



FOR  
**HEALTHCARE  
PROFESSIONALS**



## What is STRONG AYA?

STRONG AYA is an international project that aims to improve healthcare services, research and outcomes for adolescents and young Adults (AYA) 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 gathering information from AYAs, about their experience with cancer after diagnosis (e.g. symptoms), overall health and 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 gathering information from AYAs through a secure digital platform. This platform will help AYAs and healthcare professionals like yourself share information and insights into the AYA's health (e.g. symptoms) and overall wellbeing from diagnosis and beyond.

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

## How can you get involved?

Healthcare professionals play a vital role in our work. You can encourage patients to complete the survey evaluating outcomes. This can be done as many times as needed, but at least once a year.

The survey covers different aspects such as symptoms, quality of life, sleep, diet, and daily activities, to improve healthcare understanding and support.

Patient data can be collected in a variety of ways: by email, by telephone, **electronically** or at an appointment. STRONG AYA is spread across five different healthcare systems so practice may vary between hospitals. For more details, please see the patient information sheet provided.

## 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 and UK GDPR, Data Protection Act 2018 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 equip healthcare professionals by providing essential data for optimising AYA cancer care.

This intends to support shared decision-making, monitor healthcare quality, enhance research data sharing, and delivers real-world evidence. By sharing insights with policy-makers, we collectively work to address and reduce inequalities in AYA cancer care across Europe.



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



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