



Caught in the Middle: Identifying Gaps for Adolescents and Young Adults (AYAs) with Cancer

The STRONG-AYA project –
improving the future of AYAs with cancer

STAKEHOLDER FORUM REPORT

Executive summary of the report

Each year, 150,000 individuals belonging to the **Adolescents and Young Adults (AYA)** age range of 15 to 39 years old are diagnosed with cancer. They represent a unique group, facing **cancer-related struggles** such as pain, anxiety, or infertility, which interplay with **age-related difficulties** such as unemployment, or a lack of financial stability. These factors consequently contribute to making AYA cancer patients a highly vulnerable group, resulting in a decreased mental health and quality of life. In spite of these known challenges, AYA cancer may face forms of **unawareness, lack of education and policy attention**, due to 'in-betweenness' of this category between the paediatric and the adult cancer patient population, resulting in insufficient designated medical facilities and oncology services.

The **STRONG-AYA Project**, funded by the Horizon Europe and Innovate UK programmes, aims at creating a new, interdisciplinary, multi-stakeholder European network seeking to improve healthcare services, research and outcomes for AYAs. It seeks to achieve and deliver an interactive and safe data infrastructure ecosystem to gather anonymous data from AYA cancer patients that can be used as a basis for research and evidence-based policies. The STRONG-AYA Consortium held its **first Stakeholder Forum** 'Caught in the Middle: Identifying Gaps for Adolescents and Young Adults with Cancer' on 27 September 2023, bringing together 70 participants. The aim was to discuss the **exclusive achievements of the project, provide a space for relevant stakeholders to provide feedback on the project's ongoing activities and engage with the AYA Community** on the project, beyond its current development and duration.

This event report consequently focuses on the **key messages and recommendations emanating from the Forum**. With the **2024 European Parliamentary elections** in mind, the addressing of the needs of AYA cancer patients is a topical issue, and the momentum is to be seized.



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Key principles for strong AYA cancer care

Summarising the discussions that took place at the stakeholder forum, the following key principles could be suggested for strong AYA cancer care:

- **Make it visible!** Since AYAs with a cancer experience face a wide array of unmet needs, policy makers must play a key role in addressing the latter and promoting their interests, at regional, national, and European level. The 2024 European elections represent a window of opportunity to ensure the sustainability and scalability of relevant initiatives, through the development of harmonised guidelines and dedicated policy plan(s).
- **Make it inclusive!** Involvement of AYA cancer patients and their carers is a crucial component of any successful AYA cancer research which needs to be extended and mainstreamed. Researchers must adapt to patients – ensuring adequate communication and adjustments – and not the other way round.
- **Make it trustworthy!** Since collection and use of relevant patient data is instrumental for the progress of AYA cancer research, trust and data solidarity must be built, notably by ensuring adequate patient representation and a continuous demonstration of value through research for cancer patients.
- **Make it ambitious!** A wide array of age-specific factors and disease-induced factors must be taken into consideration when carrying research and policies about AYAs with cancer, to properly capture the needs of this unique group. Future initiative should consequently operate on sizable funding, allowing for the development of cancer registries, as well as for dedicated infrastructures able to deliver age-appropriate care.
- **Make it considerate!** Patients and researchers experience a wide array of challenges and barriers, ranging from language to survey fatigue, as well as a lack of financial means, time, and dedicated infrastructures. The latter must be addressed through strengthened communication, capacity-building, and engagement.
- **Make it collaborative!** Building synergies and collaborating with all relevant EU-funded projects is greatly needed, pursuing the need to ‘work with one voice’ on common objectives: improving the future of AYAs with cancer.

