



EU Network of Youth Cancer Survivors (EU-CAYAS-NET)

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Dissemination Report - focusing on highly visible project events

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Childhood Cancer Foundation	CCIRL	43	Associated Partner

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1 Executive Summary

The main aim of work package 6 (WP6) ‘Communication, Dissemination & Sustainability’ was to widely communicate & disseminate the project results and plan for sustainability of the network and Platform post-project. Deliverable D6.2 ‘Dissemination Report – focusing on highly visible project events’ details the dissemination activities carried out during the project, with a focus on the 2-day Networking Event, three 1-day Policy Events in Lithuania, Austria and Spain, three Regional Events in Balkan countries and the Closing Event, as well as activities during the 10-month extension of the project (including the final Ambassador Event, Equity, Diversity & Inclusion (EDI) in Cancer Care Stakeholder Forum and High Level Inclusivity Roundtable on EDI).

Project activities and events built on the significant experience of CCI Europe and YCE in disseminating within the community of children, adolescents and young adults (CAYA) living with and after cancer and other related stakeholder communities. The activities described within this report took place over the project’s lifespan and extended beyond EU Member States. The aim of the dissemination activities was to promote the results of the Network across the three main project themes (Quality of Life, Adolescent and Young Adult (AYA) Care and EDI¹ to ensure that the expected impacts of the project were achieved, as well as to set the stage for future activities to continue advancing the targeted actions and initiatives necessary to benefit the quality of life of young cancer survivors.

2 Introduction & Background

The EU-CAYAS-NET project has established a European Network of Youth Cancer Survivors and created a Knowledge Centre and interactive Platform (<https://beatcancer.eu/>) to foster social networking, peer support, and knowledge exchange among childhood, adolescent, and young adults (CAYA) living with and beyond cancer. The project focused on three key themes: (1) improving the quality of life of people living with and beyond cancer, (2) enhancing care for AYA with and beyond cancer, and (3) promoting EDI throughout the cancer treatment and survivorship trajectory. This report describes the dissemination activities carried out during the project to promote the results of the Network across these three main project themes (WPs 3 – 5), in particular through Highly visible project events carried out under WP6.

As they focused on project results, dissemination activities relied on the outputs of WP3 (Quality of Life), WP4 (AYA Care) and WP5 (EDI), such as White Papers, Position Papers, guidelines and more. Many different channels were used to reach as wide a range of stakeholder representatives as possible, including social media campaigns (WP6), sharing of content and promotion of events on the Platform (WP2), webinars and short videos (WP2, with content from WPs 3 – 5) and in-person events (WPs 3 – 6).

Work described in this report demonstrates how the Network has achieved the project objective to widely communicate and disseminate project results. Specific metrics under this objective, described in the Grant Agreement,² include:

¹ In the Grant Agreement, WP5 is described as focusing on Equality, Diversity and Inclusion; however, through activities in WP5, it was decided that Equity rather than Equality was a better term. Thus, results of the project focus on Equity, Diversity and Inclusion.

² As metrics under objectives in Annex 1, Part B, section 1.2 and metrics in section Annex 1, Part B, section 3.2.

- # Train-the-trainer participants for education & career support (baseline = 0, target 30 by M24), achieved in M19 with 28 participants in attendance,³
- # Workshop participants for survivors involvement in guideline development & PPI (baseline = 0, target = 20 by M24), achieved in M15 with 62 participants in attendance at the workshop,
- 15 Initiatives supported (baseline = 0, target = 10 by M34),
- Platform with social media (target = 20,000 visitors/month from at least 40 countries by M34), achieved with 66,000 unique visitors/month by M34, with visitors to the Platform from 255 territories and countries,
- Peer support (target = 1,300 by M34), achieved with a total of 1,822 peer support sessions by M34
- 2-day Networking Event in Vienna (at least 60 participants in event from target stakeholder groups), achieved in M15 with 62 participants from 19 EU Member states and 8 non-EU countries,
- 3 National Policy Events (at least 30 participants/event), achieved with:
 - 27 participants in Lithuania,
 - 49 participants in Austria, and
 - 47 participants in Spain,
- 3 Regional Events (at least 50 participants/event), achieved with:
 - 49 participants Sarajevo, Bosnia,
 - 42 participants in Bratislava, and
 - 50 participants in Zagreb,
- 4-Day Closing Event during a major music festival in Romania (at least 170 participants from stakeholders across 27 EU Member states), achieved with 168 participants in person and 12 online from 31 countries (including 21 EU Member States).

3 Approach

Activities reported here involved the participation of all Beneficiaries, with further support from Associated Partners (APs) to amplify key messages of the project. Dissemination planning and reporting was a core part of the WP6 update at monthly meetings with all Beneficiaries, three-monthly meetings with all Beneficiaries and APs and twice-yearly plenary meetings, as well as at regular meetings of the WP6 team. Dissemination activities were collected on an on-going basis using an online register, available to all Beneficiaries and Associated Partners. This register was used to update the Dissemination module on the portal, which was included in the final Periodic Reports to the funder.

4 Results

In the following sections, an overview of all activities is given (from Task 6.4), with a detailed description of the Highly visible network events (from Task 6.5). For information, communication activities (Task 6.3) are also presented (Annex 1).

³ 30 participants were registered but two were unable to join.

4.1 Highly Visible Network Events

4.1.1 2-Day Networking Event – Vienna

In M15 (24 – 25 November 2023), the 2-Day Networking Event for Ambassadors (including Guideline Workshop) was held in Vienna.⁴ The interest in this event was very high and in the end 62 participants from all over Europe took part, including BEN participants and a guest speaker. 35 senior Ambassadors and 17 new Ambassadors participated in the 2-Day Networking Event (i.e. Ambassador Training 2 and Guideline Workshop). 4 Ambassadors were from Austria, 1 from Belgium, 2 from Bosnia and Herzegovina, 1 from Bulgaria, 2 from Croatia, 1 from Czechia, 1 from Denmark, 1 from Finland, 4 from Germany, 2 from Greece, 3 from Ireland, 2 from Israel, 1 from Latvia, 3 from Lithuania, 2 from Luxembourg, 1 from Montenegro, 4 from the Netherlands, 2 from North Macedonia, 2 from Norway, 2 from Poland, 4 from Portugal, 2 from Romania, 1 from Serbia, 1 from Slovakia, 1 from Sweden, 1 from Ukraine, 1 from the UK. This covered 19 EU Member states and 8 non-EU countries.



Figure 3. Participants of the 2-Day Networking Event (with Guideline Workshop) in Vienna, November 2023

The focus of this event was on equipping the Ambassadors with the skills they need to become strong and independent patient advocates. The agenda covered: an introduction to the European Network of Youth Cancer Survivors and a deep dive into the Network’s advocacy topics (networking in the network, existing patient advocacy training, patient advocacy marketplace (via poster presentations), guideline workshop, peer support and EU-CAYAS-NET ambassadorship). In addition, a presentation and workshop were given by Maria Dutarte as a representative of the European Patients’ Academy (EUPATI, <https://eupati.eu/>). Participants from non-EU member states also showed a particularly high level of interest, as survivorship care is often poor or non-existent in their countries.

