Transforming AYA Cancer Care: From Research to Practice

Report of the first Joint Stakeholder Forum

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Acknowledgements

This report summarises the key presentations, contributions, and recommendations shared during the first joint AYA Stakeholder Forum, Transforming AYA Cancer Care: From Research to Practice, organised on 30 June 2026 by the European Cancer Organisation together with the PanCare4AYA, PredictAYA, and STRONG-AYA project consortia.

We extend our sincere thanks to all speakers who contributed their expertise and perspectives on improving outcomes and policies for adolescents and young adults (AYAs) with cancer through the PanCare4AYA, PredictAYA and STRONG-AYA projects. We also thank all participants who provided contributions during the Forum and shared supplementary commentary following the event.

Finally, we express our gratitude to all those who dedicated time to reviewing and commenting on this report as part of the wider PanCare4AYA, PredictAYA and STRONG-AYA projects review process.

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Executive summary

This report presents the key discussions, insights and conclusions from the virtual Stakeholder Forum *Transforming AYA Cancer Care: From Research to Practice*, jointly organised by the European Cancer Organisation (ECO), on behalf of the PanCare4AYA, PredictAYA and STRONG-AYA projects, on 30 June 2026.

Bringing together healthcare professionals, researchers, patient advocates, and representatives of the three Horizon Europe projects, the Forum provided a platform to exchange knowledge, highlight the importance of lived experience and patient involvement, showcase progress and identify opportunities to strengthen the translation of research into practice for adolescent and young adult (AYA) cancer care across Europe.

The report summarises contributions from the opening keynote delivered by an AYA cancer survivor, an overview of the European AYA cancer policy landscape, and presentations highlighting the latest developments from the PanCare4AYA, PredictAYA and STRONG-AYA projects. The three projects demonstrate complementary approaches to improving AYA cancer care, including developing structured survivorship pathways, advancing personalised approaches to long-term health and late effects management, and generating evidence to support improvements in clinical practice and policy.

The report also captures the key messages emerging from three interactive breakout discussions focused on (**1**) implementing evidence-based survivorship care based on the new PC4AYA guideline for surveillance of late effects, (**2**) personalising long-term follow-up with a focus on fertility and reproductive health, and (**3**) using research data to improve clinical practice and inform policy. Across the discussions, participants highlighted the importance of moving beyond evidence generation towards implementation, ensuring that research findings lead to sustainable improvements in care and outcomes for AYAs affected by cancer.

Key priorities identified included strengthening implementation pathways for survivorship guidelines, improving coordination between healthcare services and disciplines, ensuring timely and equitable access to fertility and reproductive health support, addressing wider survivorship needs including sexual health and psychosocial wellbeing, and improving the use of research data to guide care pathways and policymaking.

The report concludes with the main takeaways and recommendations identified during the Forum, emphasising the importance of sustained collaboration between European initiatives, healthcare systems, policymakers, researchers and patient organisations. Continued efforts will be needed to support national implementation, integrate evidence-based approaches into healthcare structures and ensure that progress achieved through research initiatives translates into lasting improvements in AYA cancer care and survivorship across Europe.

Introduction

Every year, more than 150,000 adolescents and young adults (AYA, aged 15–39) are diagnosed with cancer in the EU, and an estimated 300,000 are currently living with or beyond a cancer diagnosis[1]. This is a distinct patient population whose needs extend well past survival: many go on to experience the late effects of treatment, ranging from chronic pain, cardiovascular disease and fertility problems to cognitive impairment and mental health difficulties, such as anxiety and depression. These clinical burdens compound the life-stage pressures AYAs already face: education, early careers, financial independence, making this one of the most vulnerable groups across the cancer continuum.

Despite this, AYA cancer has long suffered from limited awareness, education and policy attention, largely due to its position between paediatric and adult oncology systems. Dedicated AYA cancer and survivorship care services remain scarce and inconsistent across Member States, leaving significant gaps in age-appropriate care, survivorship support, fertility and reproductive health services, psychosocial support and long-term follow-up.

