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strong aya

Interdisciplinary, multi-stakeholder European network to improve healthcare services, research and outcomes for Adolescents and Young Adults with cancer.



The future of cancer therapy



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im. Marii Skłodowskiej-Curie
Państwowy Instytut Badawczy



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WHY IS STRONG-AYA NEEDED

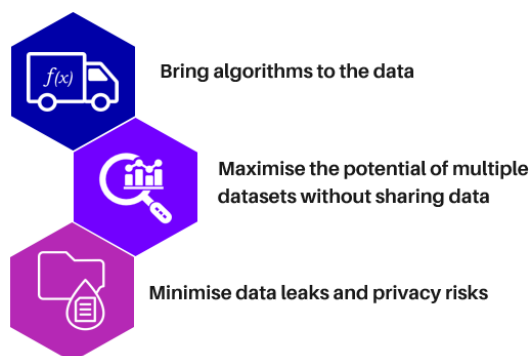
Cancer in **adolescents and young adults** (AYAs, 15-39 years at primary diagnosis) is rare but carries significant long-term personal, societal, and economic burden. AYAs represent a distinct clinical population with age-specific challenges (e.g., infertility, unemployment, financial problems) and decreased quality of life due to cancer and its treatment. AYA-specific healthcare services are scarce and vary across Europe, and AYAs remain underrepresented in research and policy. **AYAs who are at the core of society and the economy need access to age-appropriate and high-quality healthcare.**

ABOUT STRONG-AYA

STRONG-AYA addresses this gap by establishing a **pan-European, value-based data ecosystem** for AYA cancer care, research, and policy. The project develops and implements a **Core Outcome Set (COS) for AYAs**, integrating clinical and patient-reported outcomes that reflect what matters most to AYAs. This COS is being integrated in seven participating centres in five countries (NL, UK, PL, FR, IT).

The centres are connected in a **pan-European ecosystem supporting federated data analyses, outcome data management and clinical decision-making while preserving local data governance.** With this, STRONG-AYA develops **analytical tools to process and present patient outcome data** and establish feedback loops that inform patients and clinicians.

Federated analysis/learning



BENEFITS

STRONG-AYA generates a **scalable data infrastructure and novel insights** into AYA cancer care and outcomes in Europe.

The ecosystem makes available local, regional and national **repositories of (patient-reported) health data** for individual patients, patient organisations, regulatory authorities, health care providers, researchers and decision-makers.

Data in the STRONG-AYA federated infrastructure includes **relevant, reliable, standardised and representative outcome data** that can sustainably improve AYA cancer care and outcomes.

Access to the federated data supports **identification of new research questions and innovation opportunities** as well as **testing of interventions**, accelerating the implementation of age-appropriate AYA cancer services across Europe.

OUTPUTS

-  Scalable federated data infrastructure for access to and sharing of high-quality, comparable AYA research data from different centres
-  Real-world evidence across the entire disease pathway of different AYA cancers
-  AYA healthcare quality **monitoring indicators and benchmarking tools** supporting national and EU cancer policy
-  Pan-European ecosystem enabling **secure and real-time analyses** across countries in line with FAIR and ethical principles
-  Consensus-driven **Core Outcome Set (COS)** for AYAs with cancer that can be used in future research and clinical trials
-  Methods and processes for **meaningful patient/service-user engagement and co-design**
-  Accessible **dashboards** translating complex data into meaningful insights on AYA cancer care and outcomes
-  Structures and mechanisms for **governance and data ownership**

WHAT CAN STRONG AYA OFFER INTERESTED SCALE-UP PARTNERS?

Expert support and scale-up kit, including: technical requirements, legal document template; funding procurement support in the form of project specific texts; data collection protocol

Access to a patient dataset of over 23K AYAs

Relationships with other key stakeholders in AYA care and research through our network with other EU and national initiatives

Co-authorship on publications that utilize the data and value you add to this project

KEY PROJECT INFORMATION

Name:	STRONG-AYA: <i>Improving the Future of Young Adults with Cancer</i>
ID:	101057482
Type of action:	HORIZON Research and Innovation Action
Timeframe:	October 2022 – September 2027 60 months
Budget:	7.2 million EUR Funded by Horizon Europe and Innovate UK
Coordinator:	The Netherlands Cancer Institute (NKI) Prof Winette van der Graaf Dr Olga Husson
Consortium:	14 partners, 7 countries
Contact:	Email: info@strongaya.eu Website: www.strongaya.eu