The agenda is provided in Appendix 1.

4 Event description: <https://beatcancer.eu/event/2nd-eu-cayas-net-ambassador-training-24th-25th-nov-in-vienna/>



Figure 4. Participants at the Patient Advocacy Workshop, November 2023

This event was also accompanied by a media campaign, including a press release.⁵



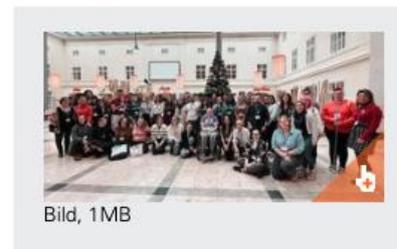
OTS0042, 29.

Junge Krebs-Survivors übernehmen das Ruder

Botschafter:innen des „European Network of Youth Cancer Survivors“ treffen sich in Wien, um über mangelnde Unterstützung nach Krebsbehandlung zu diskutieren.

Wien (OTS)- (Wien, 24.11.2023) Nach einer Krebstherapie geht das Leben nicht einfach so weiter wie bisher. Dies ist eine Realität, mit der die meisten Überlebenden von Krebserkrankungen im Kindes-, Jugend- und jungen Erwachsenenalter konfrontiert sind. In einer einzigartigen, von der EU finanzierten Netzwerkinitiative (EU-CAYAS-NET) schließen sich junge Survivors aus ganz Europa zusammen, um die Voraussetzungen für einen sinnvollen Wandel zu schaffen. Ihr Ziel ist es, Ungleichheiten abzubauen und eine umfassendere, individuellere Versorgung zu ermöglichen, damit kein junger Mensch mit oder nach einer Krebserkrankung zurückgelassen wird.

Nach fünf Jahren ohne Rückfall werden Krebspatient:innen entlassen und gelten als geheilt. Die Krankheit hinterlässt jedoch seine Spuren: Wer im Kindes-, Jugend- oder jungen Erwachsenenalter betroffen ist, hat ein höheres Risiko für behandlungs- oder krankheitsbedingte Spät- oder Langzeitfolgen, Rückfällen oder Sekundärerkrankungen. Abgesehen von einigen wenigen klinischen Vorzeigezentren, die über Europa



Childhood Cancer International - Europe

ZUM PRESSROOM

+ ADRESSE

- RÜCKFRAGEN & KONTAKT

Figure 5. Austrian National Press Release, 2-Day Networking Event (29 November 2023)

The majority of participants rated their satisfaction between 4.5 and 5 (=maximum). More than a third were participating in such an event for the first time. The rest were participating for the second time. The presentations were rated as good to very good. The same applies to the materials provided and the group activities. The poster session in which participants presented their (national) survivor projects was particularly popular. 80 to 90% of participants would recommend such an event to their peers. Almost all participants said the event met or exceeded expectations. When asked what could

⁵ Press release at national level in Austria on APA-OTS
(https://www.ots.at/presseaussendung/OTS_20231129_OTS0042/junge-krebs-survivors-uebernehmen-das-ruder-bild)

be improved, two participants said that there was too much information and that they were so overwhelmed by it so that they had difficulty taking home the core message.

4.1.2 Policy Events - Austria, Lithuania, Spain

Austria

The Austrian Policy Event was held at Albert Hall in Vienna (28 Jun 2024). The Symposium focused on challenges related to mental health and psychosocial care after cancer during childhood, adolescence and young adulthood, and highlighted key outcomes of EU-CAYAS-NET to tackle these challenges in healthcare systems. The event featured speeches, messages, and round table discussions from leading experts in pediatric oncology, mental health, and advocacy, as well as national politicians and representatives of the European Commission. Prominent figures from the medical, political, and non-profit sectors signed the Vienna Declaration ‘Improving the mental and psychosocial health of youth cancer survivors’.⁶ The declaration emphasises the importance of improving mental and psychosocial health after cancer at a young age and proposes a set of actions to reach the goal of better care.

The event was attended by a multidisciplinary group of approx. 50 national and international stakeholders from all areas, who found the event very informative and unanimously agreed that they wanted to continue to be kept informed about the project.



After the Austrian Policy Event, a 1-day DACHL Workshop on patient advocacy was organised by CCI Europe for German-speaking patient advocates. The workshop had 14 participants and 4 guest speakers. It was held in German and contained: i) Science Communication, Public Relations (PR) and Marketing training (Guest speakers). ii) Patient Advocacy and Art (Guest Speakers), iii) Train your skills related to reasoning and awareness (CCI Europe), iv) event management and patient advocacy (CCI Europe). The feedback was overall very good and the participants agreed that taking part had been worthwhile and that they would like to stay in touch.

⁶

Vienna

Declaration:

<https://beatcancer.eu/wp-content/uploads/2024/06/EU-CAYAS-NET-Vienna-Declaration-1.pdf>

Lithuania

The Policy Event ‘Transition of Care from Pediatric to Adults’ took place 27 May in Vilnius, Lithuania.⁷ The event, co-organised by POLA and the EU-CAYAS-NET project, focused on improving the transition of care for young cancer survivors from pediatric to adult healthcare. It brought together key stakeholders, including policymakers, healthcare professionals, patient advocates, and young people living with and beyond cancer themselves to discuss best practices, and government initiatives, and develop action plans for a smoother transition for young cancer survivors. The event was attended by 27 participants: 15 from Patient Organisations, 2 policymakers, 8 healthcare professionals, and 2 from other categories.

The event kicked off with opening remarks from Monika Ošmianskienė, the Chairman of the Commission for People with Disabilities of the Parliament of Lithuania. There were then presentations on the EU-CAYAS-NET project, Europe’s Beating Cancer Plan, and government initiatives related to young cancer survivors, followed by expert insights on current practices, best practices for transition care, and preliminary recommendations for improvement. Next up was a panel discussion featuring diverse perspectives from healthcare professionals, patient representatives, and young cancer survivors., followed by a collaborative discussion on action points and next steps for enhancing the transition experience in Europe. At the end of the meeting, the Vilnius Declaration on Transition from Pediatric to Adult Cancer Care⁸ was signed, outlining a commitment to improving the transition of care. The agenda is available in Appendix 2.



Figure 6. Signature of the Vilnius Declaration, 27 May 2024

The event was live streamed live and a recording is also available.⁹

⁷ <https://beatcancer.eu/event/policy-event-transition-of-care-from-pediatric-to-adults/> Event description:

⁸ <https://beatcancer.eu/resources/transition/publication/vilnius-declaration-on-transition-from-pediatric-to-adult-cancer-care/> Vilnius Declaration:

⁹ <https://www.youtube.com/watch?v=YPtmHGo3UZg>

Spain

On October 22, 2024, the Spanish Policy Event within the EU-CAYAS-NET project was co-organised by Sant Joan de Déu (FSJD), bringing together around 47 participants, including 15 patient representatives and patient organisations, 28 healthcare professionals (doctors and psychologists), and social workers, 3 policy makers and 1 participant from innovation/industry. The discussions focused on the long-term consequences of cancer survivorship and the need for lifelong follow-up care. The event also emphasized the importance of incorporating LTFU care into national cancer control plans, securing sufficient funding, and training healthcare professionals to deliver high-quality survivorship care.