About the STRONG-AYA project

STRONG-AYA is a **Horizon Europe and Innovate UK** funded project, running from 2022 to 2027 and involving 14 consortium members across seven European countries. It seeks to create a new, interdisciplinary, multi-stakeholder European network to improve healthcare services, research, and outcomes for AYAs. To do so, the project includes:

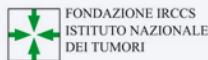
1. The development of a **Core Outcome Set (COS)** for AYAs with cancer, including most relevant measures among clinical, patient-reported and cancer registry outcomes, through an international consensus process involving patients, their carers and representatives, and healthcare professionals;
2. The implementation of the COS in five national healthcare systems across Europe and the establishment **of national infrastructures** for outcome data management and clinical decision-making;
3. The **dissemination of outcomes and facilitation of interactions** between local, regional national and pan-European stakeholders to develop data-driven analysis tools to process and present relevant outcomes.

STRONG-AYA pursues the following outcomes:

1. Equip AYAs with cancer with the data to better optimise their healthcare;
2. Enable AYA healthcare quality monitoring;
3. Establish benchmarking between the different countries on these key performance indicators.

STRONG-AYA is composed of '**ecosystems**', defined as networks of people, processes and technologies that will collect and analyse data provided by patients (reported outcomes, clinical data) and share insights with users (healthcare professionals, patients, regulators, policymakers). Of relevance, STRONG-AYA will never share identifiable patient data, as it operated under federated learning and people will retain control over it. Learn more at strongaya.eu.

The Consortium



Introduction

'Projects such as STRONG-AYA are important as it involves patients and survivors from an early stage, having a real impact in shaping the path forward. We are not mascots; we are not tokens: we are able to impact how the project is shaped from the outset' (Male, 15 years old, Leukaemia)

Each year, 150,000 individuals belonging to the **Adolescents and Young Adults (AYA)** age range of 15 to 39 years old are diagnosed with cancer. They represent a unique group, facing **cancer-related struggles** such as pain, anxiety, or infertility, which interplay with **age-related difficulties** such as unemployment, or a lack of financial stability. These factors consequently contribute to making AYA cancer patients a highly vulnerable group, resulting in a decreased mental health and quality of life. For instance, it was reported that 80% of them will experience survivorship issues in the aftermath of their diagnosis.

In spite of these known challenges, AYA cancer has been affected by a **lack of awareness, education and policy attention**, due to 'in-betweenness' of this category between the paediatric and the adult cancer patient population, resulting in insufficient designated medical facilities and oncology services. Unlike certain groups such as paediatric cancer patients, AYA-specific healthcare services are scarce and vary across Europe.

The **STRONG-AYA Project**, funded by the Horizon Europe and Innovate UK programmes, was launched in October 2022 and aims at creating a new, interdisciplinary, multi-stakeholder European network seeking to improve healthcare services, research, and outcomes for AYAs. This will consist in an interactive and safe data infrastructure ecosystem to gather anonymous data from AYA cancer patients that can be used as a basis for research and evidence-based policies.

The **STRONG-AYA Stakeholder Forum** *'Caught in the Middle: Identifying Gaps for Adolescents and Young Adults with Cancer'*, was held on 27 September 2023, and gathered 70 participants. It notably discussed the **exclusive achievements of the project**, and allowed the AYA Community to connect with stakeholders, pursuing feedback on the project and its future. This report focuses on the high-level messages, consensus, and potential recommendations arising from the Forum. In light of the 2024 European Parliamentary elections and the renewal of the College of European Commissioners, addressing the needs of AYA cancer patients is a timely and pivotal issue.

The Forum included:

- Three break-out rooms, where participants had the opportunity to select their discussion group based on their interest and profile:
 - Perspectives on data sharing and data altruism – aimed towards AYA cancer patients and their representatives,
 - Improving data collection and data support infrastructures for AYAs with cancer – aimed towards high-level AYA cancer experts,
 - From data to policy change in AYA cancer care – aimed towards the remaining stakeholders and policymakers taking part in the forum.
- A panel discussion bringing together other major projects in the field of AYA cancer care – aimed to inform early discussions on long-term implementation, sustainability and synergies for the project.

The following event report is consequently **structured around the insights shared during these sessions**, capturing the essential and most impactful recommendations from each.