150,000 AYAs are diagnosed with cancer in the EU every year

The Joint Stakeholder Forum *Transforming AYA Cancer Care: From Research to Practice* was held online on 30 June 2026 and brought together more than 130 participants from across the AYA cancer community. Organised by the European Cancer Organisation (ECO) on behalf of the PanCare4AYA, PredictAYA and STRONG-AYA projects, the Forum provided an opportunity to discuss progress, exchange perspectives and explore how research findings can support sustainable improvements in AYA cancer care and survivorship across Europe.

This report summarises the key discussions, insights and recommendations arising from the Forum, including the contributions of the three projects and the outcomes of three interactive breakout sessions focused on survivorship care implementation, fertility and reproductive health, and the translation of research data into clinical practice and policy.

1 https://cordis.europa.eu/programme/id/HORIZON_HORIZON-MISS-2024-CANCER-01-05

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Living through AYA cancer: a survivor's perspective

c, patient advocate at Youth Cancer Europe (YCE) and young adult cancer survivor, shared her personal experience of being diagnosed with colorectal cancer at the age of 26. Reflecting on the year that changed her life, she described how, in 2019, she began experiencing concerning symptoms that were repeatedly dismissed due to her young age. After more than a year of seeking medical advice, she was finally referred for a colonoscopy during the COVID-19 pandemic, which revealed a stage 3 tumour.

Mila described the shock of her diagnosis and the difficult decisions she had to make immediately afterwards, including decisions around fertility preservation just before starting chemotherapy. At such a young age, she was faced with life-changing choices while still trying to understand her diagnosis and its implications for her future.

She highlighted that her experience reflects the reality of many AYAs with cancer across Europe. Cancer can disrupt a defining stage of life, affecting education, careers, relationships, identity and future plans.

Mila emphasised the need for healthcare systems that recognise AYAs as a specific population and are designed around the whole person, providing age-appropriate care, psychosocial support, fertility support, survivorship care and meaningful involvement of AYAs in decisions affecting their health and future.

> *We are more than the scans, the numbers, the percentages, the illness, the tests, the results, and the statistics. We are human beings - and we as AYAs are the future.*
>
> Mila Ogalla Toledo

Through her advocacy work with YCE and involvement in EU-funded initiatives focused on AYA cancer, Mila highlighted the importance of ensuring that lived experience informs research, healthcare design and policymaking.

Mila concluded by highlighting that AYAs are more than diagnoses, treatments, scans and statistics. They are individuals with ambitions, futures and a vital role in shaping the future of cancer care.

The AYA cancer landscape in Europe: an overview

The importance of AYA cancer and survivorship care is increasingly recognised within European cancer policy. Europe's Beating Cancer Plan has identified survivorship and quality of life as key priorities, while Horizon Europe and EU4Health are funding research and initiatives to improve outcomes for this age group. The PanCare4AYA, PredictAYA and STRONG-AYA projects sit within this wider policy push, each contributing evidence and tools to help translate these priorities into practice.

This policy attention sits within a broader, growing ecosystem of European collaboration, creating opportunities to improve coordination, share knowledge and develop more tailored models of care across Member States. AYA cancer also gained recognition on the global political agenda for the first time in June 2026, when it featured in the G7 leaders' call on cancer, with the G7 statement highlighting the importance of accelerating international data access for paediatric, adolescent and young adult cancers. Initiatives such as the Joint Action on Networks of Expertise (JANE-2) and the European Network of Comprehensive Cancer Centres (EUnetCCC) are further strengthening coordination between cancer centres and networks across Europe, helping to align research, clinical practice and policy.

Together, these developments reflect a unique window of opportunity to translate growing policy recognition – supported by EU funding instruments, cross-European networks and international political attention – into concrete, lasting improvements in AYA cancer and survivorship care, in Europe and beyond. Sustained collaboration between researchers, healthcare professionals, policymakers and patient advocates will be essential to make the most of these opportunities.



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PanCare4AYA – advancing survivorship care after AYA cancer

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PanCare4AYA is a five-year Horizon Europe research project (2025–2030) coordinated by the Princess Máxima Center (PMC) aiming to improve survivorship care for adolescents and young adults (AYAs) affected by cancer. Building on existing expertise from childhood cancer survivorship care, the project focuses on developing approaches tailored to the specific needs of AYA cancer survivors.