The event concluded with the signing of the Barcelona Declaration,¹⁰ a commitment to advocating for policy changes that ensure equal access to long-term follow-up care across Europe. This declaration will be submitted to the European Commission, aiming to promote structural and political action to enhance the quality of life for young cancer survivors, alleviate the burden on healthcare systems, and facilitate more effective societal reintegration.

From feedback to the organisers, the event was considered very successful and encouraging at the national level, and there is a willingness to continue communication and cooperation.

The agenda is provided in Appendix 3.



Figure 7. Policy Event in Barcelona

4.1.3 Regional Events

Bosnia

The first of the three regional events, Regional Young Cancer Survivors Convention, took place in Sarajevo, Bosnia from 08 – 12 Aug 2023 (M12) of the project, with 49 participants in attendance

¹⁰

Barcelona

Declaration:

https://beatcancer.eu/wp-content/uploads/2024/06/EU-CAYAS-NET-Declaration-Barcelona_2.pdf

including survivors from Bosnia (22 participants), Serbia (8 participants), Montenegro (4 participants), Slovenia (1 participant), Croatia (7 participants) and Macedonia (4 participants).

Hosted by AP ‘Heart for Children’ with support from EU-CAYAS-NET, the convention included educational and social activities with a focus on raising awareness about late effects of treatment and establishing a system for monitoring late effects. ‘Heart for Children’ hosts this regional convention annually in one of the countries of the former Yugoslavia. The opening of the convention was attended by the Prime Minister of the Sarajevo Canton Nihad Uk, as well as the Director of the Association ‘Heart for Children’ Fikret Kubat, Board Member of Childhood Cancer International Europe Lejla Kamerić and EU-CAYAS-NET network representative Arnela Kamerić.

The agenda is provided in Appendix 4.



Figure 8. Participants of the Regional Event in Sarajevo, Bosnia (August 2023)

Four EU-CAYAS-NET Ambassadors attended the event to share their experiences with the Network.

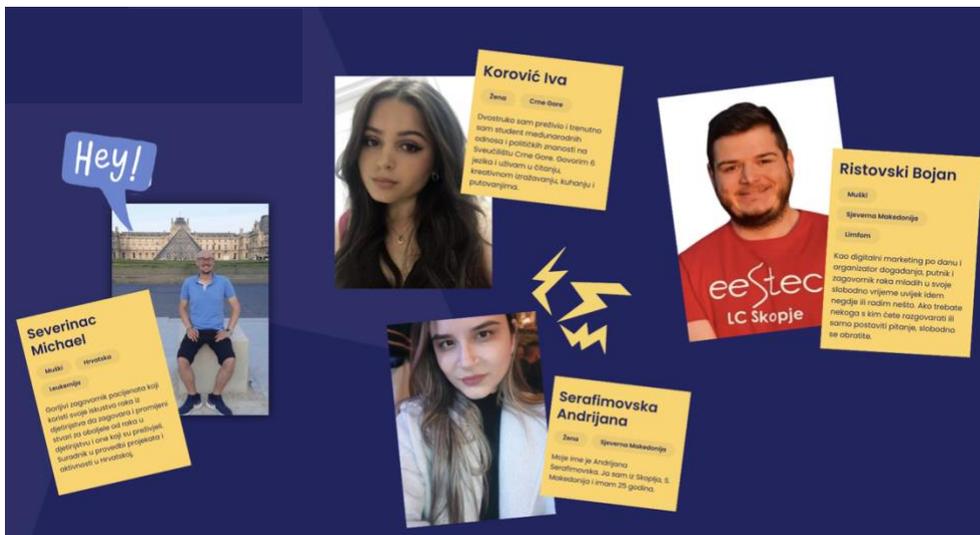


Figure 9. Ambassadors attending the Regional Event in Sarajevo, Bosnia

The event was promoted on the communication and dissemination channels of the Network, as well as in national media.¹¹

¹¹ <https://sarajevotimes.com/regional-convention-of-young-people-cured-of-cancer-in-sarajevo/>

Bratislava

From 13 - 15 June 2024, a Regional Event for Young Cancer Survivors was hosted in Bratislava as part of the EU-CAYAS-NET project. The event brought together 35 participants from several countries, including Slovakia (10 participants), Czech Republic (8 participants), Hungary (6 participants), Austria (6 participants), and Poland (5 participants). The event was hosted by Associated Partners from the region.

Over three days, the event featured interactive workshops, survivor-led discussions, and a cross-border exchange of experiences. Key themes included barriers to psychosocial care, navigating the health system after cancer treatment, and inclusive survivor support across Central Europe. A highlight of the programme was a collaborative session on peer mentorship models, where participants from different countries presented grassroots initiatives and discussed how to adapt them within their local healthcare systems. The event also served as a platform to recruit and empower new youth Ambassadors for the EU-CAYAS-NET network in underrepresented countries.

Zagreb

From 07 - 09 June 2024, the 11th Regional Convention of Young Cancer Survivors was co-hosted by AP Krijesnica with CCI Europe as part of EU-CAYAS-NET under the theme "Zagreb Calls You!". The event gathered over 50 participants, including CAYA cancer survivors, from youth groups across Croatia (15 participants), Bosnia and Herzegovina (15 participants), Serbia (12 participants), Montenegro (5 participants), and North Macedonia (4 participants).



Figure 10. Participants of the Regional Event in Zagreb, Croatia (June 2024)

Over the course of three days, a series of workshops, discussions, and a concluding panel discussion were held. The convention highlighted shared challenges faced by young survivors across the region, with two key areas identified as priorities for further action:

1. **Transition from Pediatric to Adult Care** The transition from pediatric to adult care remains a significant challenge, often leaving young survivors without adequate support. Many participants reported that they do not attend specialist follow-ups or are not even referred for them. Peer discussions emerged as an essential resource, enabling young survivors to guide one another in seeking necessary specialist examinations crucial for timely medical interventions and better long-term health outcomes.
2. **Establishing a System for Monitoring Late Effects of Treatment** The need for a structured follow-up system to monitor the late effects of cancer treatment was strongly emphasized. Several participants shared their experiences of being treated by doctors unfamiliar with these late effects, leading to delays in diagnosing new health conditions, which then progress and become more difficult to manage. Additionally, mental health and fertility were recognized as critical topics requiring increased awareness and research.

These concerns continue to be central to young cancer survivors, highlighting the need for comprehensive, survivor-centered approaches in healthcare policies across the region.

Special thanks go to Prof. Dr. Jelena Roganović and Assoc. Prof. Dr. Lorna Zadavec Zaletel, whose contributions to the panel discussion provided valuable insights into their professional dedication to addressing late effects of cancer treatment. Their ongoing efforts to improve survivor care and establish structured follow-up monitoring across the region remain instrumental.

Appreciation is extended to all participants of the convention for dedicating their time, sharing their experiences, and fostering mutual support within the survivor community. Their voices play a crucial role in shaping future advocacy efforts and improving the quality of life for young cancer survivors across the region.

Participant feedback was positive with 58% rating the event at 5/5. Detailed evaluation feedback is in Appendix 5.

