

STRONG AYA: Implementing a Core Outcome Set for Adolescents and Young Adults with Cancer Utilising a European Federated Learning Ecosystem. A HORIZON EU and Innovate UK initiative.

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Background: Cancer incidence and survival rates among AYAs aged 15-39 years are rising. AYA face specific challenges, distinct from children or older adult cancer patients. TYA benefit from age-appropriate healthcare services. However, AYA cancer care is fragmented, and the outcomes measured for this group are not harmonised, limiting both research and care.

Aims: The STRONG AYA Consortium aims to create efficient, standardised methods for data collection in research and routine care, improving service planning, delivery, improvements in outcomes and the communication of patient-reported outcomes (PROs) between Adolescents and Young Adults (AYAs) and their healthcare providers. The STRONG AYA project will evaluate the feasibility of a Core Outcome Set (COS) for AYAs diagnosed with cancer during its implementation within a European Federated Learning (FL) ecosystem.

Methods: The STRONG AYA Consortium has developed a COS through a comprehensive literature review and consensus processes with key stakeholders including AYA cancer survivors. The COS includes core clinical and PRO domains, across which AYAs are particularly impacted by cancer and they wish were monitored and addressed. The COS will be evaluated in routine clinical practice across five countries, including England, through:

1. Retrospective Implementation: Estimating COS domains using approved existing data from Electronic Health Records (EHRs).
2. Prospective Implementation: Administering the COS to AYA patients in multiple hospitals.
3. COS Summaries: Integrating COS summaries into EHRs and portals, to enhance access for patients, carers, and healthcare professionals.
4. Engagement: Evaluating patient and clinician engagement with the COS and its summaries.
5. Federated Learning (FL) : Privacy-preserving analysis of COS data, allowing the creation of predictive models for AYAs.

Conclusion: The successful implementation of the COS will establish benchmarking between countries, provide real-world evidence to oncology decision makers, share insights and reduce inequalities by improving the value of services provided to AYAs diagnosed with cancer.

References:

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