The project brings together 28 organisations across 14 countries to develop an international clinical guideline for survivorship screening and follow-up care. The guideline will be implemented via the *AYA Cancer Survivor Screen* programme. The programme combines evidence-based clinical recommendations delivered through a Survivorship Care Plan with person-centred care approaches, peer-to-peer support and digital solutions to support survivors throughout their long-term care journey.

The *AYA Cancer Survivor Screen* programme will be tested with 1,000 AYA cancer survivors across 11 countries to evaluate its feasibility, effectiveness and implementation potential. A Replication Toolkit will also be developed to support the future scale-up and integration of the programme across Europe.

The *AYA Cancer Survivor Screen* programme includes a preparation phase before a clinic visit, during which survivors complete a short questionnaire focused on their needs and preferences. This information, combined with treatment history and guideline-based clinical recommendations, will inform an individual survivorship care plan. During the clinic visit, survivors will receive relevant assessments, follow-up recommendations and referrals for additional diagnostic tests, where needed. A post-clinic follow-up will then support discussion of results, finalisation of the Survivorship Care Plan and agreement on future care arrangements, including the role of hospital-based services, general practitioners or other care providers.

The project's clinical guideline will be finalised in 2026. To date, guideline groups comprising healthcare professionals, researchers and patient advocates have developed recommendations covering around 50 late effects, based on existing guidance and available evidence. Additional work is ongoing to adapt treatment summaries and Survivorship Care Plans, map existing peer support services, develop training materials and prepare participating clinics for the multi-country implementation study in 2027.

PanCare4AYA aims to increase recognition of the importance of AYA cancer survivorship care among survivors, healthcare professionals, policymakers and society more broadly. By harmonising guideline recommendations, developing a structured survivorship care programme and creating tools that can be replicated across countries, the project seeks to improve quality of life and strengthen long-term care for AYA cancer survivors throughout Europe.

You can learn more about PanCare4AYA on their website.



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PredictAYA – improving understanding of long-term and reproductive health outcomes

PREDICT AYA

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bsky.app/profile/predict-aya.bsky.social

PredictAYA is a five-year Horizon Europe project (2025–2030), coordinated by Karolinska Institutet and bringing together 18 partners across 10 countries. The project aims to improve understanding, prediction and prevention of late effects among adolescents and young adults (AYAs) affected by cancer, with a particular focus on fertility and reproductive health.

AYA cancer survivors can experience a range of long-term physical and psychosocial consequences following treatment, including gonadal toxicity, infertility and impacts on sexual health and overall quality of life. For many young people fertility-related concerns are among the most significant survivorship challenges, affecting future life plans and wellbeing. However, there is currently limited evidence to accurately predict who is most at risk of developing treatment-related late effects and how these risks can be addressed.

PredictAYA aims to improve knowledge of the incidence, severity and impact of late effects among AYA cancer survivors across Europe. The project will use existing data sources alongside newly established survivor cohorts to develop predictive models that support more personalised screening, risk assessment and fertility counselling.

The project combines multiple research approaches, including epidemiological studies using large-scale clinical data, clinical studies collecting retrospective and prospective patient information, patient-reported experiences and biological samples, genomic analyses to identify potential predictors of treatment-related toxicity, and in vitro models to better understand the mechanisms behind treatment effects.

By generating evidence-based prediction tools, PredictAYA aims to support more individualised survivorship care and improve clinical practice. The project also seeks to strengthen awareness and education around fertility preservation, reproductive health and the management of late effects, contributing to improved quality of life for AYA cancer survivors. Through enhanced cross-border collaboration, the project will support the development of future cancer care approaches and guidelines across Europe.

Patient and stakeholder involvement is a central element of PredictAYA. A Patient and Relatives Advisory Board and an Ethics Reflection Group have been established to ensure that the perspectives of people with lived experience inform the project's activities and outcomes.

During its first year, PredictAYA has completed the study protocols for its retrospective and prospective research activities. The project structures supporting patient engagement and ethical reflection are operational, and partners have presented initial work at international scientific meetings. A first manuscript on the burden of gynaecological cancers in the AYA population has also been prepared for submission.

