably, survival disparities between countries suggest that differences in stage at diagnosis, access to treatment, and referral to specialist centres play a critical role in outcomes. Additionally, for certain malignancies, AYAs experience lower survival rates than younger children with the same disease, underscoring the need for tailored treatment strategies and improved access to specialised care.[4,5] Beyond survival, AYAs face a range of psychosocial late effects, including disrupted education, employment challenges, financial toxicity, and weakened social networks, all of which contribute to a diminished quality of life.[6,7]

In the United States in 2019, the total economic and human cost of cancer in AYAs diagnosed was $23.5 billion; a lifetime cost of $259 324 per person.[8] This financial burden is multifaceted, encompassing direct health care costs, productivity losses, and diminished well-being. Notably, the majority of these costs (70%) are borne directly by AYA cancer survivors and their families in the United States, with productivity-related excess costs amounting to $199 000 per person over their lifetime. In Europe, data also highlight significant financial burdens; overall health care expenditure for cancer in 2018 amounted to €199 billion (if we estimate that ∼5% of all cancer diagnoses occur in AYAs, that would mean €9.95 billion), with ∼35% of these costs resulting from loss of productivity, ∼25% due to premature mortality, and ∼10% from morbidity.[9] Beyond direct medical expenses, indirect costs such as income loss are profound; for instance, AYA survivors experience an average 8.5%

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reduction in annual earnings compared with peers without cancer, with younger AYAs (aged 18-25 years) facing an income decline of up to 15.5%.[10] Additionally, up to 70% of AYA cancer patients report income loss during treatment, and up to 38% are forced to permanently leave their jobs.[11]

In addition to the economic burden, the psychosocial challenges and normative developmental milestones, AYAs also face substantial physical sequelae—fertility-related challenges, cardiovascular morbidity, and second malignant tumours contribute to increased rates of early mortality. Despite advances in cancer treatment, health care systems and cancer care services continue to inadequately meet the specific needs of AYAs.[12] This neglect underscores the urgent need for targeted interventions and health policies that will address the specific challenges faced by this population.

RATIONALE

Addressing the challenges outlined has resulted in the development of specialised AYA services largely, but not solely, in major clinical centres and in Western and Northern Europe. Smaller populations, rural areas, and Southern and Eastern Europe receive nonspecialist services, which therefore results in inequitable disparities in access, care quality, and outcomes.

This paper outlines minimum standards for specialist AYA cancer care to establish a benchmark for age-appropriate, high-quality services across Europe. Given the unique medical, psychosocial, and financial challenges faced by AYAs with cancer, these standards aim to address existing gaps in care, research, and policy. By providing clear recommendations, this narrative review serves as a call to action for policymakers, health care professionals, and advocacy groups to ensure equitable access to comprehensive AYA cancer care throughout the European Union (EU).

METHODOLOGY

This review resulted from an iterative, multiphase process to identify and prioritise essential services for AYAs with cancer, integrating comprehensive literature review, participatory research, and consensus-building methodologies. A review of academic and grey literature was completed between October and December 2023, using PubMed and Google Scholar with keywords such as ‘adolescent and young adult’ and ‘cancer’. Inclusion criteria were (i) publications in English, (ii) focus on AYA populations (15-39 years of age), and (iii) articles discussing psychosocial care and service delivery. Exclusion criteria included publications focusing exclusively on paediatric or older adult populations, non-oncological conditions, or those lacking relevance to service provision or patient experience. Extracted information informed the development of a comprehensive list of services and needs, which was used by patient and public involvement and engagement (PPI&E) groups during peer visits to cancer services with AYA specialisations. Peer visits[13] used active observation and participatory approaches at five major cancer care centres in Italy, Belgium, and The Netherlands. These centres were selected based on the following criteria: (i) recognised provision of specialised AYA services, (ii) geographical and health system diversity, and (iii) willingness to participate in the project. Insights from these visits, coded through content analysis[14] by two independent researchers, informed the study’s qualitative component. Consensus on cancer care priorities and minimum standards was sought using a modified Delphi process.[15] Specific attention was paid to ensure diversity in the consensus-building process, including representation from over 14 countries and an age range of AYAs with lived experience spanning 18-39 years. Two online iterative survey rounds facilitated rating of the importance (0-9) and, subsequently, ranking of services. The findings from the two rounds were presented at an online roundtable in December 2023, with presenters being health care professionals ($n = 8$), young people with lived experience ($n = 8$), and external participants ($n = 50$) who discussed barriers, policy criteria, clinical frameworks, and patient-reported outcomes. The overall outcomes provided the foundation for recommendations for age-appropriate, equitable AYA cancer care across Europe presented in this paper. The complete methodology and detailed descriptions of all parts, including participant selection and guidelines, have been published online.[13]

EXISTING EVIDENCE, GAPS IN KNOWLEDGE AND OPPORTUNITIES

The existing disparities in care and outcomes of AYAs stem from gaps in research and implementation of services in clinical practice, but also policy. Addressing these issues requires a robust, evidence-based policy framework that integrates AYA-specific care into cancer care and treatment systems equitably across Europe. The following sections highlight key areas where system-level policy interventions could drive meaningful improvements, though they do not represent an exhaustive list of unmet needs.

