



EUROPEAN UNION

Quality of Life, survivorship and palliative care: holistic quality care models and patient engagement



**5 years Cancer Mission:
Stronger Through Connection**

BRUSSELS
29 SEPTEMBER – 01 OCTOBER



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Exploratory study on the provision of care for Adolescent and Young Adult (AYA) cancer patients in the Union

30 September 2026



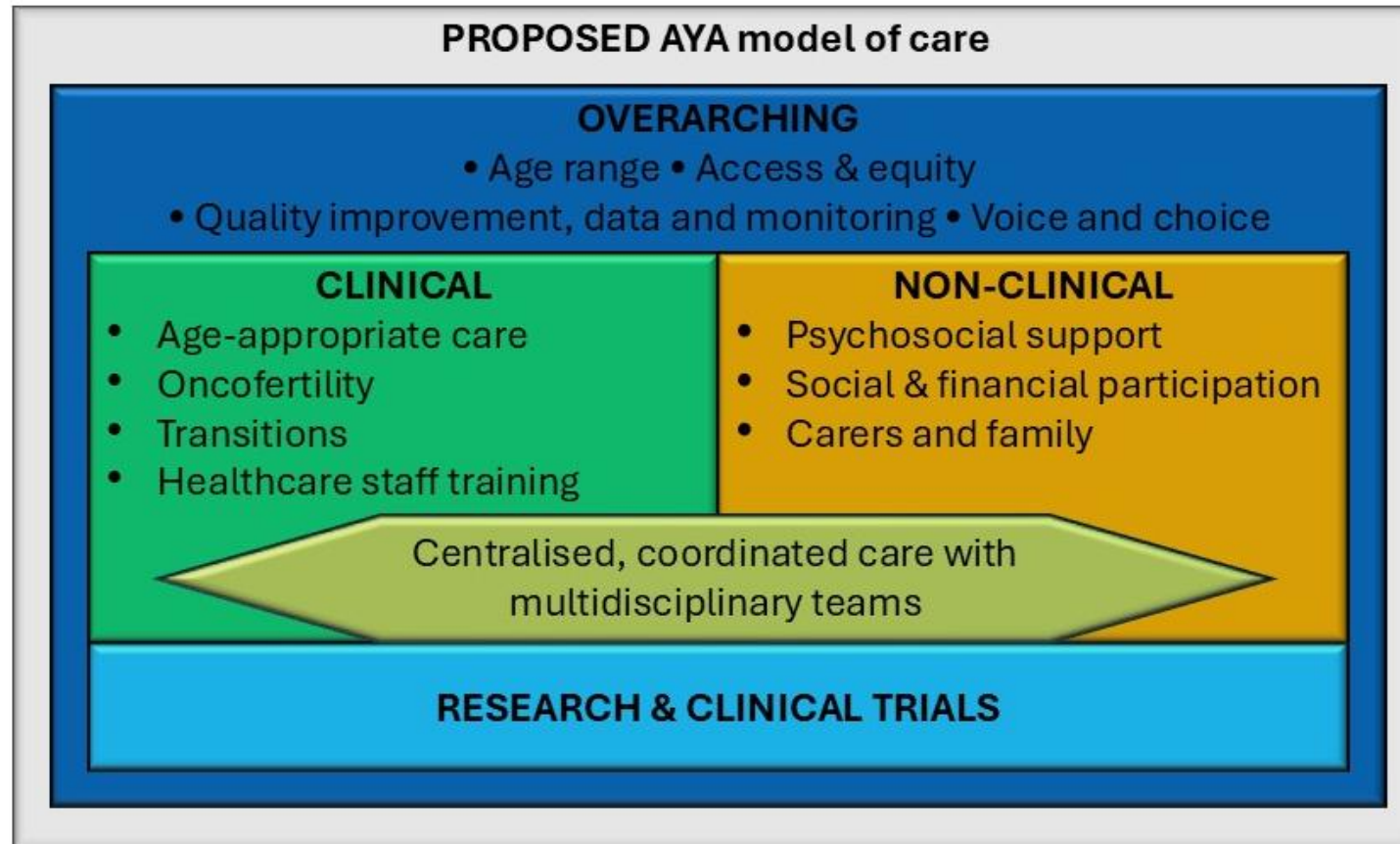
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Supporting quality of life in AYA cancer care

