



FOR  
**ADOLESCENTS  
AND YOUNG  
ADULTS**



## 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 talked to young people with cancer, their families, doctors, and researchers worldwide to find out what matters most to young people 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 taken all this information and condensed it into a simple list, which we call a Core Outcome Set.

Now, we are using this list to inform the next steps. We are 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.

By understanding what is needed, we can personalise the care we provide to better match what young people really need.



## What information are we collecting?

We are collecting information about your cancer experiences after diagnosis (e.g. symptoms), your health, and overall wellbeing.

## Why are we collecting this information?

To improve cancer care services and life after diagnosis and treatment. Your input could shape the future of cancer care.

## How will we use this information?

Information you offer us will be collected on a secure digital platform. Our intention is that you have the option to share your cancer experiences and personal knowledge with your health care team, if you wish. This can help gather insights into your health (e.g. symptoms) and overall wellbeing from diagnosis and beyond.

We are designing ways for you, plus others such as healthcare professionals, who hold the relevant permissions, to access and utilise the information without revealing individual identities. Your individual information is combined with those of other patients to create collective information. 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?

We will ask you to fill out a survey covering aspects of your cancer experiences and wellbeing, (such as symptoms, quality of life, sleep, diet and daily activities).

Your information can be collected in a variety of ways: by email, telephone, electronically or at your next clinic appointment. STRONG AYA is spread across five different healthcare systems so approaches may vary between hospitals.

Feel free to fill out the survey as many times as needed, but we kindly ask for at least one survey to be completed once a year. For more details, please see the patient information sheet provided.

In addition, we would like you to collaborate with us on designing and developing our digital platform. If you're interested in getting involved or just want more information, please get in touch with your local study coordinator.

## 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 young people with cancer?

The information you share could help healthcare teams make personalised decisions to make sure the right type of support is provided.

Plus, by monitoring healthcare quality in different countries, our aim is to work towards ensuring that everyone gets the best care- no matter where they live. You are not just part of a community; you are part of a movement that is changing how we take care of young people after their cancer diagnosis.

So, get ready to see positive changes coming your way.



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