Fragmentation of AYA cancer care, research, and services in the European space

AYAs with cancer frequently navigate a fragmented care landscape, falling between paediatric and adult oncology services that are inadequately designed to address their unique, life-stage-specific needs.[16,17] This fragmentation in care results in high rates of unmet needs, with over half of AYAs reporting significant gaps during and after treatment, ranging from insufficient access to in-home nursing (29%) to a lack of support groups (75%).[18]

The availability of holistic, supportive services—critical to mitigating the long-term physical and psychosocial effects of cancer—varies significantly across countries and health care systems. Access depends heavily on health care providers’ awareness of the complex needs of AYAs, the presence of adequate services, and functional referral pathways. As a result, many AYAs are often excluded from

Box 1. Language around framing of adolescents and young adults (AYAs) as a distinct group matters

Advancing AYA cancer care requires clear and specific terminology. Without explicit recognition, this demographic risk is being overlooked in policy and funding decisions. When the European Commission published Europe's Beating Cancer Plan[19] in 2021, 'youth' or 'young people' were generally only mentioned under the 'Putting Childhood Cancer under the Spotlight' section. This framing left them without distinct recognition in the European Union (EU)'s foundational cancer strategy.

Thanks to persistent youth patient advocacy, the European Parliament's BECA Committee (BECA stands for a Special Committee on Beating Cancer, established by the European Parliament in order to support and shape the implementation of the Europe's Beating Cancer Plan) addressed this gap in its 2022 report,[20] explicitly calling for AYAs to be recognised as a distinct group with specific medical, psychosocial, and mental health needs. However, these priorities were not immediately reflected in actions or funding. The momentum led Directorate-General for Research and Innovation to initiate a year-long dialogue with young people with lived cancer experience. Throughout 2023, consultations with the Cancer Mission highlighted concerns about AYA cancer management and identified key research priorities, including the need for more effective treatments and better strategies to address mental health and late effects.

The December 2023 Summary Report confirmed that these consultations influenced the new EU4Health and Horizon Work Programmes, introducing targeted funding. This progression underscores that once clear and consistent language was established to define AYAs as a distinct population, the EU was able to develop a stronger framework, leading to dedicated policies and projects.

essential resources such as fertility preservation, mental health support, pain management, physical therapy, occupational therapy, and financial guidance.[12,16]

At least in part, the fragmentation of services can also be accounted for by the lack of high-quality, representative research on AYA cancer care, which results in the lack of comprehensive evidence-based guidelines specific to the European context. Much of the existing research relies on cross-sectional studies with self-selected samples, non-standardised age ranges, and geographically, culturally, and linguistically unrepresentative populations. These limitations contribute to slow policy or practice change, perpetuating disparities. Targeted investment in rigorous, representative research is essential to build a solid foundation for effective guidelines and interventions (see Box 1).

Fertility preservation and family planning

Fertility preservation is a particularly salient issue for AYAs, as cancer-related fertility impairment and concerns profoundly affect parenthood, sexuality, body image, self-esteem, and overall quality of life.[21] Although evidence-based international guidelines for fertility preservation exist,[22] their implementation across Europe remains inconsistent. A European survey of 629 AYAs with lived experience highlighted significant inequalities in access to fertility preservation services, with gaps varying widely across countries and health care systems.[23] Overall, only 53% of respondents were made aware of the available medical options for fertility preservation during their cancer care. Furthermore, this difference was significantly different between parts of Europe: individuals from Eastern Europe were less informed than their counterparts in the West. Moreover, 27% said fertility-related concerns greatly impacted their level of anxiety and depression, and 17% reported a great impact on their quality of life. So, monitoring fertility-related distress throughout the cancer continuum should also be incorporated as a critical step to improving mental health and quality of life for this population.

To address between-country discrepancies and the negative downstream effect of lack of fertility preservation opportunities, accessible fertility preservation programmes must become integral to cancer prehabilitation and rehabilitation for AYAs. Policymakers and service providers should prioritise the implementation of existing fertility preservation guidelines and actively involve AYAs in the development of improved frameworks. Recently, evidence-based and AYA cocreated decision-making aids for fertility preservation have also started emerging (e.g. https://cancerfertilityandme.org.uk/).