Through its research and collaborative approach, PredictAYA aims to enable earlier identification, prevention and management of treatment-related late effects, ensuring that AYA cancer survivors receive care that better reflects their long-term needs.

You can learn more about PredictAYA on their website.



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STRONG-AYA – defining core outcomes to strengthen AYA cancer care

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STRONG-AYA is a five-year Horizon Europe project (2022–2027) coordinated by the Netherlands Cancer Institute (NKI) dedicated to improving healthcare services, research and outcomes for AYAs affected by cancer. The project aims to establish common standards for measuring outcomes most relevant to AYAs, strengthen data-driven approaches and support more person-centred AYA cancer care across Europe.

Despite increasing recognition of the specific needs of AYAs with cancer, there remains significant variation in how outcomes are measured and evaluated across healthcare systems. The lack of harmonised data limits opportunities for comparison, research and the development of evidence-based improvements in care.

A major achievement of STRONG-AYA has been the development of a European Core Outcome Set (COS) for AYA cancer care[1]. Developed through patient interviews and stakeholder consultation, the Core Outcome Set identifies outcomes that are most relevant to young people affected by cancer. In addition to traditional clinical outcomes such as survival, cancer progression, organ function and fertility, it includes patient-reported outcomes covering quality of life, fatigue, pain, psychological wellbeing, access to mental health support, social participation, education, employment and financial challenges.

1 Development of a core outcome set for adolescents and young adults with cancer - The Lancet Oncology: https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(25)00533-9/abstract

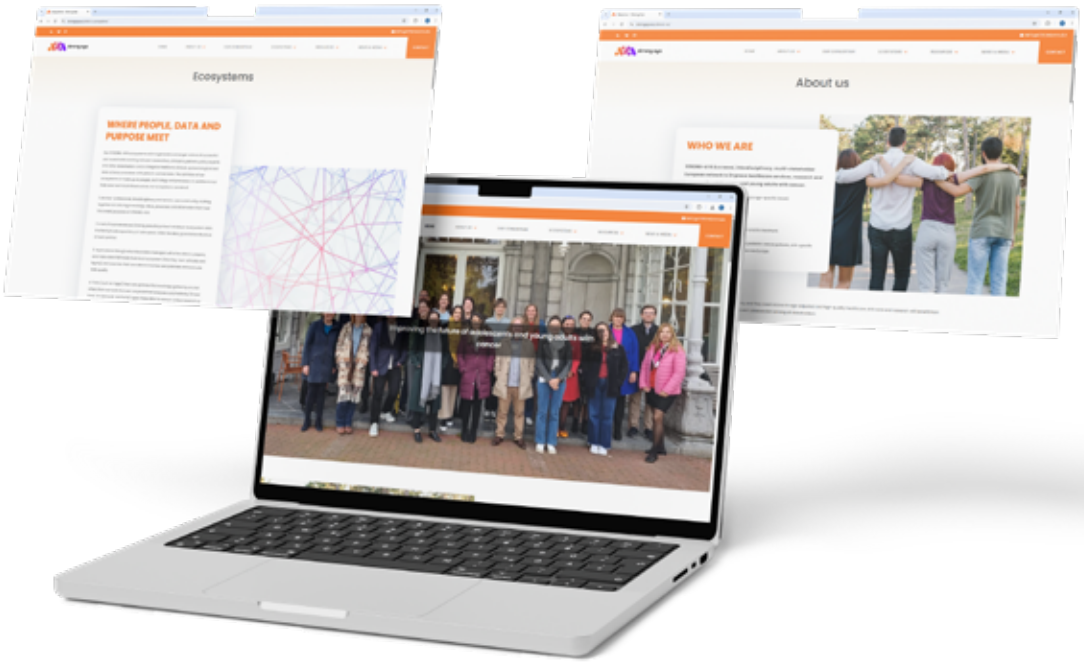
The Core Outcome Set is being implemented across five European countries: France, Italy, the Netherlands, Poland and the United Kingdom. The project combines retrospective and prospective data collection, creating a comprehensive evidence base to better understand AYA cancer outcomes. To date, retrospective data from more than 28,900 individuals have been collected, while prospective data collection is ongoing, with hundreds of patients already enrolled.