4.1.4 Closing Event

From 01 - 04 August 2024, YCE hosted the 4-day Closing Event of the EU-CAYAS-NET project in Cluj-Napoca, Romania. The event welcomed **180 participants** (168 in-person and 12 online for the General Assembly) from **31 countries**, including EU and non-EU members. Participants came from Romania (60 participants), Lithuania (12 participants), the Netherlands (12 participants), Poland (9 participants), Austria (9 participants), Ireland (8 participants), Portugal (6 participants), Hungary (6 participants), Spain (5 participants), Ukraine (5 participants), Belgium (5 participants), Croatia (4 participants), Greece (4 participants), Bulgaria (4 participants), Finland (4 participants), Slovenia (3 participants), the UK (3 participants), Serbia (3 participants), Italy (3 participants), Bosnia and Herzegovina (2 participants), North Macedonia (2 participants), Germany (2 participants), and individual participants from Moldova, France, Sweden, Armenia, Brazil, Canada, Czech Republic, the Philippines, and Slovakia.



Figure 11. Participants of the Closing Event

The Closing Event marked the culmination of nearly three years of collaborative work under EU-CAYAS-NET and was hosted by Youth Cancer Europe. Over the course of four days, the programme included:

- **The Final General Assembly Meeting**, where all beneficiaries and associated partners reviewed the project’s milestones and agreed on future collaboration and sustainability steps.
- **Workshops and co-creation sessions**, such as the “Sustainability Strategy Workshop” and thematic roundtables on peer support, education & career pathways, and equity in survivorship.
- **Interactive Ambassador activities**, where youth Ambassadors presented national and local achievements, led networking exercises, and took part in planning future community actions.
- **A dedicated session on the future of the Platform and Discord community**, with technical training and brainstorming on new content and outreach methods.
- **Creative sessions**, including storytelling, digital advocacy, and public speaking, aimed at empowering young survivors to amplify their voices in national and European-level policymaking.
- **Social and cultural activities** to build connection and community, including a welcome dinner, guided city tour, and an open mic night featuring music, poetry, and survivor stories.

The agenda is provided in Appendix 6.

The event was a celebration of resilience, advocacy, and solidarity, and provided a strong launchpad for the next phase of the European Network of Youth Cancer Survivors.



Figure 12. Session at the Closing Event

4.2 Summary of Dissemination Activities & Key Outputs on the Platform

A summary of all dissemination activities is provided in Appendix 7.

In addition to these dissemination activities, key outputs of the project under each theme, as summarised below, have been posted to the Platform.¹²

4.2.1 WP3

White Paper

The ‘Optimising Quality of Life after Youth Cancer’ White Paper¹³ summarizes actionable recommendations from WP3 ‘Quality of Life’, addressing mental health, education & career support, transition and follow-up care gaps across Europe.

¹² <https://beatcancer.eu/project-deliverables/>

¹³ https://beatcancer.eu/wp-content/uploads/2024/07/EU-CAYAS-NET_Quality-of-Life_White_Paper.pdf



Figure 13. White Paper 'Optimising Quality of Life after Youth Cancer'

Transition Guideline

The guideline on transition from paediatric to adult care has been accepted for publication in the peer-reviewed journal *The Lancet Oncology*. Once published in *The Lancet Oncology*, recommendations from the paper will be shared as a resource on the Platform. The guideline has been disseminated through a poster presentation and a panel moderation related to Transition at the International Symposium on Late Complications after Childhood Cancer (ISLCCC, 19–21 June 2025). The guidelines were also disseminated during the 30th PanCare meeting (Sep 2024), in the panel session 'Reducing inequalities and improving quality of life of cancer patients and survivors' at the World Cancer Day 2025: HaDEA project showcase 'Fostering synergies to beat cancer: The impact of EU-funded projects' (Feb 2025) and through a presentation at the Pediatric Cardio-Oncology Conference in Cincinnati (07–09 Nov 2024). A one-page summary of the recommendations was developed to provide an overview

at a glance, with translations to German, Spanish, French, Serbo-Croatian, Italian, Lithuanian, Dutch and Romanian.¹⁴

Education and Career Materials from around Europe

The education and career support materials from around Europe that were identified during the project have been posted to the Platform as an interactive map.



Figure 14. Map of Education and Career Materials from around Europe, identified during the project

Mental Health and Psychosocial Care

‘Recommendations for Mental Health & Psychosocial Care after CAYA cancer - Standard, not luxury’ are available via the Platform,¹⁵ with translations to German, Spanish, French, Serbo-Croatian, Italian, Lithuanian, Dutch and Romanian.¹⁶ Pocket Cards for Mental Health Awareness and Guidance were created as a support material, and are also available in many languages.¹⁷

Train-the-Trainer concept for Healthcare Professionals on education & career support for survivors

The Train-the-Trainer concept was tested and evaluated at a workshop held in Vienna (12 - 13 Mar 2024) with 30 participants from 16 countries.



Figure 15. Train-the-Trainer for Education & Career Support

¹⁴ <https://beatcancer.eu/resources/quality-of-life/article/quality-of-life-project-outputs/>

¹⁵ https://beatcancer.eu/wp-content/uploads/2024/10/EU-CAYAS-NET-D3.1_readyforupload.pdf

¹⁶ <https://beatcancer.eu/resources/quality-of-life/article/quality-of-life-project-outputs/>

¹⁷ <https://beatcancer.eu/resources/mental-health/brochure/pocket-cards-for-mental-health-awareness-and-guidance/>

The finalised concept was then made available for download on the Platform.¹⁸ Additionally, a corresponding manual was made available for download, which can be used to prepare for training delivery, as well as serves as a handbook for use during the training workshop.¹⁹ The manual includes specific examples of group work or worksheets with corresponding tasks.

Late Effects and Long-Term Follow-Up (LTFU) Care

A European Map of LTFU care was developed to give an overview of the current situation in Europe, along with a form to submit updates as the landscape of available care is dynamic.²⁰ ‘Recommendations for LTFU care to be seen as the final step of successful cancer treatment’ are available on the Platform.²¹ A one-page roadmap was developed to support advocacy for better LTFU care, with translations to German, Spanish, French, Serbo-Croatian, Italian, Lithuanian, Dutch and Romanian.²² ‘From Experience to Action: A Guide to Talking with Survivors About Late Effects’ was also created for healthcare professionals and posted to the Platform.²³

4.2.2 WP4

Report on Findings of the AYA Care Peer Visits

A report on the findings from the AYA Care Peer Visits entitled ‘Levelling Up AYA Cancer Care: Insights from Innovative Peer Visits Across Europe’ was disseminated during EU-CAYAS-NET meetings, shared with Network Ambassadors, and made accessible on the Platform²⁴ and Youth Cancer Europe’s website.²⁵ Results from this report also fed into the Position Paper on AYA Care.

Report on the AYA Round Table

A Report on the AYA Care Online Round Table ‘Upscaling AYA Cancer Care: Towards Establishing Minimum Standards for Care for AYA Across Europe;’ was posted to the Platform, summarising the main key ideas discussed during the event.²⁶ Results from this report fed into the Position Paper on AYA Care.