Financial discrimination

Financial discrimination presents another major challenge for AYAs. AYA cancer survivors often encounter barriers in accessing life insurance, mortgages, or travel insurance many years after their successful treatment. Policies such as the 'Right to Be Forgotten' (RBF) provide a promising solution, allowing individuals to withhold disclosure of a past cancer diagnosis under specific circumstances. Northern Europe has been at the forefront of this initiative, with Belgium, The Netherlands, and France implementing progressive policies. For example, Belgium enacted a law in January 2025 exempting individuals diagnosed before age 21 years from disclosure requirements.[24] Slovenia is the most recent country to pass the RBF proposal in November 2024.[25]

Despite these advances, financial discrimination persists across much of Europe, raising the question of whether the problem lies in a lack of evidence or poor implementation.

While research increasingly highlights the (unjustified) economic hardship faced by all young cancer survivors, policy uptake remains inconsistent. The challenge is not just about generating more data but ensuring that existing evidence translates into equitable, enforceable protections across all European countries. Expanding RBF policies and harmonising their implementation could significantly reduce financial burdens on AYAs, supporting their long-term socioeconomic stability and full participation in society.

Limited representation of AYAs in cancer control strategies and clinical trials

Despite the specific needs of AYAs, National Cancer Control Plans (NCCPs) rarely address this population as distinct. Only 39% of NCCPs include paediatric cancer strategies, and just 23% feature dedicated paediatric cancer sections,[26] with limited mention of AYA-specific strategies. Although some places such as Ireland have included AYAs with childhood cancer in their NCCP, it is important that this practice disseminates further, filling gaps in care provision and providing funding for those services.

Beyond oversight in NCCPs, AYAs also face limited access to clinical trials, which impedes the development of age-appropriate treatment protocols. Internationally, AYA participation in clinical trials remains low, with enrolment rates ranging from just 5% to 34% in published studies.[12] This gap is partly due to the unavailability of trials designed to accommodate their unique biological and psychosocial needs.[27] The lack of AYA representation in research also perpetuates a cycle of disengagement—fewer AYAs enrol in trials, leading to less evidence tailored to their needs, which in turn discourages further participation.

A recent review on patient involvement in clinical research found that while 85% of cancer trials incorporated patient input in the development phase, only 67% maintained patient engagement throughout the research lifecycle.[28] Key elements of successful patient involvement include clearly defined roles for patient partners, diversity in patient representation, dedicated funding for patient engagement, and the provision of training and support materials. Strengthening these aspects could help bridge the gap in AYA participation and ensure their voices are integrated into research and policy development. Beyond clinical trials, representation disparities extend to informational resources, with >40% of AYAs reporting that the materials they receive fail to reflect their lived experiences.[29] This lack of tailored resources further contributes to disengagement and limits the effectiveness of supportive care initiatives.

The EU's Beating Cancer Plan launched in Europe in 2021 and subsequent revision in 2022 (see Box 1) present an opportunity to address these systemic gaps in cancer prevention, treatment, and care by promoting an integrated, multistakeholder, health-in-all policies approach, by funding research initiatives and European consortia that incorporate AYA-specific issues into broader cancer care frameworks. While European funding initiatives increasingly support research consortia incorporating AYA-specific concerns, national and regional policies must go further. Targeted policy measures that recognise local health care contexts are essential to fully integrating AYA needs into cancer prevention, treatment, and survivorship frameworks.