A key innovation of STRONG-AYA is the development of a federated data infrastructure, which enables collaborative research while allowing participating institutions to retain control of their own data. Through federated analysis approaches, researchers can use and analyse data across different countries without requiring centralised transfer of sensitive patient information, supporting both data privacy and cross-border collaboration.

Patient involvement is central to the project, with people affected by cancer participating as equal partners through a patient advisory board and contributing to the co-creation of activities such as a patient portal. STRONG-AYA also works closely with other European AYA initiatives to ensure alignment, maximise synergies and strengthen the wider AYA cancer research and care ecosystem.

With the Core Outcome Set established, the federated infrastructure operational and implementation progressing across participating countries, STRONG-AYA is working towards creating a sustainable European framework for AYA cancer research and care.

You can learn more about STRONG-AYA on their website.



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Breakout discussions: from research to practice

The second part of the Forum featured three interactive breakout discussions, each addressing a key priority in advancing AYA cancer care across Europe. The sessions explored:

- Implementation of evidence-based survivorship care
- Aproaches to personalising long-term follow-up with a particular focus on fertility and reproductive health
- The use of research data to inform clinical practice and evidence-based policy

Bringing together healthcare professionals, researchers, patient advocates, survivors and caregivers, the discussions generated a wide range of practical insights and recommendations. The following sections present the main conclusions and key messages that emerged from each breakout discussion, highlighting priorities and opportunities for translating research into sustainable improvements in AYA cancer care across Europe.



Implementing evidence-based survivorship care in AYA cancer

Discussions in this breakout room focused on the challenges and opportunities associated with implementing survivorship care for AYA cancer survivors, with particular attention to healthcare professional knowledge gaps, guideline implementation and the need for coordinated approaches across Europe.

A key issue identified was the lack of clear governance structures for survivorship care guidelines. While developing evidence-based recommendations is essential, questions remain regarding long-term ownership, maintenance and updating of guidelines, including who has the mandate and resources to ensure their continuous update as new evidence becomes available over time.

Healthcare professional knowledge gaps around late effects remain an important barrier to effective survivorship care. Participants highlighted the need to integrate survivorship care into education and training, strengthen interdisciplinary approaches and ensure that healthcare professionals across different settings have the knowledge required to support AYA cancer survivors throughout their lives.

The discussion also highlighted that implementation is largely a national and regional responsibility, given the significant differences between healthcare systems across Europe. The role of hospitals, primary care and general practitioners in long-term follow-up varies considerably between countries, creating challenges for developing consistent models of care. Participants stressed the importance of considering national contexts and existing healthcare structures when implementing survivorship guidelines.

Patient organisations were recognised as key partners in driving awareness and encouraging policy uptake. By sharing information and resources directly with AYA cancer survivors, as well as advocating for survivorship care and engaging with decision-makers, patient organisations can help ensure that guidelines are shared with survivors and translated into practice. Participants also highlighted the potential role of European collaboration initiatives, including JANE-2 and EUnetCCC, in supporting knowledge exchange, coordination and the dissemination of survivorship care approaches across Europe. Networks of Expertise and accreditation frameworks, such as Comprehensive Cancer Centres (CCC), were also discussed as potential mechanisms to support dissemination and implementation.

The importance of embedding survivorship care within national cancer plans, quality frameworks and accreditation processes was highlighted as a way to support implementation and monitoring, as well as encourage adoption. Developing quality indicators and linking survivorship standards to existing healthcare structures could support more consistent implementation across countries.

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Participants also discussed the need for survivorship care plans to be viewed as evolving documents that adapt to the changing needs of AYA cancer survivors throughout different stages of life. As AYA cancer survivors transition from adolescence into adulthood, their priorities and circumstances may change, requiring ongoing review and coordination between different healthcare providers in collaboration with survivors.