‘Specialist AYA Units Minimum Standards’ Position Paper

The ‘Recommendations and Implementation Roadmap for Minimum Standards of Specialist AYA Cancer Care Units’ is available on the Platform.²⁷ Translations are available in German, French,

¹⁸ <https://beatcancer.eu/wp-content/uploads/2024/07/EU-CAYAS-NET-D3.2-submission-26Jul2024.pdf>

¹⁹ <https://beatcancer.eu/resources/career/article/educational-career-pathways-cancer-survivors/>

²⁰ <https://www.pancare.eu/european-map/>

²¹ <https://beatcancer.eu/wp-content/uploads/2024/07/EU-CAYAS-NET-D3.4-submission-05Nov2024.pdf>

²² <https://beatcancer.eu/resources/quality-of-life/article/quality-of-life-project-outputs/>

²³ <https://beatcancer.eu/wp-content/uploads/2024/07/From-Experience-to-Action-A-Guide-to-Talking-with-Survivors-About-Late-Effects-First-draft-darksketches.pdf>

²⁴ <https://beatcancer.eu/resources/long-term-follow-up-care/report/aya-cancer-care-insights-europe/>

²⁵ <https://www.youthcancereurope.org/yce-conducts-5-hospital-peer-visits-in-europe/>

²⁶ <https://beatcancer.eu/wp-content/uploads/2024/03/Establishing-Minimum-Standards-of-Care-for-Adolescents-and-Young-Adults-AYA-Across-Europe.pdf>

²⁷ <https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper-3.pdf>

Lithuanian, Spanish, Dutch, Italian., Serbo-Croatian, Romanian and Greek.²⁸ An AYA Care Pocket Card was also developed to promote the Position Paper and distributed at numerous events.²⁹

4.2.3 WP5

EDI Results and Policy Recommendations

The EDI Policy Recommendations were launched at the ‘Recommendations for Equitable, Diverse and Inclusive Cancer Care in Europe’ Policy Event held at the European Parliament in Brussels (21 Mar 2024).³⁰ The recommendations (available in 12 European languages) are available on the Platform.³¹ Results of the EDI work to better understand and address disparities in cancer care arising from mapping and outreach, online surveys and scoping reviews were presented at a webinar on 30 May 2024, where the EDI policy recommendations were also presented.



Figure 16. Participants of the ‘Recommendations for Equitable, Diverse and Inclusive Cancer Care in Europe’ Policy Event, Brussels, 21 March 2024

EDI Training Programme

The EDI Principles in Cancer Care Training Event (June 2024) launched the EDI Toolkit and training programme developed during the project. EDI training sessions were held 03-12 June 2024 in Cluj-Napoca for 19 researchers, 20 healthcare professionals and 20 patient advocates. The sessions utilised the EDI Training Toolkit available on the Platform,³² with translations available in Serbo-Croatian,

²⁸ <https://beatcancer.eu/resources/quality-of-life/guidelines/recommendation-and-implementation-roadmap-for-minimum-standards-of-specialist-adolescentand-young-adult-aya-cancer-care-units-position-paper/>

²⁹ <https://beatcancer.eu/wp-content/uploads/2025/02/AYA-Pocket-Card.pdf>

³⁰ <https://beatcancer.eu/event/equitable-diverse-and-inclusive-cancer-care-in-europe/>

³¹ <https://beatcancer.eu/resources/equality-diversity-and-inclusion/article/recommendations-for-equitable-cancer-care/>

³² https://beatcancer.eu/wp-content/uploads/2024/04/Equity-Diversity-and-Inclusion-Principles-in-Cancer-Care-Train-the-Trainer-Toolkit_compressed.pdf

Dutch, German, Italian, French, Lithuanian and Spanish.³³ The 59 diverse participants reported increased EDI knowledge and confidence in post-training evaluations. Pocket Cards were also developed to support dissemination of the recommendations.³⁴

5 Impact & Conclusion

The EU-CAYAS-NET project has successfully established a European Network of Youth Cancer Survivors and created a Knowledge Centre and interactive Platform (<https://beatcancer.eu/>) to foster social networking, peer support, and knowledge exchange among CAYA living with and beyond cancer. Dissemination activities have been carried out during the project to promote the results of the Network across these three main project themes (WPs 3 – 5), in particular through Highly visible project events carried out under WP6. The Network has achieved the project objective to widely communicate and disseminate project results, meeting all associated metrics.

³³ <https://beatcancer.eu/resources/equality-diversity-and-inclusion/article/recommendations-for-equitable-cancer-care/>

³⁴ <https://beatcancer.eu/wp-content/uploads/2025/02/EDI-Pocket-Card.pdf>

6 Appendices

a. 6.1 Appendix 1 - 2-Day Networking Event



European Network of
YOUTH CANCER SURVIVORS

EU-CAYAS-NET Ambassador Training 2, 24th & 25th Nov. 2023, Vienna

Programme outline

Day 1
November 24th:

09:30 – 09:50 – **Welcome and expectations (Why are we here, what to expect)**
CCI Europe, YCE

09:50 – 10:50 – session 1.1 – **Introduction to the European Network of Youth Cancer Survivors and deep dive into our advocacy topics Part 1**

- Why did we start the project? (*Katie Rizvi*)
- Deep dive to the advocacy topics addressed.
 - Mental Health & psychosocial care (*Carina Schneider*)
 - Education & Career Support (*Anna Zetti*)
 - Transition (*Jaap den Hartogh*)

10:50 – 11:00 **Coffee break 1**

11:00-12:00 session 1.2 – **Introduction to the European Network of Youth Cancer Survivors and deep dive into our advocacy topics Part 2**

- Long Term Follow Up Care (*Cherine Mathot*)
- AYA Care (*Ana Totovina/Elena Arsenie-Constantinescu*)
- Equality, Diversity and Inclusion (*Katie Rizvie*)

12:00 – 13:30 **Lunch break**

13:30 – 17:30 session 2 – **Guideline Workshop** (*Jikke Wams, Jaap den Hartogh, Renée Mulder, Elvira van Dalen*)

13:30 – 13:35: **Aim of the workshop**
How can patient values best be integrated into clinical guideline development”?

13:35 – 13:50: **Introduction**

- What are clinical practice guidelines?
- What are the stages of guideline development?

Example: Transition guideline

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EU-CAYAS-NET Ambassador Training 2, 24th & 25th Nov. 2023, Vienna

13:50 – 14:50: **Workshop in subgroups (10 pax)- Different phases of guideline development**

- Drafting/adapting clinical questions
- Selection of evidence
- Interpretation of conclusions of evidence
- Translation of evidence to recommendation

14:50 – 15:15 **Coffee break 2**

15:15 – 15:30 **Explanation**

- What methods are available to collect patient values?
- What is known and what is the benefit?