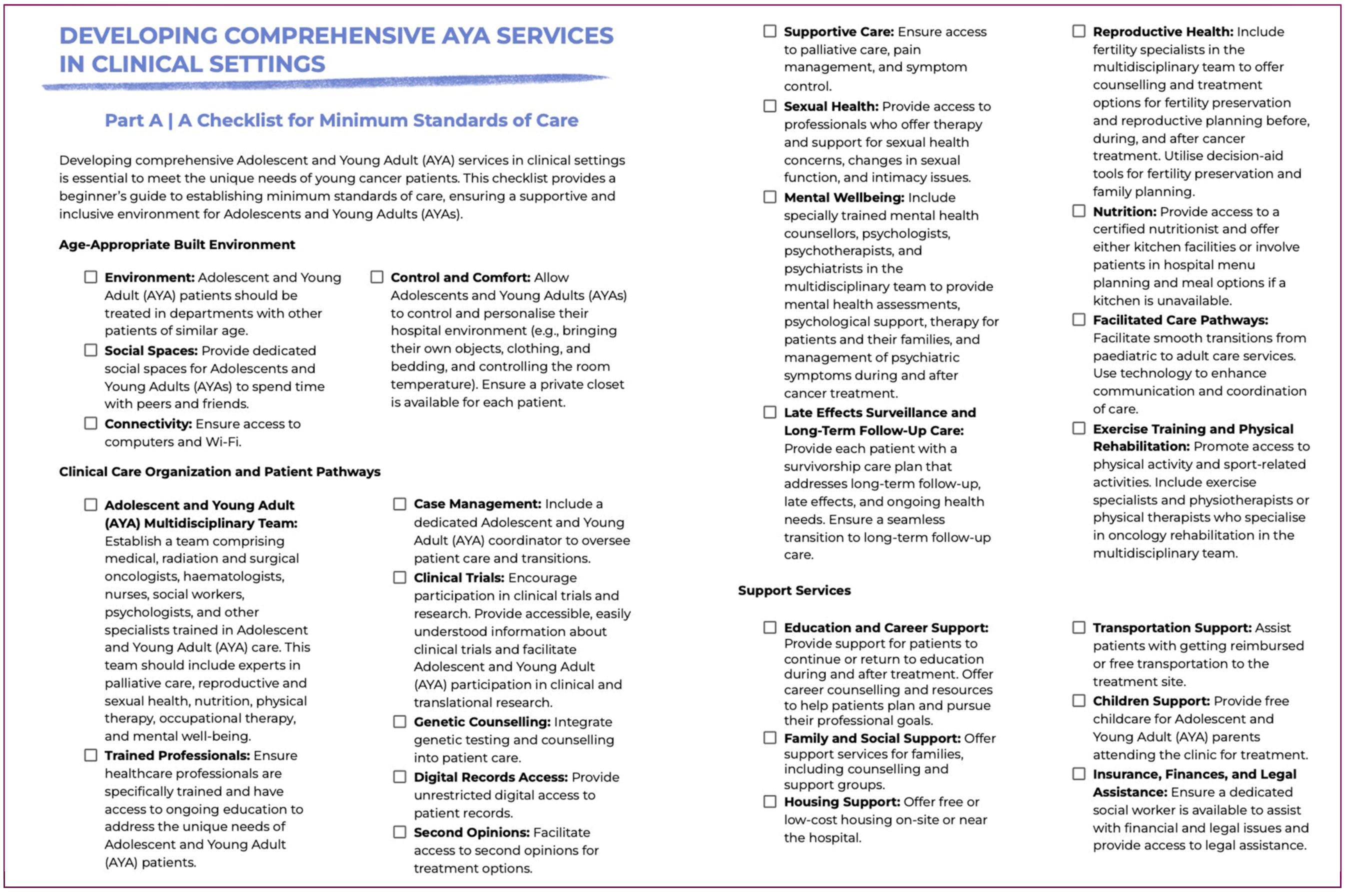
Reintegration into school and return to work

AYA cancer survivors face considerable difficulties in reintegrating into school and the workforce after treatment. While most AYAs (∼83%-89%) return to education or employment within 1-2 years post-treatment, many encounter significant disruptions during this transition.[30,31] Cognitive impairments, fatigue, and other physical effects of treatment make reintegration challenging, with up to 53% of AYAs reporting long-term cognitive issues years after diagnosis.[32] Educational interruptions during treatment often result in delays, affecting long-term career development.[33] In the workplace, AYA cancer survivors tend to start working later than their peers, experience more absent workdays, and report reduced work ability, with 57%-76% of survivors facing challenges up to 1 year post-treatment.[32,33]

Despite existing legal protections, many AYA cancer survivors rely on the empathy of supervisors rather than formal workplace policies designed to support them.[34] This highlights the need for better awareness and enforcement of workplace protections. Some countries, such as Germany, offer vocational reintegration programmes through social security agencies, but these provisions require ongoing evaluation, as excessive work demands often emerge months after returning to employment.[35] Strengthening and standardising return-to-work policies, including targeted occupational counselling, could improve long-term employment outcomes. The frequent use of occupational adjustments (reported by 82.3% of survivors) underscores the need for policies that formally recognise and protect these accommodations.[35] Policies that promote structured reintegration programmes, ensure workplace protections, and support educational adjustments would help mitigate long-term socioeconomic consequences for AYA survivors and facilitate their successful transition back into society.

A ROADMAP TO ADVANCE EVIDENCE, POLICY, RESEARCH, AND PRACTICE

In June 2024, the EU Network of Youth Cancer Survivors (EU-CAYAS-NET) website published a recommended implementation roadmap and checklist (see Figure 1). This outlines eight targeted, actionable, and evidence-based recommendations designed to improve cancer care for AYAs across Europe. Table 1 is presented as a roadmap reflecting sequence from more immediate actionable recommendations to those requiring longer term planning and resources. Rooted in principles of age-appropriate care, holistic support, and equity, these 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.
- ☐ **Children Support:** Provide free childcare for Adolescent and Young Adult (AYA) parents attending the clinic for treatment.
- ☐ **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.

Figure 1. A checklist of actions that local institutions can take to develop adolescent and young adult (AYA)-specific services within the clinical settings (image adapted[13] with permission).

address the distinct challenges AYAs face throughout their cancer journey.