Overall, the discussion highlighted the lack of coordination as a central challenge, including fragmentation between disciplines, between hospital and primary care, and between countries. Addressing these gaps will require stronger coordination, investment in education and training, and collaboration between healthcare professionals, policymakers, patient organisations and European initiatives to ensure that all AYA cancer survivors have access to high-quality, long-term survivorship care.

Summary of conclusions

- Establish clear governance and mechanisms to sustainably maintain, update and implement evidence-based survivorship care guidelines across Europe.
- Strengthen healthcare professional education and training on AYA cancer late effects and survivorship care, promoting interdisciplinary collaboration across care settings.
- Adapt survivorship care implementation to national and regional healthcare systems, while promoting common standards across Europe.
- Embed survivorship care within national cancer plans, quality frameworks and accreditation processes to strengthen accountability and implementation.
- Foster collaboration between hospitals, primary care, patient organisations and European initiatives to improve coordination and knowledge exchange.
- Develop survivorship care plans as personalised, evolving documents that are regularly reviewed and adapted to survivors' changing needs.
- Reduce fragmentation between disciplines, healthcare sectors and countries by strengthening integrated long-term follow-up pathways for all AYA cancer survivors.

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Personalising follow-up and supporting long-term health for AYAs with cancer, with a focus on fertility

Participants in this breakout room explored whether fertility and reproductive health needs are adequately addressed for AYAs with cancer, highlighting both progress in fertility preservation pathways and persistent gaps in personalised follow-up care. Discussions focused on timely access to information, variation in clinical practice, healthcare professional knowledge gaps and the need to integrate reproductive health more consistently into AYA cancer care.

Participants recognised that fertility preservation pathways are relatively well established in some countries, including Belgium, Denmark, Norway and Sweden. However, challenges remain regarding when and how information is provided. Participants emphasised the importance of discussing fertility preservation early enough to support informed decision-making, as introducing these conversations immediately before treatment can create additional distress and limit patients' ability to consider available options.

The discussion highlighted differences in fertility preservation approaches between patient groups, particularly between males and females. While sperm preservation can often be organised quickly, fertility preservation options for girls and young women may require more complex procedures and coordination. Participants noted the need to increase awareness and experience of approaches such as ovarian tissue cryopreservation across oncology settings, alongside stronger knowledge exchange between paediatric and adult oncology services.

Participants also discussed fertility preservation decisions for patients with poorer or uncertain prognoses, highlighting the importance of individualised decision-making rather than relying on prognosis alone to determine access. Decisions should consider the potential risks of procedures while recognising that some patients with initially poor prognoses may achieve long-term survival and benefit from preserved fertility options.

The discussion highlighted persistent gender inequalities in access to fertility information. Participants noted that boys and young men often have clearer pathways to fertility counselling and sperm preservation, whereas some girls and young women may only learn about potential fertility risks years later, sometimes during transition to adult care. Delayed communication of fertility risks was recognised as a source of distress and a potential barrier to trust in healthcare services.

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Participants emphasised that **reproductive health extends beyond fertility preservation**. Sexual health, including concerns related to relationships, body image, early menopause and long-term wellbeing, remains under-addressed in AYA cancer care. Integrating sexual health support into routine care pathways was identified as essential, rather than relying on survivors to seek support independently.

Delayed communication of fertility risks was recognised as a source of distress and a potential barrier to trust in healthcare services.

Healthcare professional confidence, training and time constraints were identified as important barriers to addressing fertility and sexual health needs. Strengthening education and ensuring healthcare professionals have the confidence and resources to initiate these discussions were highlighted as key priorities.

The importance of providing information in appropriate formats and throughout the cancer journey was also emphasised. Fertility and sexual health should be recognised as ongoing components of AYA care and survivorship planning, supported by improved coordination between oncology, reproductive medicine and survivorship services.

Overall, the discussion highlighted persistent gaps in the integration of fertility and sexual health into AYA cancer care and survivorship. Addressing these challenges will require stronger collaboration between services, improved professional training and more consistent approaches to ensure all AYAs have access to timely information and comprehensive long-term support.