15:30 – 15:45: **Interview**

Experiences of survivors in participating in guideline development

15:45 – 16:30: **Workshop in subgroups (10 pax)- Mind-mapping exercise**

- What stages?
- How to integrate patient values?
- Discussion on barriers and facilitators of participation

16:30 – 16:45 **Coffee Break 3**

16:45 – 17:30: **Plenary Discussion**

“How can patient values best be integrated into clinical guideline development”, based on the conclusions of the subgroups

19:00 – 23:00: **Dinner and social programme**

At Soulkitchen Vienna (<https://www.soulkitchenvienna.at/>)

Telephone: +43 650 8655554

E-Mail: office@soulkitchenvienna.at

Hintere Zollamtstrasse 2 B

1030 Vienna



EU-CAYAS-NET Ambassador Training 2, 24th & 25th Nov. 2023, Vienna

Day 2
November 25th:

09:00 - 09:15 – **Arrival and registration**

09:15-09:30 – **Introduction to Day 2: Recap of feedback from 1st Ambassador event** (*Carina Schneider*)

09:30 - 11:00 – session 1: **Patient Advocacy**

- **What is Patient Advocacy?** (*Sarunas Narbutas, Katie Rizvi*)
09:30 - 09:45
 - Introduction to what patient advocacy is
 - Real life examples
- **Networking in the network project** (*Sarunas Narbutas*)
- **Existing Patient Advocacy Trainings** (*Carina Schneider*)
09:45 - 10:00
 - "There's no shortcut for gaining knowledge"
- **Patient Advocacy Market Place**
10:00 - 11:00
 - Poster presentations

11:00 - 11:15 **Coffee Break 1**

11:15 - 12:30 - session 2 – **EUPATI presentation and workshop** (*Maria Duterte*)

12:30 - 14:00 **Lunch break**

14:00 - 15:00 - session 3.1 – **Ambassadorship part 1** (*Katie Rizvi & Senior Ambassadors*)

- Examples of what Ambassadors have already done
- Ambassadors hosting /instrumental in Peer Visits
- Expectations from project Ambassadors

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EU-CAYAS-NET Ambassador Training 2. 24th & 25th Nov. 2023, Vienna

15:00 – 15:30 – session 3.2 – **Ambassadorship part 2** (Hannah Gsell & Senior Ambassadors)

- Onboarding to the Network
 - **How do I (as Ambassador) onboard new people to the network?**
 - **Tools for onboarding new people**

15:30 – 15:45 **Coffee Break 1**

15:45 – 17:15 – session 4 – **Peer Support** (Carina Schneider & Senior Ambassadors)

- What is Peer Support? Different needs and ways to receive / give peer support
 - Face-to-face / on-site peer support
 - peer support in EU-CAYAS-NET
- Safeguarding measures
- Draw on existing experience and expertise

17:15 – 17:30 – **Wrap up and goodbye**



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EU-CAYAS-NET Ambassador Training 2, 24th & 25th Nov. 2023, Vienna

Poster Presentation

As part of the Patient Advocacy Training, we cordially invite you to submit a poster about an advocacy project, an initiative you put forward in your country/region or any other opportunity that you have been working on to advocate in the area of CAYA cancer.

We are looking for best practice examples that will be presented to show the great wealth of patient advocacy going on in our countries during the patient advocacy market place session on **Saturday, 25th November, 10:00am - 11:00 am.**

Topics can include awareness initiatives, policy events, round table discussions, media appearances and audio-visual campaigns etc. which you have been or will be part of. The sky is the limit 😊 If you are not sure if your topic fits, don't hesitate to ask us!

Procedure:

- During this session you will stand with your poster, while the other participants will be divided into small groups that will walk from poster to poster at 5-10 minute intervals (depending on how many posters are submitted).
- We therefore ask you to limit the content of your poster to the essentials so that it can be explained in a maximum of 5 minutes and there is time for questions and answers.
- All Ambassadors receive a template. In case you would like to submit a poster, please fill in the template by **MONDAY, 20th November 9am CET** and send it to ambassador@beatcancer.eu. CCI Europe will then print your poster and bring it to the event.

Please note that submissions after the deadline can no longer be considered.

We would be delighted to receive numerous submissions!



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b. 6.2 Appendix 2 - Lithuanian Policy Event



Policy event
"Transition of Care from Pediatric to Adults"

AGENDA

Time	Topic	Speaker
09:00 - 09:30	Registration	
09:30 - 09:40	Opening words	Monika Gėmionakienė , Chairman of the Commission for People with Disabilities, Member of Parliament
09:40 - 10:00	Introduction to the EU-CAYAS-NET Project: Topics, Deliverables, and FCSA's Role	Neringa Čiokienė , Director of Lithuanian Cancer Patient Coalition
10:10 - 10:30	Europe's Beating Cancer Plan and Mission on Cancer: A Comprehensive Overview	Laura Pėkleienė , Research Council of Lithuania, National Contact Point
10:30 - 10:50	EU level Recommendations on Equality, Diversity and Inclusion	Katie Rizvi , Founder and Executive Director of Youth Cancer Europe
10:50 - 11:10	EU-CAYAS-NET approach to improve Quality of life	Carina Schneider , Managing Director of Childhood Cancer International Europe
11:10 - 11:40	Coffee Break	



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Policy event
"Transition of Care from Pediatric to Adults"

Time	Topic	Speaker
11:40 – 12:10	EU-CAYAS-NET's Recommendations for Best Transition from Pediatric to Adult Care	<p>Jilke Wama, PhD Candidate at Prinses Máxima Centrum</p> <p>Joop den Hartogh, Project Lead at Prinses Máxima Centrum</p>
12:10 – 13:40	Transition of Care from Pediatric to Adults: A Panel Discussion	<p>Moderator: Sarūnas Narbutas, Founder and Chairman of Youth Cancer Europe</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Andželika Balčiūnienė, Advisor at Specialized Health Care Division, Personal Health Care Department, Ministry of Health of the Republic • Jelena Bascon, Head of the Centre for Paediatric Oncology and Haematology at Vilnius University Hospital Santaros Klinikos, Children's Hospital • Giedrė Rutkauskienė, Head of the Paediatric Oncology and Haematology Centre at the Hospital of Lithuanian University of Health Sciences Kauno Klinikos • Birutė Brašiūnienė, Head of Chemotherapy Department, National Cancer Institute, Member of ESMO Practising Oncologists Working Group (POWG) • Emilija Gimžauskaitė - Česlevičienė, Aušrinė Kevalaitė, EU-CAYAS-NET Ambassadors
13:40 – 13:50	Vilnius Declaration Signing	
13:50 – 14:00	Closing words	<p>▾ Monika Čiūmionaitienė, Chairman of the Commission for People with Disabilities, Member of Parliament</p> <p>Merina Čiūkienė, Managing Director of Lithuanian Cancer Patient Coalition</p>



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c. 6.3 Appendix 3 - Spanish Policy Event