Findings from EU 27, Norway and Iceland, informed by a validated model of care





Supporting quality of life in AYA cancer care

Findings from EU 27, Norway and Iceland, informed by a validated model of care

Continuity of care	Support for everyday life	Voice and choice
Age-appropriate follow-up and transitions between services remain uneven	Psychological, practical and family support are not consistently embedded	AYA involvement in service development remains inconsistent
Priority: Improve transition pathways; clear coordination between services	Priority: Implement routine needs assessment and clear routes to access support	Priority: Create opportunities for shared decisions and meaningful involvement in shaping services



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Thank you

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Cinzia Brunelli

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EUonQoL: making quality of life visible, measurable, and actionable

The gap: we are missing patient voices

Cancer incidence, cure rates and survival rates are well-monitored.

Quality of Life data collection is fragmented, inconsistent, or absent.

Lived patient experiences remain invisible in health policy planning and evaluation



The response: the EUonQoL-kit



- ✓ Co-designed with patients
- ✓ Available across 3 stages of the cancer care continuum: active treatment, survivorship, in need of palliative care
- ✓ Psychometrically validated and available in multiple European languages
- ✓ Digitally administered
- ✓ Available in static and dynamic (adaptive) versions

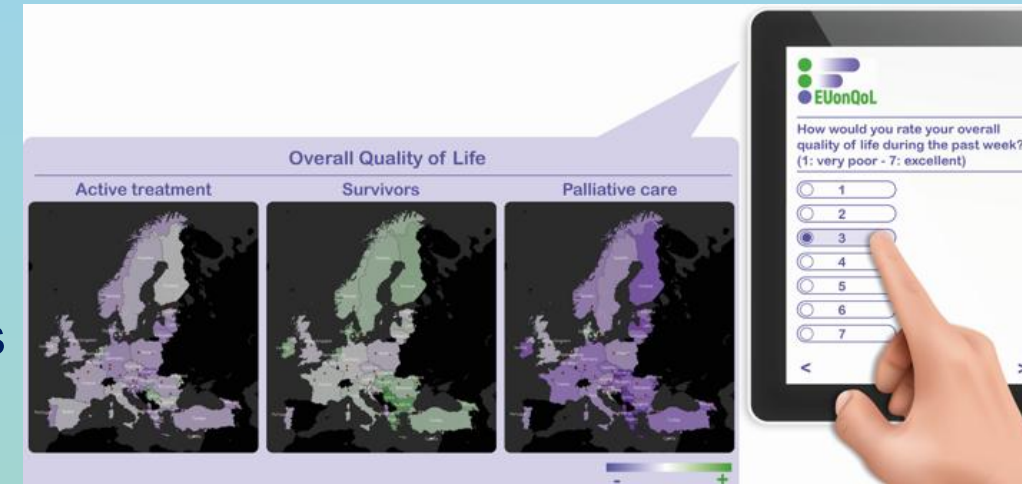


EUonQoL: making quality of life visible, measurable, and actionable

From prototype implementation to European standard

The EUonQoL Survey-HUB & Implementation guidelines

- Centralized web-platform for safe data collection and sharing.
- A roadmap for integrating standardized QoL assessments into routine cancer care and national health policies across Europe.



Strong European Partnerships

Collaborating with key EU initiatives (CCI4EU, EUnetCCC, ECHOS II, JANE-2) to avoid fragmentation.

The Path to Adoption

Bottom-Up: Engagement from patients, patient associations, and local communities.

Top-Down: Commitment from health authorities to integrate the kit into national health systems and future periodic surveys.



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www.euonqol.eu



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