

The STRONG-AYA initiative: From pan-European ecosystem to clinical practice. Using data to Improve outcomes in Adolescent and Young Adult Cancer patients

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BACKGROUND: Cancer in Adolescents and Young Adults (AYA)(15-39 year olds) occurs at a key developmental time of life. This means they are not only at risk of physical health implications but also delayed or non-achievement of key developmental milestones. In those that survive, cancer can result in long lasting impairment of quality of life (QoL).

Population-based cancer registries (PBCR) record all new cases of cancer within a defined population. They are important for monitoring trends in cancer incidence, mortality and survival over time, facilitating the setting of policy priorities and the planning of services. Whilst detailed research can be carried out using PBCR in common cancers, in AYA cancers the utility is often limited by the lack of AYA specific data items collected relating not only to the distinct cancers common in this population but the need to assess long term impact on QoL.

STRONG-AYA is an international multidisciplinary consortium founded to address the data needs of AYA. Focusing on systematized data collection, federated learning (FL) methodology and novel data visualisation concepts. A standardised Core Outcome Set (COS) has been developed to measure AYA specific outcomes through both clinical data and Patient Reported Outcomes (PROs). COS data collection, both retrospective and prospective is now underway across five countries.

We describe how data from the Yorkshire Specialist Register of Cancer in Children and Young People (YSRCCYP), a PBCR in the north of England, UK is being used within the STRONG-AYA ecosystem and how the subsequent analyses are being utilised in a real-world hospital application to guide patient consultations.

METHODS: We connected the YSRCCYP data to a STRONG-AYA Vantage6 data station within the University of Leeds. Through this the YSRCCYP dataset contributes to the ecosystem and aggregated descriptive statistics for the entire ecosystem are retrieved. The results are then transferred to the PROMPT software co-hosted between the University of Leeds and Leeds Teaching Hospitals NHS Trust (LTHT) and integrated into patient electronic healthcare records (EHR). Initial work has focused on visualisation of PROs relating to the outcomes of the Hospital Anxiety and Depression Scale. Figure 1 demonstrates the data flow.