European Network of YOUTH CANCER SURVIVORS		Policy event Seguimiento a largo plazo de jóvenes supervivientes de cáncer del desarrollo
Hora	Tema	Ponente/s
09:30 – 10:00	Registro y acreditación	
10:00 – 10:15	Bienvenida Institucional	Dr. Joan Comella – Director de Investigación, Innovación y Docencia, Hospital Sant Joan de Déu Sra. Luisa Basset – Federación Española de Padres de Niños con Cáncer Dr. Luis Madero – Sociedad Española de Hematología y Oncología Pediátricas
10:15 – 10:30	El/la superviviente: una visión transversal	Dr. Andrés Morales – Chief Medical Officer, Pediatric Cancer Center Barcelona- HSJD
10:30 – 11:00	EU-CAYAS.net Introducción, resultados, conclusiones	Begonya Nafria , Coordinadora, Área de Participación del Paciente en Investigación, FSJD
11:00 – 11:30	Mi experiencia, nuestra realidad	MODERADORA: Dra. Isabel Rabella, • Juan Martínez – Superviviente, Asociación Galban, Asturias • Pablo Huidobro – Superviviente Asociación Faro, La Rioja • Daniel Marín – Superviviente, KIDS Barcelona • Sergio Torres – Superviviente, Pulseras Candela
11:30 – 11:50	Seguimiento a largo plazo. Modelos y perspectivas	Dra. Ana Carolina Izurieta Pacheco – Oncóloga, Unidad de Supervivientes, Pediatric Cancer Center Barcelona- HSJD Dra. María Teresa Tormo – Oncóloga, Hospital la Fe de Valencia
11:50 – 12:10	Pausa- Café	
12:10 – 12:30	La Atención Psicosocial en el seguimiento a largo plazo; un panel para la reflexión	MODERADOR: Daniel Toro – Psicólogo, HSJD • Marta Pérez – Psicóloga, HSJD • Irene Cervera Morales – Psicóloga, Aspanion • Sonia Simón – Superviviente, Caminantes – Aspanion, Comunidad Valenciana



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European Network of  YOUTH CANCER SURVIVORS		Policy event Seguimiento a largo plazo de jóvenes supervivientes de cáncer del desarrollo
12:30 – 12:50	Políticas Sociales. Formación, sensibilización e integración	Montse Metilkovez Castillo – Trabajadora Social, ICO Badalona Tania González Sanchis – Trabajadora Social, HSJD Laura Mora - Superviviente, Caminantes-Aspanion, Comunidad Valenciana Javier Hortal - Asion –Asociación Infantil Oncológica de Madrid
12:50 –13:10	La importancia de una buena transición	Marí Carmen Molero – Gestora de Pacientes, Unidad de Supervivientes, PCCB- HSJD Dra. Julia Balaguer - Hospital La Fe de Valencia Pau Belmonte – Superviviente
13:10 – 13:30	Hábitos de salud y salud medioambiental	Moderadora: Dra. Elena Codina – Pediatra- Unidad de Medicina Ambiental, HSJD <ul style="list-style-type: none"> • Dra. Esther Martínez – Pediatra, Unidad de Medicina Integrativa, HSJD • Dr. Juan Antonio Ortega – Pediatric Environmental Health Speciality Unit – Hospital Clinico Universitario Virgen Arrixaca (Murcia)
13:30 – 14:30	Pausa- Almuerzo	
14:30 – 15:45	Declaración de Barcelona	Sesión práctica de trabajo en grupos
15:45-16:00	Cierre de la Jornada	Dr. Andrés Morales – Chief Medical Officer, Pediatric Cancer Center Barcelona- HSJD Sra. Luisa Basset - Federación Española de Padres de Niños con Cáncer Dra. Ana Carolina Izurieta Pacheco – Oncóloga, Unidad de Supervivientes, Pediatric Cancer Center Barcelona- HSJD



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d. 6.4 Appendix 4 - Sarajevo Event



BRINEM O SEBI, VOLIM SEBE



SRCE ZA DJECU



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REGIONALNA KONVENCIJA MLADIH IZLIJEČENIH OD RAKA



DAN 1

UTORAK, 8.8.

- 13:00 - 14:00 - okupljanje u hotelu Courtyard by Marriott Sarajevo, pozdravljanje i upoznavanjem sa planom konvencije
- 14:30 - ručak u hotelu
- 17:00 - okupljanje za otvaranje konvencije:
 - Predstavljanje domaćina (Udruženje Srce za djecu), CCI Europe i sponzora konvencije
 - Predstavljanje gostiju
 - Predstavljanje učesnika (meet and greet)
 - Radionica "Šta ima" (predstavljanje problema/rješenja kojemladice imaju sa follow up)
- 19:00 - večera u hotelu
- 20-21:30 - Zabavno/edukativni program (kviz Nisam ti pametan) 1:30 h
- Slobodno vrijeme



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REGIONALNA KONVENCIJA MLADIH IZLIJEČENIH OD RAKA



DAN 2

SRIJEDA, 9.8.

- do 9:00 - doručak
- 9:45 - odlazak na piramide
- 10:45 - obilazak parka ravne sa Osmanagićem i kafe pauza
- 13:30 - ručak
- Prikazivanje filma Heroj
- 19:00 - večera u hotelu

DAN 3

ČETVRTAK, 10.8.

- do 10:00 - doručak
- Obilazak Sarajeva (agencija insajder-kombinovana tura)
- 19:00 - večera na tabiji
- Slobodno vrijeme



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REGIONALNA KONVENCIJA MLADIH IZLIJEČENIH OD RAKA



DAN 4

PETAK, 11.8.

- do 9:00 - doručak
- 9:30 - 11:00 - Radionica sa Dr. Lornom
- 11:15 (dolazak u 12:30) - polazak na Javorov do
- Avanturističko /sportska aktivnost (šetanje, zabavne igre)
- Ručak
- Motivaciona radionica Ina i Sabina
- Pisanje pisama
- Rimska diskusija na balkanski način sa doktoricama (integriranje follow up programa u tvoju sredinu)
- 19:00 - večera u hotelu
- SFF zatvaranje konvencije

DAN 5

SUBOTA, 12.8.

- doručak i igramo se razlaza



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BRINEM O SEBI, VOLIM SEBE

HVALA I VIDIMO SE SLJEDEĆE GODINE!

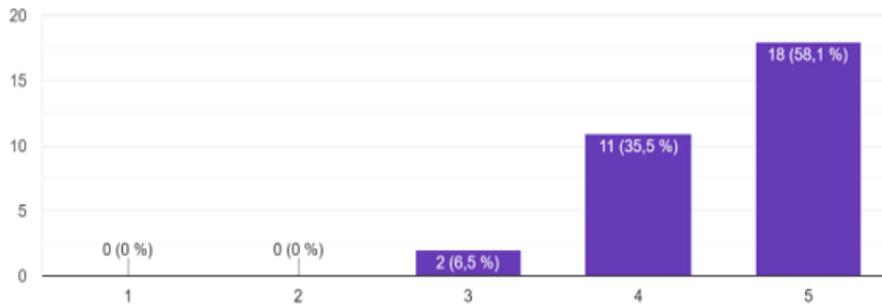


e. 6.5 Appendix 5 - Zagreb Regional Event

How would they rate the Convention as a whole?

Koju biste ocjenu dali cjelokupnoj Konvenciji?

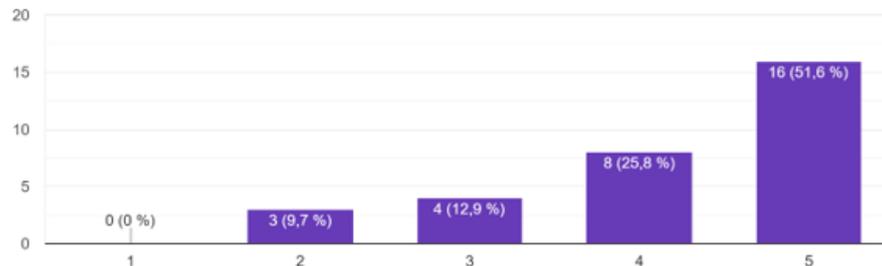
31 odgovor



How satisfied were they with connecting with other survivors and networking activities?