Not without the patients: How to successfully build trust and engage cancer patients in AYA cancer projects

It was first agreed amongst participants that patients, their carers, representatives, and advocates form an **integral part of research and a beneficial one**¹, their participation needing to be **extended and mainstreamed**. Indeed, representation is meaningful, allowing patients to actively contribute and feel included in the process, but also to share impactful outcomes that can shape current and future research. This effort can be defined as '*data solidarity*', where individuals contribute to better healthcare and to building future trust.

Nevertheless, it was agreed that building such a trust between patients and researchers was not so straightforward. The challenges and issues faced when participating in research were thoroughly discussed, and it was notably brought up that **patients can feel utilised**, particularly when there is a **lack of communication and/or time** devoted to them. They also face system barriers, and it was considered pivotal to **adjust to the needs** of different patients groups and better communicate. For instance, since adolescents and young adults face age-specific vulnerabilities, heightened by their cancer diagnosis, treatment and post-treatment, it is recommended that adequate dialogues and formats be implemented.

Ways to successfully involve patients were consequently discussed by the group. It was agreed that researchers **must bear responsibility and follow-up with patients after research**, through continuous engagement. This notably concerns clinicians, yet also families and carers, who are involved in the full cancer journey and often forgotten or neglected. In addition, **involving patient representative organisations** and allowing them to play an active role in the process was advocated for. More generally, the **necessity to increase cancer education** was also brought up and underlined by the group.

¹ See Porter and al (2023) '*Patient Advocates and researchers as Partners in Cancer research: A Winning Combination*', ASCO, Vol.43: https://ascopubs.org/doi/full/10.1200/EDBK_100035

Policy recommendations pertaining to patient involvement in AYA cancer research:

- Involvement of AYA cancer patients and their carers is a crucial component of any successful AYA cancer research that needs to be extended and mainstreamed.
- Researchers must put in place methodologies that ensure that patient involvement is meaningful, including through adequate communication and adjusting to the specific expectations, needs and vulnerabilities of different patient groups such as AYA cancer patients. Researchers should adapt to patients, not the other way round.
- Collection and use of relevant patient data in particular is instrumental for the progress of AYA cancer research – however it requires trust and data solidarity being built, which should not be assumed by default. Prerequisites for this include adequate patient representation throughout the research process and the continuous demonstration of value through research for cancer patients.
- Involving AYA cancer patients in research may represent hurdles specific to this age group. The most striking one is the heterogeneity nature of AYAs, ranging from young teenagers to adults approaching their 40s. On the one side, working with minors induces some ethical limitations, as parental consent may be required, whilst on the other hand the eldest young adults may not be able to participate in projects due to their financial limitations and instability.

Advancing AYA cancer research: Identifying challenges to collect better data

Adolescents and Young Adults, in cancer-free settings, experience a development of their physical and neurodevelopmental features, as well as their family and romantic relationships. They experience independence, as well as new academic and professional goals, as they construct their social and cultural identity. On the other hand, AYAs can face financial difficulties and precarious labour conditions and can be discriminated because, for example, of their sexual orientation, gender identity, or ethnical background. Moreover, data collection in research for these specific factors in general population is uncommon thus, leading to underrepresentation of the existing inequities. AYAs with cancer are no exception to this, as they face a mutually reinforcing combination of these age-specific and disease-related challenges.

It was therefore first agreed by the group that this **array of factors must be taken into consideration during research on AYA cancer and that data collected for research purposes must also look at factors potentially leading to inequalities such as ethnic background, sexual orientation, etc.** Secondly, the barriers from gathering research information from AYAs were discussed by participants and experts. An obvious common hurdle faced by both AYAs, and researchers is spoken **language**, which often prevents any form of cross-country interaction, in the context of research and clinical trials. This adds to the fact that the medical vocabulary may not be the easiest to understand for an individual external to the field.