Establish national knowledge hubs for AYA cancer care

Finding current and reliable information about cancer requires skills such as health literacy. Centralised national knowledge hubs (e.g. https://www.teenagecancertrust.org/) could offer standardised, evidence-based information tailored to the needs of AYAs with cancer. These hubs should offer verified educational materials covering medical, psychosocial, and survivorship aspects of care, ensuring accessibility through culturally adapted and translated resources that have been co-designed and user tested. Furthermore, linking these hubs to EU- or otherwise-funded initiatives would facilitate collaboration among researchers, health care professionals, and AYAs, allowing for knowledge exchange and better awareness of best practices. Additionally, incorporating artificial intelligence-driven tools for personalised health literacy support could enhance navigation and engagement.

Strengthen training and resource optimisation for health care professionals

Enhancing the specific expertise of health professionals in AYA oncology through targeted training is essential to improving care delivery and patient—provider communication. Structured educational programmes should be developed in collaboration with public—private partnerships, integrating content on cultural competence, psychosocial support, and evidence-based interventions such as cognitive-behavioural therapy (CBT) for managing anxiety related to cancer recurrence, which has been observed in up to 62% of AYAs.[36] Digital and telehealth advancements could facilitate development and implementation of a digital matchmaking platform to enable clinicians to be adequately trained and able to identify and implement effective, personalised interventions, ensuring alignment with AYA-specific needs. Additionally, the introduction of AYA-specific curricula in medical education (such as is already mandatory for oncology nurses delivering AYA care in The Netherlands) will ensure that future health care professionals and researchers are equipped with the knowledge and skills necessary to address the complex needs of AYAs. This strategic investment in training and resource allocation will optimise care delivery, improve treatment adherence, and enhance overall patient experiences.

Integrate AYA-specific care across oncology settings

Access to age-specific expertise within the care of all cancer types is crucial to providing AYA patients with access to care that is not only medically appropriate but also

Table 1. **Summary table of recommendations**

Recommendation	Description	Potential stakeholders responsible
1. Establish national knowledge hubs for AYA cancer care	Nationwide timely AYA cancer knowledge and support hubs are recommended, providing reliable, culturally appropriate resources on cancer care, treatment, and support, linking to EU-funded initiatives and leveraging AI to tailor content to individual needs.	European Commission Media Research institutions Public health organisations Health care providers Professional health care societies Patient organisations
2. Strengthen training and resource optimisation for health care professionals	Development of structured educational programs and AYA-specific curricula to enhance clinicians' ability to address the unique medical and psychosocial needs of this group. Leveraging digital and telehealth advancements can further support training and personalised care delivery, improving patient outcomes and treatment adherence.	Governmental bodies for education Educational institutions and research training centres CPD organisations (Inter)national societies in psychosocial care Patient advocacy organisations
3. Integrate AYA-specific care across oncology settings	Integrate AYA-specific care within existing paediatric, adult, and emerging AYA oncology services to improve treatment adherence and patient outcomes. Key strategies include AYA-trained navigators, multidisciplinary referral pathways, and dedicated care coordinators to ensure continuity of care and tailored psychosocial support.	Government bodies regulating public health Secondary and tertiary hospitals and health care facilities Patient organisations and charities
4. Expand access to mental health services for AYAs during and after treatment	Endure access to structured mental health interventions and integrate key performance indicators (KPIs) into National Cancer Control Plans. Expand the role of AYA care coordinators to ensure equitable access to psychosocial support, improving long-term well-being and quality of life.	Public health and research institutions National bodies as ministries of health Public and private health care providers
5. Promote shared decision making and patient participation in care planning	AYAs prefer a collaborative approach to treatment decisions, seeking input from oncologists and family members. Integrating AYAs into interdisciplinary tumour board discussions, developing decision-making aids, and fostering open dialogue can empower patients, improve adherence, and promote personalised, patient-centred care.	(Inter)national professional health care societies Research institutions Private and public health care providers
6. Enhance digital health integration and data interoperability	Digital health platforms can support care access across providers, but barriers like system fragmentation and digital literacy must be addressed. Prioritising interoperability between national health care data systems and developing secure, user-friendly digital tools will improve patient engagement, data accessibility, and care continuity.	Government bodies regulating public health European Commission National HTA bodies Medical tech organisations Health care providers Patient organisations
7. Advance research and innovation in AYA oncology and survivorship care	Recognizing AYAs as a distinct patient group has created opportunities for research innovation, including integrating AYA data into national cancer registries and enhancing the use of patient-reported outcome measures. The value of real-world data in improving patient education, treatment, and survivorship care needs further showcasing.	National public health institutes and HTA bodies Research institutions Patients organisations
8. Advocate for policy reforms to address inequities in AYA cancer care	Expand initiatives such as the 'Right to Be Forgotten' and standardising reimbursement for fertility preservation can reduce financial and geographic disparities. Collaborative policy advocacy involving funding bodies, health authorities, and patient organisations is essential to embedding AYA-specific needs into national and European health care strategies.	European Commission Health care regulatory bodies Public health organisations