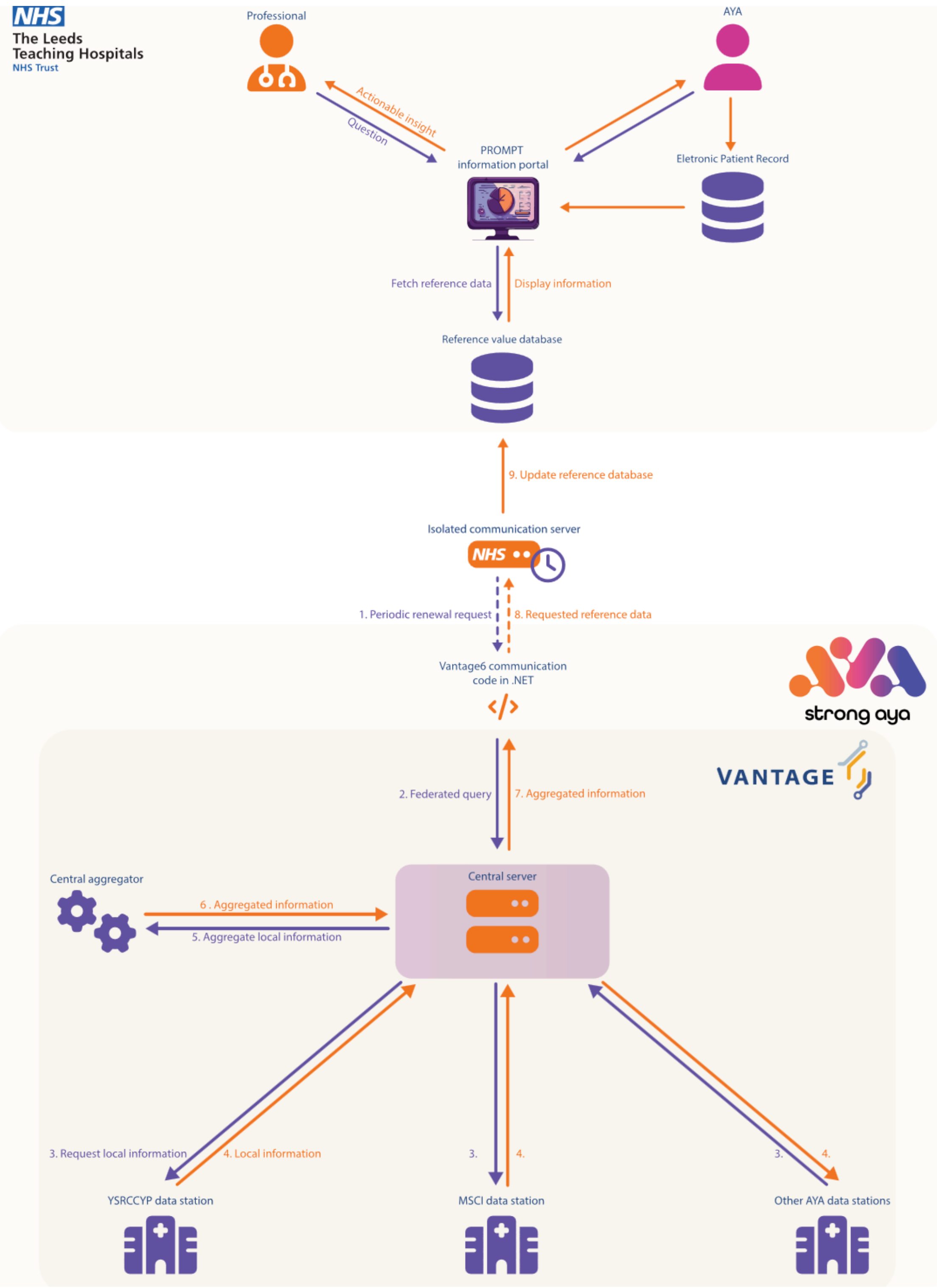


Figure 1. the workflow of populating the PROMPT information portal using reference data coming from the STRONG AYA ecosystem.

CONCLUSION: Through STRONG AYA, regional PBCR data gains added value by incorporating a co-developed COS for AYA and by being part of a pan-European ecosystem. This effort enables the unique data needs of AYA to be met facilitating research into QoL and survivorship outcomes in a safe and secure manner. By visualising such insights within clinical settings, this approach can directly inform patient care and drive shared decision-making, improving AYA patient care and outcomes on an international scale.

RESULTS: We present a proof of concept demonstrating how the results from a fictitious patient can be visualised alongside the results of consortium wide FL.



Figure 2: PROMPT clinician view of a patient PROMs displayed as a line graph with overlaid green band showing the aggregate interquartile Q1, median (Q2), and Q3 levels determined through federated descriptive statistics returned from the STRONG AYA ecosystem.

Patient Date of birth NHS number				Ava Strong 01/01/2000 123-123-1001		Pathway Assigned to pathway		Strong-AYA 01 June 2025		PROMPT Patient Reported Outcomes Admin Login		
Table	Graph	Notifications	Communications	Dashboard								
Measure	Follow-up	Month3	Month3	Month2	Month2	Month1	Month1	Baseline	Baseline			
		08/09/2025 18:30	08/09/2025 18:30	08/08/2025 18:30	08/08/2025 18:30	08/07/2025 18:30	08/07/2025 18:30	08/06/2025 18:30	08/06/2025 18:30			
	Anxiety Score (HAD5)	3		11		13		6		ANXIETY SCORE (HADS) = 13 REPORTED = Tue 08 Jul @ 18:30		
	Depression Score (HAD5)	3		9		6				GRADE = (Above Strong-AYA Q3 threshold)		
	QoL Score (QLQ-C30)		50		41.66667		75		66.66666			

Figure 3: PROMPT clinician view of a patient PROMs displayed in a table with colour thresholds set to reference interquartile ranges determined through federated descriptive statistics returned from the STRONG AYA ecosystem

DISCUSSION:

- PROs have clinical value in facilitating the identification and monitoring of symptoms, evaluation of long-term treatment outcomes and supporting shared decision-making.
- Our intention is that cross-sectional analyses presented via the HCP portal will help AYA navigate challenges and hurdles presented to them along their treatment journey, enabling AYA to normalise their challenges against peers of the same age with the same cancer across Europe.
- Through presentation of longitudinal analyses we aspire to enable AYA to conceptualize how these might change over time and identify a need for intervention.
- Future work will focus on the presentation of consortium wide survival analysis.
- AYA specific comparator data was a previous limitation of PROMPT. Here we provide reference range data that can be catered to an individual's specific case, as well as being dynamic and contemporaneous.

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