Concerning barriers specifically faced by AYAs, it was agreed that they experience **survey fatigue**, surveys being highly precise and scientific, consequently not resonating with the target group. AYAs are also oversubscribed and stimulated as a group. It was for instance highlighted that some parameters such as benchmarking and cross-country comparisons are of paramount importance to researchers, but less so to patients. It is thus considered primordial that the **importance of AYA cancer research projects is well understood by AYA cancer patients** and that indeed **project's goals are relevant to patients' expectations and needs**. Finally any project collecting data from AYA cancer patients should make clear how it will be processed and benefit patient outcomes ultimately, in order to build confidence, trust and willingness to participate.

From a researcher's perspective, **financial costs and the lack of performing infrastructures in many lower-income Member States**, as well as the time which must be devoted to such magnitude projects, altogether represent hurdles. One way to alleviate such issues could be to have dual systems of data collections, either at home – for the more engaged and privileged patients – or in wards and hospitals – enabling to build stronger ties and to see more patients in a shorter time –. It would notably enable to compensate the lack of dedicated

infrastructures in the most rural and/or deprived regions, and gain substantial amounts of time, since patients would not have to travel and bear with waiting times. Researchers also experience a **difficulty to interoperate** between countries, or even between regions or hospitals, due to those same impediments.

Furthermore, there was consensus amongst the group concerning the need to work together on **new ways of interplaying efficiently with AYA-specific data**. Data indeed needs to be interactive, up-to-date, safe and anonymous, which is what the STRONG-AYA project seeks to implement. Researchers were consequently keen to see long-term data integration with other databases, to ensure long-term sustainability. They strongly emphasised the need for qualitative data sets, to properly assist with planning survivorship.

Finally, the group stressed the importance of **communicating properly on the findings stemming from data**, to foster concrete policy change based on sound evidence.

More than data: how to foster concrete changes in the AYA cancer policy?

The group first discussed the unmet needs that AYAs face in their cancer journey, which need to be **better and further addressed by the project, other projects and policymakers**. There was consensus that the **services dedicated to this specific age range needed to be developed**, because of their current inadequacy and shortfalls. The **transition between paediatric care and adult care is not well addressed** and could for example be supported by dedicated navigators. AYAs with cancer indeed face a lack of continued support and counselling in their journey, most particularly as they are long-term survivors, experiencing distress in some of the aspects of 'adult life'. This for example includes difficulties working, accessing financial services, but also pursuing a romantic or sexual relationship, or conceiving children. A vast array of factors must consequently be considered when constructing policies pertaining to AYAs with cancer, as they can also belong to a vulnerable group, a marginalised community and more generally experience social inequalities. Altogether, this can bring another layer of discrimination and psychological care needs which must not be downplayed.

Secondly, another section of the discussion focused on the **challenges for policy advancement and translation** that policymakers could face and must take into consideration. This notably include a **lack of interest and investment for AYAs**, driven by a deficiency of education and guidance at European level. A striking example is the lack of agreement on a common definition for AYAs across Europe, as it is ranging from 15 to 39 year old in some countries and 14 to 24 year old in others. To tackle such issues, a more unified dialogue and community response must be built, to enable more publicity at later stages.

Thirdly, the group discussed how to **ensure the sustainability and scalability of the project in the long-term**, taking into account the potential ethical and legal issues surrounding data collection. It was conceded that self-sustainability needed to be reached, as the project can be affected by a shift in the policy agenda. The **2024 European Elections thus represent an opportunity** which must be seized, to educate and act on the issues pertaining to AYA cancer patients and survivors. Key legislative files such as the *European Health Data Space*² or the *Pharmaceutical Package*³ are for instance set to be negotiated at institutional level in the upcoming months and could play a topical role in the cancer landscape.