AYA, adolescent and young adult; CPD, continued professional development; HTA, health technology assessment.

responsive to their developmental stage and psychosocial needs, therefore potentially improving treatment adherence. This includes the provision of AYA-trained cancer service navigators and support programmes to guide AYAs through the complex health care landscape. These can promote timely and appropriate interventions, support for shared treatment-related decision making, and assistance navigating the challenges of life during and after cancer. Given the practical constraints in establishing dedicated AYA oncology units, efforts should focus on integrating AYA-specific care within both existing paediatric and adult cancer services as well as AYA-specific services (as those develop). AYAs frequently experience a mismatch between their developmental needs and the structure of traditional cancer care pathways. AYA-specific care should also be embedded in multidisciplinary frameworks, including referral pathways for fertility preservation and long-term psychosocial support. Where fully integrated teams are

Box 2. Ongoing and upcoming adolescent and young adult- (AYA)-related projects in Europe

Several European Union- (EU)-funded projects and collaborative efforts are actively working to address the unmet needs of AYAs with cancer. These initiatives focus on improving health care access, quality of life, mental health support, and survivorship outcomes through research, digital innovation, and policy integration.

The STRONG-AYA project is establishing a pan-European data ecosystem to integrate patient-reported outcomes and clinical data, enhancing value-based care and policy making for AYA oncology. Similarly, EU Network of Youth Cancer Survivors (EU-CAYAS-NET) (https://beatcancer.eu/) is developing an interactive platform to empower young cancer survivors, focusing on quality of life, health care access, and inclusion, which will be carried forward in YARN (just awarded).

Addressing psychosocial needs, MELODIC is dedicated to early mental health intervention for young cancer patients and their caregivers, while E-QuoL (https://equolproject.eu/) develops e-health tools to improve long-term quality of life. Prevention-focused efforts include SUNRISE (https://thesunriseproject.eu/), which targets harmful adolescent behaviours linked to cancer risk through a digital life-skills programme implemented in schools. Meanwhile, FORTEe (https://fortee-project.eu/) promotes structured exercise interventions to support young cancer patients during and after treatment.

At the policy and health care systems level, the ENTYAC network unites stakeholders to advance AYA-specific oncology initiatives and has contributed to several EU projects, including PREDICT-AYA and PANCARE4AYA (the former aiming to improve the understanding and management of late effects, while the latter's goal is to implement follow-up guidelines for AYAs). Additionally, the Joint Action on Networks of Expertise (JANE)[49] has designated AYA cancer care as a priority, fostering cross-border collaboration to reduce disparities in treatment and access to specialised care. As part of this initiative, JANE has established a dedicated Network of Expertise for AYA cancer, aiming to bridge the gap between paediatric and adult oncology services while ensuring access to specialised knowledge, innovative treatments, and structured care pathways. In parallel, the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) have established a Working Group[12,50] to enhance AYA-focused education and knowledge sharing between adult and paediatric oncology specialists.

These initiatives reflect a growing commitment to addressing the unique challenges faced by AYAs with cancer. By leveraging digital tools, interdisciplinary collaboration, and policy-driven approaches, the EU continues to strengthen AYA oncology care, ensuring that young patients receive the support they need at all stages of their cancer journey.

not feasible, a dedicated AYA care coordinator can facilitate patient navigation and continuity of care. One of the examples where AYA care is embedded in the health care network is the AYA 'Young and Cancer' Network in The Netherlands (https://ayazorgnetwerk.nl/).

Expand access to mental health services for AYAs during and after treatment

Mental health support is a critical component of comprehensive cancer care. Cancer diagnosis and treatment can cause significant distress, anxiety, and depression in patients of all ages, but AYAs face unique psychosocial challenges due to their developmental stage, and commonly report feelings of distress, anxiety, and depression, which can persist long after treatment, affecting long-term mental health.[37-39] Many AYAs exhibit maladaptive coping strategies, including substance use or avoidance, which can contribute to both physical and psychological health complications.[40-43] Treatment-related changes in physical appearance, such as hair loss or weight fluctuations, can contribute to negative body image, leading to social withdrawal, distress, and increased risk of depression.[44,45] Despite the prevalence of these issues, access to psychosocial interventions remains inconsistent across AYA oncology services, and engagement in structured mental health programmes, such as CBT, remains low.[46,47] Expanding access to on-demand counselling and peer support groups will ensure continuity of care beyond active treatment, addressing the unique challenges of survivorship, and integrating comprehensive psychosocial support into AYA oncology care is essential for improving quality of life and overall well-being.[48]

To standardise and prioritise mental health services, key performance indicators (e.g. STRONG-AYA Core Outcome Set; see Box 2) should be developed and integrated into NCCPs, encouraging local governments to allocate resources for structured psychosocial support. The role of AYA care coordinators should be expanded to ensure seamless integration of mental health services within broader cancer care pathways.

