

Important consultations on improving AYA Cancer Care across the EU:

Information for stakeholders and a joint call for participation!

Across the European Union, several complementary EU-funded initiatives are currently advancing efforts to improve **Adolescent and Young Adult (AYA) cancer care**. Two of these actions—the ICF-led AYA Cancer Care Study and the JANE 2, Network of expertise on AYAs with cancers, initiative— both funded by the EU4Health Programme, are running in parallel and in close alignment. While distinct in scope and methodology, both initiatives are intentionally engaging stakeholders at this stage to ensure that future EU-level recommendations and implementation efforts are grounded in robust, real-world evidence.

Both actions are critical to improve care for the AYA population. In order to do so, they are actively seeking to **gather evidence-based insights** from the most relevant stakeholders across Europe. Both have therefore launched stakeholder consultations. To help you understand the purpose of each project, how they complement one another, and why participating in both consultations is valuable, we have prepared this **brief communication**.

Why your response matters

Both initiatives aim to improve AYA cancer care, but each addresses **different features and evidence gaps**. By engaging with both initiatives, stakeholders help ensure that EU-level action on AYA cancer care is informed by:

- National, regional, and system-level realities, and
- On-the-ground operational experience, including input from institutional actors and AYA representatives

Together, these perspectives **strengthen the credibility, relevance, acceptability and practical usefulness of future recommendations and implementation efforts**. Responding to both consultations enables stakeholders to make a meaningful and targeted contribution, while helping ensure that **diverse realities and experiences are accurately reflected at the EU level**.

? What is the ICF AYA Cancer Care Study?

The **European Health and Digital Executive Agency (HaDEA)**, acting under the powers delegated by the European Commission, has initiated an **“Exploratory study on the provision of care for Adolescent and Young Adult (AYA) cancer patients in the Union,”** under service contract No. HaDEA/2024/OP/0027.

This study aims to assess **the provision of healthcare to AYA cancer patients and survivors** across the EU Member States, Iceland and Norway by mapping existing approaches, identifying barriers and enabling factors to the **integration of dedicated AYA services**, and highlighting best practices and innovative approaches into the provision of healthcare to AYA cancer patients and survivors.

Focusing on capturing **national and system-level realities**, policies, and structural conditions shaping AYA cancer care across countries, the study will deliver:

- An **evidence based, stakeholder validated EU-wide AYA model of quality care**, reflecting clinical, psychosocial and system-level components of healthcare and services tailored to the unique needs of AYA cancer patients and survivors.
- A **comparative mapping** of national provision of AYA cancer care in the EU-27, Iceland, and Norway against this model.
- Actionable recommendations** for stronger integration of dedicated AYA services across Europe.

Stakeholder engagement is a central pillar of the study. Building on interviews and focus groups already conducted, a **survey** consultation gathers system-level insights on current provision, barriers, enabling factors and good practices across countries. Together with ongoing national-level interviews, the survey findings will inform the **comparative mapping of the national provision** as well as the **actionable recommendations**.

Survey participation The survey is open to AYA patient and carer representatives, health and care professionals, national and regional authorities, public health institutes, clinical trial coordinators, pharmaceutical representatives, and researchers. The survey is live between 17 March and 12 May 2026.

? What is the JANE 2 Network of Expertise on the AYA expert consultation survey?

JANE 2 is an EU-funded initiative supporting the implementation of Europe’s Beating Cancer Plan through the development and strengthening of **Networks of Expertise (NoEs)** across multiple areas of cancer care, including AYA oncology.

The NoE on AYAs aims to be a **network** where healthcare professionals collaborate with NGOs, patient groups and other relevant stakeholders working with/involved in AYAs with cancer. It will also **strengthen collaboration** between paediatric and adult cancer services to improve AYA care, from prevention to survivorship.

The specific objectives of the NoE are as follows:

- To support the development of an AYA dedicated program
- To develop specific clinical recommendations on AYA-specific topics - such as age-specific psychosocial support, fertility - and different types of cancer across age groups
- To promote cancer research in AYAs
- To raise awareness of cancer in AYAs
- To monitor AYA cancer epidemiology, leveraging what is available or underway
- To define and promote dedicated training on cancer in AYAs
- To support patient and public involvement and engagement

To support these objectives, the NoE launched an **expert consultation via survey** in EU Member States, Iceland, Moldova, Norway, Switzerland, the UK, and Ukraine. The aim is to collect information on the **current availability of services and identify gaps** in several complementary areas, including care organisation and service development, clinical research and access to trials, clinical recommendations, training, monitoring of AYA cancer (quality) indicators, and the sustainability of national AYA programmes or initiatives. The survey findings will be **complemented by targeted interviews with selected experts** to enable a more in-depth understanding of national contexts and challenges.

Survey participation This information is important because it will provide a comprehensive overview of current practices and contextual factors and identify needs, gaps, and opportunities across countries, regions and institutions. It will also support the NoE on AYA in planning future activities, setting priorities of implementation strategies and establishing or strengthening collaboration in the years ahead (the expert consultation is expected to be launched in May 2026).

How are the two actions complementary and addressing unique areas of research for AYA cancer care?



SYNERGIES

Both are **EU-level initiatives** backed by the European Commission's commitment to improving AYA cancer care. Funded through EU4Health via HaDEA, they directly support the objectives of Europe's Beating Cancer Plan.

Both initiatives **explicitly target the AYA population** and focus on improvements in AYA oncology care provision in the EU.

Both value **diverse multi-stakeholder engagement** by consulting healthcare professionals, researchers, health authorities, AYA patient representatives, and carers, amongst others.



UNIQUE FEATURES

The ICF AYA Study ensures your **national/system** perspective is captured. It seeks to map approaches for AYA cancer care available at national (or where relevant, regional/local) level. This exercise is guided by a unique AYA care model that has been developed from a comprehensive literature review.

JANE 2 NoE on AYA experts consultation survey **focuses on gaps to address** at the national level. It will capture perspectives on multiple levels: system, national, regional, institutional, and AYA. This information will contribute to prioritising the NoE activities to ensure AYA cancer care is strengthened in practice across EU MS, IS, MD, NO, CH, GB, and UA.

The ICF AYA study focuses **exclusively on AYA cancer care**. It will spotlight good practices and innovative approaches of healthcare services tailored to AYA cancer patients and survivors. It will also uncover barriers and enabling factors for the implementation of quality AYA care.

JANE 2 NoE on AYA is a broader **long-term initiative** aimed at improving AYA care, working on different complementary activities: health care organisation, development of AYA dedicated training, guidelines, quality monitoring systems, clinical trials, and sustainability of models.

The ICF AYA study seeks **broad input from all interested stakeholders**. A mapping of the most important stakeholder groups have been undertaken and consultations targeted to their expertise and experience. This ensures all perspectives are captured, analysed, and presented in a balanced manner.

The JANE 2 NoE on AYA experts consultation works with **selected Key Informants per country**, linked to local networks and practice settings to provide information on the status quo in different areas. The expert consultation is envisioned as one comprehensive, consolidated and coordinated answer per country with the main stakeholders (health care providers, policy-makers/authorities, and AYAs/NOGs/PAGs).



Do you have questions or would like to know more?

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