Adolescents & Young Adults (AYA) and Cancer

Facts, figures and policy priorities for European and national decision-makers

15–39
age range defining AYA cancer

>300,000
AYA ***patients living with or beyond*** cancer in the EU

1.2 M
AYAs ***diagnosed*** with cancer ***worldwide*** each year

≈150 000
AYAs ***diagnosed*** with cancer in the ***EU*** each year

A joint factsheet from:

strong aya · PanCare 4AYA · PREDICT AYA

The challenge: AYA cancer care & survivorship

- AYA cancer includes a distinct mix of cancer types and life-stage needs.
- AYA-cancer-specific health services remain scarce and uneven across Europe, unlike the dedicated pathways for other age groups.
- Many AYA cancer survivors develop long-term 'late effects' of treatment, including reproductive and fertility problems, heart and other organ damage, chronic pain, cognitive impairment, and mental-health conditions such as anxiety and depression.
- There are few tools to predict who is at risk, and little guidance on when survivorship screening should begin, late effects can appear years after treatment ends.
- Disease outcomes and quality of life are closely intertwined; they should be analysed together.

Policy recommendations

AT NATIONAL LEVEL

National decision-makers should…

- Establish dedicated, age-appropriate AYA cancer units or multidisciplinary teams spanning paediatric and adult oncology.
- Integrate structured, risk-adapted long-term follow-up for AYA cancer survivors into national cancer control plans, so that late effects (fertility problems, cardiac and cognitive impairment, mental-health conditions) are systematically monitored rather than left to chance.
- Require national health data infrastructures to collect patient-reported outcomes for AYA patients, using an agreed core outcome set, alongside clinical and treatment data, to support quality monitoring, research and future risk-prediction tools.
- Guarantee timely access to fertility preservation counselling and psychosocial support, from diagnosis through survivorship.

AT EU LEVEL

EU institutions should…

- Build on the EU's existing recognition of AYA cancer as a priority by translating it into dedicated funding lines.
- Support harmonised, comparable outcome measures and survivorship screening standards for AYA cancer across Member States.
- Sustain and scale EU funding for AYA-dedicated research and innovation, spanning data infrastructure, biomarker and risk-prediction research, and screening innovations, through Horizon Europe and future EU research and health programmes.
- Embed AYA survivorship, including psychosocial, educational and vocational reintegration, not only clinical follow-up, as an explicit priority within EU cancer, youth and employment strategies.

Recognising AYA as a distinct patient group

Country case studies

Perspectives on AYA cancer care beyond Europe.

CASE STUDY INDIA

In **India**, Clinical teams at Tata Memorial Hospital and Apollo, working with the TYAcan network (Teenage and Young Adult Cancer), built dedicated pathways for AYA: routine onco-fertility assessment at diagnosis, supportive care integrated into treatment rather than added afterwards, and clinical spaces made explicitly inclusive and safer for LGBTQ+ patients. Evidence was generated where it was missing and national surveys mapped remaining gaps, feeding into national guideline development.

CASE STUDY LATIN AMERICA

Faced with fragmented systems and constrained resources, the region paired legal reform with new services: **Argentina** legislated to extend paediatric cancer coverage and opened the first dedicated AYA ward in a general hospital, with comparable reform under way in **Chile** and formal paediatric–adult shared care established elsewhere. The AYA Chapter created in 2023 within the Latin American Society of Paediatric Oncology (SLAOP), with its Brazilian counterpart SOBOPE, spread this beyond single institutions by placing AYA sessions inside both paediatric and adult congresses.

About the three projects

STRONG-AYA

2022–2027

A Europe-wide network creating a shared way to **measure** what matters most to young cancer patients. It is developing a common set of **core outcomes**, applying it in five national health systems (France, Italy, Netherlands, Poland, UK), and turning patient data into insights for clinicians and policymakers.

Coordinated by
Netherlands Cancer Institute

PanCare4AYA

2025–2030

Developing the first international **clinical guideline for screening and long-term follow-up**, delivered through the person-centred 'AYA Cancer Survivor Screen' programme. To be tested with 1,000 survivors in 11 countries so high-quality survivorship care can be scaled up.

Coordinated by
Prinses Máxima Centrum

PredictAYA

2025–2030

Protecting **fertility and reproductive health**. By combining cancer registries, genomic biobanks and new patient cohorts, it builds genetic-based prediction models and biomarkers to identify which young survivors are at highest risk of treatment-related organ toxicity — paving the way for personalised screening and counselling.

Coordinated by
Karolinska Institutet

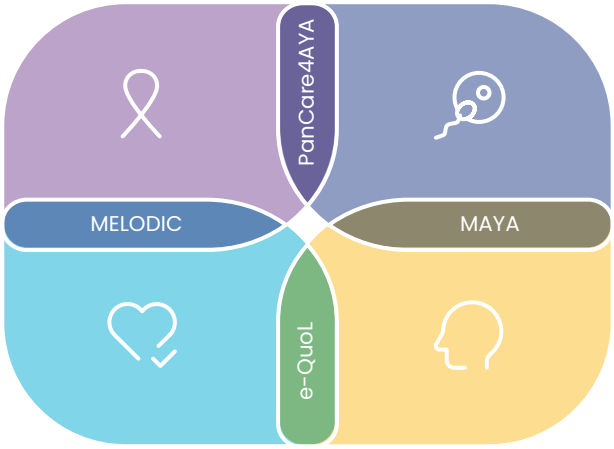
AYA initiatives landscape

Survivorship & late effects

PanCare4AYA
LATE-AYA

Quality of life, PROMs & policy

STRONG-AYA



Fertility & reproductive health

PredictAYA

Psychosocial support & digital innovation

YARN
TRANSCEND-XR

e-Quol e-health tools to promote equality in quality of life for childhood to young adulthood cancer patients, survivors and their families • equolproject.eu
LATE-AYA Understanding and addressing LATE-effects of treatment of AYA cancer survivors with AI-based digital phenotyping and non-invasive holistic approach • late-aya.eu
MAYA Smart mirrors supporting healthier lives of AYA after cancer • maya-horizon.eu
PanCare4AYA Patient-centred, evidence-based late effect screening and follow-up care of survivors of AYA cancer • pancare4aya.eu
PredictAYA Predicting and preventing late effects in AYA cancer survivors, with a focus on fertility and reproductive health • predictaya.eu
TRANSCEND-XR Co-creation and implementation of an intervention to improve testicular cancer late effects understanding and unmet supportive care needs of AYA survivors using extended reality • transcend-xr.eu

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