

Standards of care and outcomes for adolescents and young adults with cancer

What is this study about?

Adolescents and young adults (AYAs) with cancer require access to oncology services that provide expert cancer care and consider their unique **age-specific** and **complex** psychosocial and physical needs.

We invite you to take part in a research study (in collaboration with Youth Cancer Europe) which aims to gather information about what **minimum services** for AYAs with cancer should involve and what outcomes are most important for them.

Specifically, we are looking to write a position paper on minimum standards of care for AYAs across Europe, and create a Core Outcome Set which identifies the most important outcomes to assess for AYAs with cancer, from the point of view of **AYAs, their caregivers, healthcare professionals, researchers** and **policy makers**. The overall aim to improve care for AYAs with cancer.

What does taking part involve?

To develop our recommendations and a Core Outcome Set (COS), we need to arrive at a consensus, which considers opinions from AYAs, their caregivers, healthcare professionals, researchers and policy makers.

We will ask you to complete **up to 3 online surveys** spread across a span of **(maximum) 4 months**.

In the first round, you will be given a list of services and outcomes relevant to AYA cancer care and asked to rank them based on your perceived level of importance.

Each survey should take between 15 – 20 minutes to complete. There will be approximately **3-4 weeks** between each survey.

Who are we looking to recruit?

You are eligible to take part in this study if you meet **any of the following criteria**:

- **You** received a cancer diagnosis between the ages of 15 and 39.
- You are a **parent / partner / caregiver / representative** to an individual who received a cancer diagnosis between the ages of 15 and 39.
- You are a **healthcare professional** (working with AYAs with cancer)
- You are a **researcher** (in the field of AYA cancer)
- You are a **polycymaker** (relevant expertise to AYA cancer)

How do I get involved?

The first survey will go out in September 2023. We are currently raising awareness and gathering interest of this study. If you are interested in participating, or would like some further information, please contact the researcher, Kirsty Way – k.way@soton.ac.uk