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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01 BACKGROUND

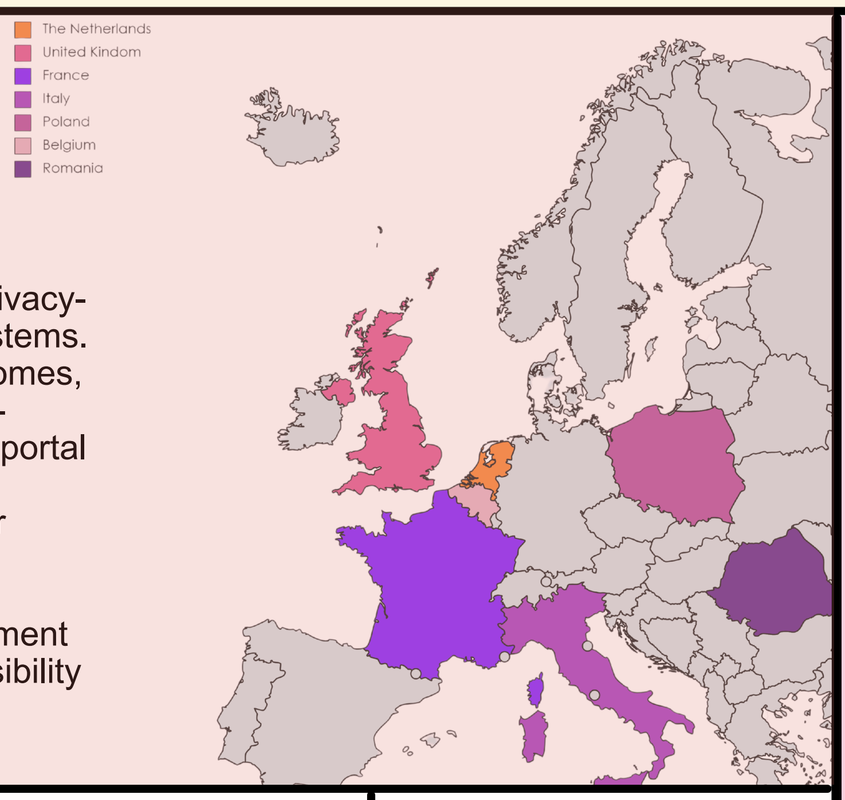
- Cancer incidence and survival rates among adolescents and young adults (AYAs) aged 15–39 are rising.
- AYAs have unique needs that require age-appropriate, specialised care to improve outcomes and experience.
- Currently, data on AYA cancer is collected in fragmented and inconsistent ways, limiting efforts to deliver coordinated care and generate meaningful research evidence.
- The STRONG AYA consortium have developed a Core Outcome Set (COS) with patients, carers, clinicians, researchers, and policy makers to identify key clinical and patient-reported outcomes for AYAs with cancer.

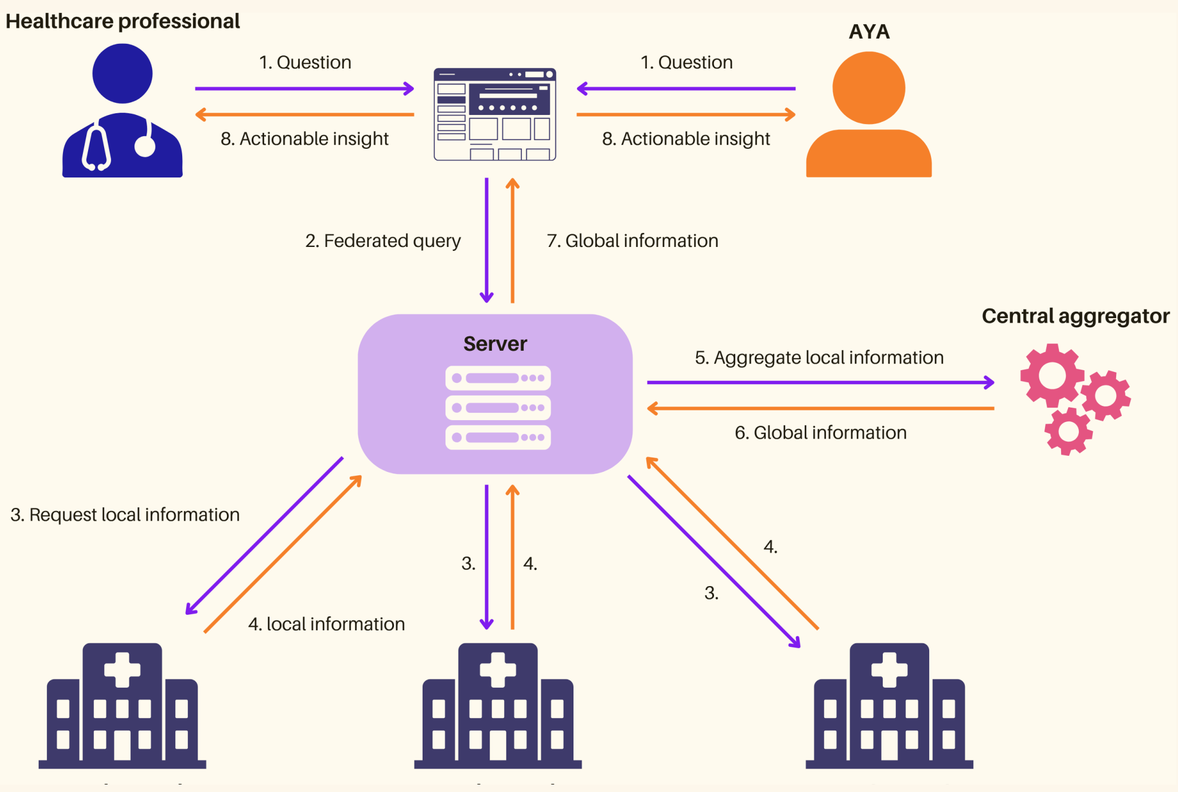
02 AIMS

Across five European countries:

- Establish local, national, and international privacy-preserving Federated Learning (FL)[5] ecosystems.
- Build a secure dataset of AYA-relevant outcomes, stored within local and national ecosystems - Embed results to a shared Patient and HCP portal to support clinical decision-making.
- Generate predictive insights into AYA cancer outcomes using the aggregated data.

In Leeds Teaching Hospital Trust (LTHT): Implement the COS in routine clinical care, evaluate its feasibility for patients and staff, and refine its delivery.





For more information, please scan the QR code below:

03 METHODS

1. The COS will be implemented in LTHT clinical practice by:

- Delivering the COS to 200 LTHT patients across 3 years.
- Harmonising existing PPM+ data with the COS.
- Encouraging clinicians and patients to engage with the COS via bespoke portals.
- Evaluating patients' and clinicians views on the COS and its implementation via interviews.

2.FL is the privacy-preserving analysis of COS data, allowing the creation of predictive models for AYAs directly where the data is stored.

Recruitment of Patients In LTHT

📅 Ongoing until June 2027.

🏥 Across all oncology specialties.

🎯 For patients aged 15–39, at least 10 weeks post-diagnosis.

🔗 To refer eligible patients, please contact the STRONG AYA team.

04 CONCLUSION

- A pan-European, privacy-preserving FL ecosystem enables analysis of data on rarer cancers.
- This approach enhances the development of predictive models and supports evidence-based care for AYAs.
- Implementing the COS will benchmark outcomes across countries, generate real-world evidence, and reduce inequalities by improving services.
- A patient and healthcare professional portal will improve communication, support personalised care, and help AYAs view their outcomes in a broader European context.

05 REFERENCES

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