Promote shared decision making and patient participation in care planning

Empowering AYAs to actively participate in their treatment decisions may improve engagement and adherence, as well as promote patient autonomy. Almost up to two-thirds of AYAs prefer to share decision-making responsibilities with their oncologists, while many also seek input from family members, demonstrating a desire for collaborative engagement in their care.[51] AYAs with lived experience involved in the consortium and the development of this paper suggested that AYAs should be included in interdisciplinary tumour board discussions, enabling them to contribute to care planning, as long as ethical and privacy considerations are maintained. In order to address any decisional conflict due to limited knowledge or emotional distress, the development of AYA-specific decision-making aids may further facilitate meaningful participation. Health care providers should encourage open dialogues, including triadic communication[52] when appropriate, which can ultimately lead to more personalised and patient-centred cancer care.

Enhance digital health integration and data interoperability

Given the mobility of young populations due to education and employment opportunities, ensuring seamless access to health care services across different providers can be essential. Digital health platforms (e.g. STRONG-AYA, see Box 2) offer opportunities for data integration, enabling AYAs to manage their care irrespective of location. However, barriers related to digital literacy and system fragmentation persist. To address this, interoperability between national health care data systems must be prioritised, such as the European Data Space, alongside the development of patient-centred digital tools that facilitate secure, user-friendly access to key information within medical records and personalised health resources. Strengthening data privacy protections while optimising access and health literacy components is a challenge but can enhance digital engagement and improve continuity of care.

Advance research and innovation in AYA oncology and survivorship care

Since the recognition of AYAs as a distinct patient group in some European and worldwide health care systems, new research and innovation opportunities have arisen. These include integrating national cancer registries around AYA data, improving the utilisation of patient-reported outcome measures, and codeveloping culturally adapted tools to better capture AYA-specific health concerns. Initiatives such as STRONG-AYA underscore the value of such real-world data to refine patient education, cancer treatment, and survivorship care.[53] Because significant research and data gaps persist, particularly when it comes to the long-term and late effects of cancer treatment, survivorship care must be recognised as a core component of AYA cancer care. This includes systemic integration of survivorship care plans, risk-based follow-up protocols, and clearly defined transition pathways from paediatric or AYA services to adult care. Strengthening data collection on late effects, survivorship outcomes, and long-term quality of life will support evidence-based policy making in the AYA sphere.

Advocate for policy reforms to address inequities in AYA cancer care

Looking towards the future, systemic policy changes are required to mitigate disparities in AYA cancer care across Europe. Initiatives such as the ‘RBF’, which protects cancer survivors from financial discrimination, should be expanded to ensure equitable access to insurance and employment opportunities. Furthermore, reimbursement policies for fertility preservation should be standardised across health care systems to prevent socioeconomic or geographical barriers from limiting access to essential reproductive services. Policy advocacy efforts should be driven by collaboration between the (inter)national funding bodies, national health authorities, and patient advocacy organisations, ensuring that AYA-specific needs are embedded within broader health care strategies at both the European and national levels.

IMPLEMENTING MINIMUM STANDARDS OF CLINICAL CARE FOR AYAS

While the recommendations outlined in this paper aim to address systemic shortcomings in AYA cancer care, their implementation, particularly those requiring policy changes at the national level, may take time. Therefore, it is crucial to establish minimum essential standards that can be integrated into local clinical settings with minimal disruption (see Figure 1). These standards focus on age-appropriate care and can be as simple as ensuring that AYAs in clinics have access to Wi-Fi to support their education or employment, or encouraging physical activity to promote well-being. In resource-constrained settings, even low-cost interventions such as allocating designated clinic time to AYAs, training existing staff on AYA-specific needs, or creating informal peer support groups, can result in meaningful improvements. The priorities identified here align closely with those proposed by the European Society for Medical Oncology (ESMO)—European Society for Paediatric Oncology (SIOPE) AYA Working Group,[12] reflecting strong support from the health care community to implement these foundational improvements.

The key requirements for any centre treating AYAs, whether in paediatric or adult oncology settings, should include a multidisciplinary team (MDT) for structured case discussions, clinical trials for AYA cancers, and flexibility in age eligibility for treatments. Centres must provide expertise across diverse AYA-specific tumour types, incorporating both paediatric and adult oncology collaboration within a dedicated AYA MDT. Age-appropriate care should also include psychosocial support, peer activities, fertility preservation, and late-effects clinics. Furthermore, genetic counselling and genetic testing for hereditary risks, along with age-specific palliative care and staff training, should be integrated. Finally, transition programmes between paediatric, AYA, and adult services, along with strong referral pathways and clear standards of care, ensure coordinated, high-quality treatment throughout the AYA cancer journey.

