



FOR
**COMMISSIONERS &
POLICY-MAKERS**



www.strongaya.eu

What is STRONG AYA?

STRONG AYA is an international project that aims to improve healthcare services, research and outcomes for adolescents and young adults (AYAs) with cancer, defined as individuals aged 15-39 years at cancer diagnosis.

What we are doing

We have been talking to young people with cancer, their families, doctors, and researchers worldwide to find out what is most important in understanding and treating cancer for this age group. They told us about things like wanting to socialise, managing fertility concerns, dealing with 'chemo brain,' and feeling heard by their doctors. We have put all this info into a simple list we call a Core Outcome Set (COS).

We are using the COS to help us with the next steps, through collecting information from young people across healthcare systems in five European countries.

Check out the '**what information are we collecting**' and '**how you can get involved**' sections to understand how you can help.

Our goal is to share what we have learned, encourage collaboration between different groups, and use smart tools to make sure healthcare professionals and researchers have the best information for deciding on age-appropriate care.

By understanding the specific needs of young people with cancer, we want to make sure the care provided really meets what they truly need.



What information are we collecting?

We are collecting information from AYAs (aged 15-39 years), about their cancer experiences after diagnosis (e.g. symptoms), their health, and overall wellbeing.

Why are we collecting this information?

To improve cancer care services and quality of life after diagnosis and treatment.

How will we use this information?

We are collecting information from patients through a secure digital platform. This platform will help AYAs and healthcare professionals have the option to share information and get a better understanding into the AYA's health (e.g. symptoms) and overall wellbeing from diagnosis and beyond, should they wish.

Patients' individual information is combined with that of other patients to create collective information so that no one is identifiable. This collective information can help us understand health trends, discuss improvements and provide evidence for clinical, research, and policy purposes.

How can you get involved?

Encourage healthcare providers to facilitate patient participation in our annual survey, accessible online, on paper, or with assistance from our team in person, over the phone, or via secure video-chat.

This survey focuses on various aspects of health and wellbeing.

Data privacy and ethics

We take privacy seriously. In STRONG-AYA, we strictly adhere to data protection, privacy and patient rights, following regulations such as EU GDPR and national guidelines.

The use of this platform has been checked and approved by the relevant health service and academic research ethics committees in the participating centres.

How will this benefit me?

STRONG AYA aims to provide crucial insights into patient experiences and needs. This data aids in informed decision making for resource allocation, service improvement, and strategic planning.

The survey data will contribute to more effective and tailored healthcare services. This strategic approach ensures a more sustainable healthcare system that aligns with both patient needs and economic considerations.



Improving the future of cancer care for adolescents and young adults with cancer.



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