European collaboration defines core outcome set to improve cancer research and care for adolescents and young adults (the STRONG-AYA project)

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In a new *Lancet Oncology* publication, a European team of researchers, clinicians, and young people with lived experience of cancer have defined **what data should be collected in adolescent and young adult (AYA) cancer research and care**. This has been done by developing a **Core Outcome Set (COS)**. Developing a COS allows to ask AYAs what areas of their lives, as they go through cancer treatment, are most important to collect data about.

AYAs (individuals first diagnosed with cancer between 15-39 years of age) face unique challenges due to cancer and its treatment, such as infertility, unemployment or financial problems, as well as other physical effects occurring later in life. **These challenges are often not adequately captured in cancer research and care**. Across different health systems in different countries, AYAs often fall between children's and adult oncology, which means age appropriate care is often not available for them.

To address these gaps, **the EU-funded STRONG-AYA project developed a set of outcomes for cancer research and care to consistently measure what matters most to AYAs**. This Core Outcome Set (COS) includes **20 outcomes**, spanning clinical effects, such as the impact of treatment on different organs, and patient-reported experiences in areas such as quality of life, fertility, mental health, ability to work or study, social relationships, and financial problems.

Researchers in the STRONG-AYA project first identified over 140 potential outcomes through an extensive literature review and interviews with AYAs, caregivers, and healthcare professionals. These outcomes were then prioritised by different working groups. "*We worked with AYAs to make sure that we know exactly what is most important to them when they are undergoing cancer treatment. Young people with cancer consistently tell us that social and psychological support or navigating changes to work or schoolwork is just as important as the clinical care*," said **Anne-Sophie Darlington**, lead author and Professor of Child and Family Psychological Health at the University of Southampton. *"Having this list of outcomes that we know matter to AYAs will allow us to ask the right questions and collect data that will feel meaningful to them."*

By standardising outcome measurement, the COS can support **better comparison and pooling of data of across studies, and future clinical trials could use the COS to look at outcomes beyond traditional clinical measures**. "*Currently, clinical trials often focus on outcomes that matter most to doctors, such as survival and short-term side effects, but overlook issues that are crucial to young people with cancer, including long-term impacts and how treatment affects their return to everyday life*," said **Martin McCabe**, co-author and Professor of Paediatric and Young Adult Oncology at the University of Manchester. "*By developing this Core Outcome Set, we now have a much clearer picture of the information that should be routinely collected in clinical trials and discussed with patients, helping us build a more holistic understanding of how cancer affects young people's lives*."

The STRONG-AYA team is now focusing on evaluating the implementation of the COS across different healthcare systems. The COS is tested with AYAs in participating centres in the

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United Kingdom, France, the Netherlands, Poland and Italy. Future work could also explore its applicability in other healthcare systems in Europe and beyond. "*Implementing the COS has the potential to transform how outcomes are measured, compared, and ultimately acted upon for this patient group*," said **Winette van der Graaf**, co-coordinator of the STRONG-AYA project and Medical Oncologist and Professor at the Netherlands Cancer Institute. "*With this, we can put the voices of young people with cancer at the centre of our research and care.*" **Tomaž Deželak**, patient advocate at Youth Cancer Europe and member of the STRONG-AYA patient advisory board added: "*What I appreciate most about STRONG-AYA is that it's not just talking about patient experience, but it's about doing something with it. It's putting the spotlight on what really matters to young people with cancer and turning that into real, measurable practice that can improve lives*."

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