By adopting these minimum standards of care, health care providers can make immediate improvements to AYA oncology care while broader policy-driven changes continue to evolve. The stepwise approach enables scalability, even in centres with limited resources, to begin with achievable changes and build towards more comprehensive AYA service provision over time.

THE CRITICAL ROLE OF CONTINUED PPI&E

Patient-centricity is at the heart of this work and these recommendations. Patient involvement and engagement is foundational to creating health care systems and research approaches that are inclusive, equitable, and effective. Moving away from traditional, top-down models of care, the integration of patients as active collaborators reflects the evolving emphasis on person-centred approaches and shared decision making in modern health care.[54] Patients are uniquely positioned to inform health care delivery, policy, and research through their lived experiences, providing insights that no clinician or researcher can replicate. When incorporated meaningfully, their involvement improves care quality, enhances research outcomes, and fosters trust and transparency between stakeholders.[55,56]

However, achieving impactful patient involvement requires thoughtful strategies to address systemic barriers and avoid pitfalls such as tokenism, where the input of patients may be solicited but ultimately underutilised.[57] True partnership demands a collaborative process in which patients are empowered as equal contributors. A recent publication proposed five ways through which we can further integrate AYAs into European research projects and health care: (i) ensure AYAs are involved at every stage of research and care, (ii) enable patient-led initiatives, (iii) leverage their diverse skills, (iv) provide fair compensation, and (v) allocate funding to foster equity and inclusion for meaningful and sustainable patient engagement.[58]

The initiative behind these recommendations, co-designed and co-led by AYAs with lived experience, demonstrate how active involvement creates self-sustaining systems that prioritise holistic care and long-term quality of life. By following these recommendations, we can overcome traditional top-down approaches and transition towards participatory models that respect and integrate patient expertise. This collaborative approach ensures that health care and research initiatives are not only person-centred but also sustainable and equitable, creating systems that truly address the long-term needs of AYAs.

CONCLUSIONS

The EU-CAYAS-NET development of Minimum Standards for Specialist Adolescent and Young Adult (AYA) Cancer Care Units across Europe marks a pivotal step towards addressing the profound inequities faced by young people with cancer. However, the current landscape of AYA cancer care, research initiatives, and networks across Europe remains fragmented. Multiple parallel efforts by different consortia, working groups, professional societies, and patient advocacy organisations are underway, each with commendable objectives but often operating next to each other. In some instances, this has resulted in overlapping activities, duplication of efforts, and even unintentional competition for resources and visibility. To truly advance the EU AYA cancer care, there is an urgent need to foster synergies rather than silos. Harmonising efforts across countries, health care systems and professionals, and stakeholder groups will be key to optimising impact, reducing inefficiencies, and ensuring that all young people across Europe benefit equally from innovations in cure, care, and supportive services. Collaborative frameworks must be established to align goals, share best practices, and co-create solutions adaptable to different national and local contexts.

Despite the high level of engagement from all stakeholders in this work, the study has its limitations. Selection bias in stakeholders and AYA centres that participated may limit representativeness of findings. Furthermore, it is important to acknowledge that the diversity of health care systems and care models across Europe will affect the generalisability of the recommendations presented.

Moving forward, the collective commitment of policymakers, health care providers, researchers, and patient communities will be essential in building a cohesive and integrated EU AYA cancer care ecosystem that prioritises equity, diversity, inclusivity, and sustainability. These Minimum Standards for Specialist Adolescent and Young Adult (AYA) Cancer Care Units should be integrated into comprehensive accreditation and designation frameworks, such as those established by the Organisation of European Cancer Institutes (OECI). Incorporating these standards ensures that institutions recognised as Comprehensive Cancer Centres are equipped to address the unique medical, psychosocial, and developmental needs of AYA patients. Embedding AYA-specific criteria within such accreditation programmes promotes consistent, high-quality care and supports the advancement of specialised services within multidisciplinary cancer care settings as required in the European Beating Cancer Plan. Only through strategic coordination and partnership can we ensure that the promise of these minimum standards translates into tangible improvements in outcomes and quality of life for all AYAs with cancer across Europe.

ACKNOWLEDGEMENTS

We sincerely thank all young people with lived experience of cancer, their caregivers, researchers, and health care professionals who participated in any part of the work that informed the writing of this paper. We thank all the members—individual and organisations—who have taken part in the European Consortium EU-CAYAS-NET. The work related to this publication was funded and carried out by the members of the European Consortium EU-CAYAS-NET, supported by the European Commission (EU4Health EU4H-2021-PJ-04:101056918). The authors confirm that

they had full access to the data in the study, and the final responsibility for the decision to submit for publication was shared.

FUNDING

This work was supported by the European Commission's EU4Health programme [grant number EU4H-2021-PJ-04:101056918].

DISCLOSURE

The authors have declared no conflicts of interest.

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