Summary of conclusions

- Discuss fertility preservation early and proactively, ensuring AYAs have sufficient time to understand and consider available options before treatment begins.
- Address gender inequalities in fertility counselling and preservation, ensuring equitable access to information and services for girls and young women.
- Strengthen collaboration and knowledge exchange between paediatric, adult oncology and reproductive health services, including wider awareness of emerging fertility preservation approaches.
- Integrate sexual health into routine AYA cancer care and survivorship planning, recognising its impact on quality of life, relationships and long-term wellbeing.
- Improve healthcare professional training and confidence to support discussions on fertility and sexual health throughout the cancer journey.
- Provide information through multiple formats and at different stages of care, recognising that patients may not be able to absorb all information at diagnosis.
- Embed fertility and reproductive health support within coordinated, personalised long-term follow-up pathways for all AYA survivors.

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Using research data to enhance AYA cancer care and inform policy

The discussion in this breakout room examined how research evidence and data can be better translated into improvements in AYA cancer care, policy development and clinical practice.

Participants highlighted that while important progress has been made in generating data on AYA cancer, challenges remain in ensuring that this data collection leads to meaningful action.

A key discussion point was the burden of completing questionnaires and patient-reported outcome measures (PROMs). Participants noted that patients may not see the value of providing this information if it does not lead to visible improvements in their care. Data collection should therefore be integrated into care pathways in a way that provides benefits for both patients and research, with clearer feedback mechanisms and a stronger connection between data collection and action.

Participants stressed the importance of having a clear strategy for the use of data, including defining the outcomes that research should support. Cross-country comparisons and benchmarking were highlighted as valuable tools to identify gaps, assess the quality of implementation, support policy objectives and demonstrate areas for improvement, with the aim of moving toward a more harmonised approach across countries. Initiatives such as STRONG-AYA were recognised as having the potential to provide this evidence base to inform national and European approaches.

Data collection should therefore be integrated into care pathways in a way that provides benefits for both patients and research, with clearer feedback mechanisms and a stronger connection between data collection and action.

National case studies illustrated what this can look like in practice. The Netherlands was cited as an early front-runner in structuring AYA cancer care, while Belgium is moving toward a more structured model, potentially to be integrated into its forthcoming National Cancer Plan.

This raised a broader question, echoed across several contributions, of what actually shifts AYA cancer care up the political agenda: patient testimony, data, or a combination of both, and whether such national successes can be replicated elsewhere.

A funder's perspective added a further dimension: building consortia that include not only researchers but also patient organisations and groups representing vulnerable populations from the very start of a project helps ensure the right priorities are embedded from the outset and strengthens the resulting case for policy change alongside the data itself.

The discussion also highlighted the **ongoing gap between research and policy implementation**. Participants noted the need to translate findings into clear, accessible recommendations for policymakers, as research reports alone do not always lead to change. While European initiatives can provide evidence and frameworks, implementation requires action at the national level, taking into account different healthcare systems, political priorities and, as several participants noted, a wider context of ageing populations, shrinking tax bases and competing geopolitical priorities that make it harder to secure space for health, and specifically AYA care, within national welfare systems.

Summary of conclusions

- Embed PROMs and data collection into care pathways, with clear feedback loops so patients see tangible benefit from participating.
- Define a clear data strategy upfront, specifying the outcomes research should serve, rather than collecting data without a defined use.
- Use cross-country benchmarking to identify gaps and drive convergence toward a harmonised European approach, with STRONG-AYA positioned as a key evidence base.
- Build on national frontrunners, such as the Netherlands, and emerging models like Belgium's forthcoming National Cancer Plan, as templates for other countries.
- Combine patient testimony with data systematically and involve patient organisations and vulnerable-population groups in consortia from the outset, to strengthen the case for political prioritisation.
- Translate research findings into short, accessible recommendations for policymakers, recognising that EU frameworks set direction, but implementation depends on national action and context.

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Conclusions

The three breakout discussions highlighted shared priorities for strengthening AYA cancer care and survivorship across Europe. Participants emphasised that evidence-based survivorship guidelines are only the first step, requiring sustained implementation, regular updates, national integration and involvement of survivors, patient organisations and primary care. Stronger governance structures, sustainable ownership and integration of survivorship care into education, training, quality frameworks and national cancer plans were also identified as key priorities.