It was consequently largely agreed that a comprehensive, overarching, long-term and strategic policy plan addressing AYA cancer and the unique challenges and needs they face needed to be developed. It should include **sizable funding**,

² https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space_en

³ https://health.ec.europa.eu/medicinal-products/pharmaceutical-strategy-europe_en

age-specific guidelines and a push for **dedicated infrastructures able to deliver age-appropriate care**. The incorporation and use of different policy tools was debated, including the **development of cancer registries focused on specific data collection**, as well as **benchmarking** – within the European Union but also beyond its frontiers –, to learn and exchange best practices. The question of amending legal limitations was raised, as in some countries an individual under 18 cannot participate in clinical trials. Harmonisation at EU level is thus consequently favoured and should be included in such a policy plan.

Finally, there was an emerging consensus that **synergies and collaboration with other EU-funded projects was greatly needed**, pursuing the need to ‘*work with one voice*’ on common objectives. Different projects were notably identified:

1. The *European Network for Teenagers and Young Adults with Cancer* (ENTYAC), which maps AYA cancer progress across Europe. It would notably benefit from progress made in the AYA cancer care policy agenda across Member States, most particularly if STRONG-AYA pursues its implementation goals, and would support dissemination to various actors, from the local range to the European one.
2. The *Joint Action on Networks of Expertise* (JANE, followed by JANE II), which aims at shaping domains of expertise over a 2-year span, one including AYAs with cancer. JANE’s networks of expertise could notably strongly benefit from STRONG-AYA’s novel data ecosystems, to find the most fitted-for-purpose solutions in the community.
3. The *EU Network of Youth Cancer Survivors* (EU-CAYAS-NET) which prioritises addressing AYA cancer patient needs in research and policy, through a network of survivors. It could notably cooperate with STRONG-AYA, as both pursue the same objectives, and could promote their findings jointly, with a stronger and more powerful voice.
4. The *Joint Action Towards the European Health Data Space* (TEHDAS) which seeks to develop principles for the cross-border secondary use of data, including on cancer. As the European Health Data Space will be fully negotiated and legally adopted in 2024, it would benefit from integrating existing pan-European data infrastructure projects such as STRONG-AYA, to build a stronger and more resilient European health data union.

Conclusions

The next steps for STRONG-AYA will be diverse, the first one being the development and finalisation of the Core Outcome Set. The collection of data in the first participating centres is set to take place throughout 2024.

Once data is collected and the Core Outcome Set for AYAs with cancer is developed, the latter will be implemented in the five national healthcare systems identified across Europe. The establishment of national infrastructures for outcome data management and clinical decision-making and a pan-European ecosystem will be the next logical step, prior to disseminating outcomes to stakeholders and policy-makers.

The STRONG-AYA consortium will **strive to further promote and disseminate the key messages raised during the 27 September 2023 Stakeholder Forum**. National and European policymakers will be contacted, in an effort to speak a common language. Similar high-level events will be held until the termination of the project in 2027.

Glossary

AYA	AYA is an acronym standing for adolescents and young adults. AYA oncology thus refers to care focused on individuals aged 15 to 39 years old, diagnosed with cancer.
Core Outcome Set	Agreed standardised set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or health care.
European Health Data Space (EHDS)	A health specific European ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework that aims to empower individuals through 1) increased digital access to and control of their electronic personal health data, at national level and EU-wide, and support to their free movement, fostering a genuine single market for electronic health record systems, relevant medical devices and high risk AI systems and 2) providing a consistent, trustworthy and efficient set-up for the use of health data for research, innovation, policy-making and regulatory activities.
Federated learning	A way to train AI models without external interference to the data, offering a way to unlock information whilst keeping data safe and without sharing it with third parties.

Acknowledgements

This report summarises the key presentations, contributions and recommendations shared at the first STRONG-AYA Stakeholder Forum 'Caught in the Middle: Identifying Gaps for Adolescents and Young Adults with Cancer' organised on 27 September 2023 by the European Cancer Organisation together with the project consortium.

We thank all speakers who contributed their perspectives and expertise on how to improve outcomes and policies for AYAs with cancer through the STRONG-AYA project. We also thank those who provided contributions online during the Forum and provided supplementary commentary after the event. Finally, we also convey gratitude to all those who took time to review and comment on this report during its wider review, as part of the STRONG-AYA project.

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