Discussions on fertility and long-term follow-up underscored the importance of timely and equitable access to fertility preservation and counselling, while recognising the need to better address sexual health throughout the survivorship pathway. Participants stressed that information should be revisited over time as survivors' needs evolve, and highlighted the importance of coordination between oncology, fertility and supportive care services.

The session on research data highlighted the importance of collecting meaningful quality-of-life data and ensuring that patient-reported outcomes inform clinical care and policy. Participants called for greater patient involvement in data collection, improved cross-country collaboration and benchmarking, and clearer links between research activities, improvements in care and policy decision-making.

> Across all discussions, there was broad agreement that maintaining collaboration beyond individual project lifetimes will be key to achieving lasting improvements in AYA cancer care across Europe. European coordination mechanisms and networks, including initiatives such as JANE-2 and EUnetCCC, can support knowledge exchange, implementation pathways and sustainable improvements in cancer care.

Future progress will depend on continued cooperation between European initiatives, national healthcare systems, policymakers, researchers, healthcare professionals and patient organisations to ensure that evidence is translated into equitable action.

The Forum demonstrated that Europe has the knowledge, expertise and collaborative structures needed to improve AYA cancer care; the next step is ensuring that this evidence is embedded into healthcare systems and translated into consistent action for all AYAs affected by cancer.

About the projects

Adolescents and young adults (AYAs) with cancer have unique clinical and psychosocial needs both during and after treatment that are often unmet, despite rising incidence and long-term challenges, such as late effects of cancer treatment, fertility issues, and strong impacts on mental health. Strengthening age-appropriate AYA cancer care across Europe is essential.

The EU-funded PanCare4AYA, PredictAYA, and STRONG-AYA projects address this by advancing survivorship care, improving prediction of long-term treatment effects, and fostering coordinated, data-driven approaches, helping young people not just survive, but thrive.

PanCare4AYA, led by the Princess Máxima Center, aims to improve survivorship care across Europe through an international guideline and the person-centred *AYA Cancer Survivor Screen* programme. A study with 1,000 survivors in 11 countries will test how well the programme works and gather feedback from patients and healthcare teams. Digital tools will be piloted in France, Italy, Lithuania, and the Netherlands to make follow-up care easier and more personalised.

PredictAYA, led by Karolinska Institutet, studies long-term effects of cancer treatment in AYAs (15–39 years old), including impacts on reproductive health, sexuality, and quality of life. Working with patients, clinicians, and researchers, the project identifies genetic risks, develops personalised follow-up guidelines, and explores fertility preservation, pregnancy risks, and other health outcomes.

STRONG-AYA, led by the Netherlands Cancer Institute, brings together scientists, healthcare professionals, patients, and policymakers to improve care for AYAs (15–39 years old). The project develops a Core Outcome Set (COS) implemented in five European countries (France, Italy, the Netherlands, Poland, the UK) and shares results to guide clinical practice and health policy.

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Glossary

AYA	AYA is an acronym standing for adolescents and young adults. AYA oncology thus refers to care focused on individuals aged 15 to 39 years old, diagnosed with cancer.
Core Outcome Set (COS)	Agreed standardised set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or health care.
EUnetCCC	European Network of Comprehensive Cancer Centres. A European initiative that aims to strengthen collaboration between Comprehensive Cancer Centres (CCCs) and support the development of high-quality, integrated and patient-centred cancer care across Europe through knowledge exchange, networking and coordination.
European Health Data Space (EHDS)	A European framework that aims to improve individuals' access to and control of their health data, while enabling the secure use of health data for research, innovation, policymaking and healthcare improvement.
Federated Learning	A way to train AI models without external interference to the data, offering a way to unlock information whilst keeping data safe and without sharing it with third parties.
JANE-2	Joint Action on Networks of Expertise. A European initiative supporting collaboration between specialised cancer centres and networks to improve cancer care, including through knowledge sharing, coordination and the development of Networks of Expertise.
Patient-reported Outcome Measures (PROMs)	Standardised questionnaires or tools used to collect information directly from patients about their health, symptoms, quality of life, functioning and wellbeing.

PanCare 4AYA

PREDICT AYA

strong aya

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