Koliko si zadovoljan/na igrama za upoznavanje i međusobno povezivanje?

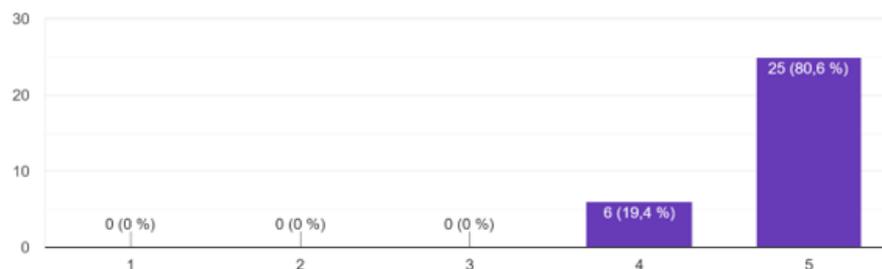
31 odgovor



How satisfied were they with the group works and discussions on the topic of survivors problems?

Koliko si zadovoljan/na grupnim radovima i diskusijama na temu problema mladih?

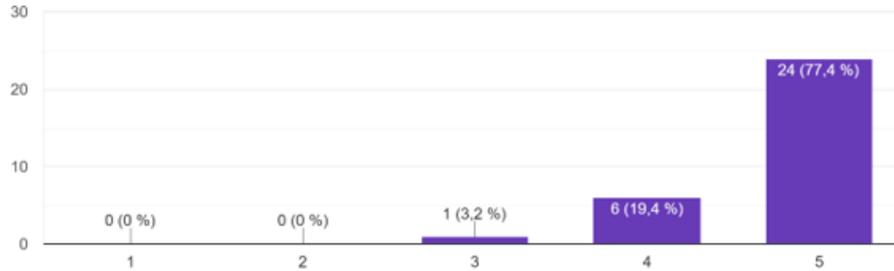
31 odgovor



How much did they benefit from sharing the experience among the participants of the convention?

Koliko ti je koristilo dijeljenje iskustva među sudionicima konvencije?

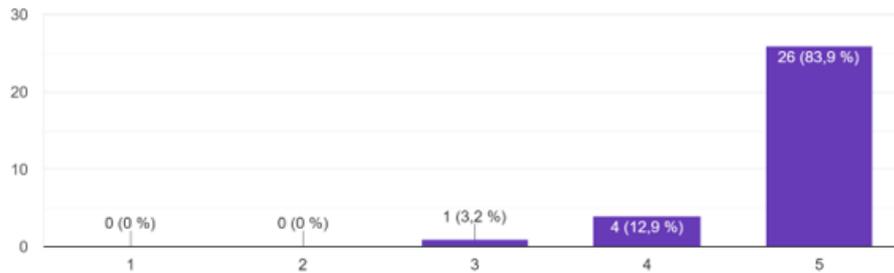
31 odgovor



How useful was the discussion about the transition from the pediatric oncology department to the adult department?

Koliko ti je koristila diskusija o tranziciji s pedijatrijskog onkološkog odjela na odjel za odrasle?

31 odgovor



f. 6.6 Appendix 6 - Closing Event

Programme overview

07
 Wednesday

08:00 and all day | Arrivals

14:00 and all day | Registrations at the XXI Dormitory of the Sport University campus

20:00 | Networking dinner at Boema House

08
 Thursday

08:00 | Breakfast available at campus (main lobby, registration area)

09:30 | General Assembly Meeting (Hybrid Set-Up) (see map for reaching the Conference Hall)

13:00 | Lunch served at the Conference Hall

14:00 | Interactive workshops for all participants -

Workshop 1 In the focus: Adolescent and Young Adult Cancer Care and EDI: ensuring Equity, Diversity, and Inclusion in Cancer Care

16:00 | **Group photo on campus** (If you're not in the picture, you were not here. 😊 Make sure you don't miss it!)

Dinner at the UNTOLD Festival grounds

20:30 | UNTOLD group photo (exact location to be confirmed)

UNTOLD Meet & Greet for selected participants with Blasterjazz (timing TBC)

09
 Friday

09:00 - 11:00 | Breakfast available at campus

13:00 | Lunch served at Conference Hall

14:00 | Interactive workshops for all participants -

Workshop 2 In the focus: Position paper "Mental Health & Psychosocial Care after CAYA cancer - Standard, not luxury" / Education and Career Support

Dinner at the UNTOLD Festival grounds

UNTOLD Meet & Greet for selected participants with ALOK (timing TBC)

UNTOLD Meet & Greet for selected participants with Dimitri Vegas & Like Mike (timing TBC)

UNTOLD Meet & Greet for selected participants with Lost Frequencies (timing TBC)

UNTOLD Meet & Greet for selected participants with Zerb (timing TBC)

10
Saturday

09:00 – 11:00 | Breakfast available at campus

13:00 | Lunch served at Conference Hall

14:00 | Interactive workshops for all participants -

Workshop 3 In the focus: long term follow-up care after cancer /
Recommendations for Transition from Paediatric to Adult Cancer Care
Dinner at the UNTOLD Festival grounds

UNTOLD Meet & Greet for selected participants with Tujamo (03:00 am)

UNTOLD Meet & Greet for selected participants with Sam Smith (timing
TBC)

11
Sunday

09:00 – 11:00 | Breakfast available at campus

13:00 | Lunch served at Conference Hall

14:00 | Interactive workshops for all participants -

Workshop 4 Sustainability: Creating an action plan for the sustainability
of beatcancer.eu + FB + instagram + youtube + discord after the end of
the project

Dinner at the UNTOLD Festival grounds

UNTOLD Meet & Greet for selected participants with Martin Garrix (01:00
am)

UNTOLD Meet & Greet for selected participants with Nicky Romero (02:30
am)

12
Monday

09:00 – 11:00 | Breakfast available at campus

12:00 | Departures

g. **6.7 Appendix 7 - Dissemination Activities**

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
6th Global AYA Cancer Congress, Melbourne, AU	Conferences	Research Citizens, Industry, National Specific end user Local Regional Civil society	communities, business partners, authorities, authorities, authorities,	Task 6.4, YCE presentation of EU-CAYAS-NET to inform international community about project's results.	Delivered
Symposium on participatory research, 2024	Meetings	Research Citizens, Specific end user Local Regional Civil society	communities, authorities, authorities,	Task 6.4 - EU-CAYAS-NET presented as an example of successful example of study participants actively participating in the research process (April 2024).	Delivered
EDI, AYA Pocket Cards - EDI Training Event	Education and training events	Citizens, Specific end user Civil society		Task 6.4, EDI, AYA Pocket Cards were distributed at the EDI Training Event hosted in Timisoara, Romania	Delivered
Presentation at ESMO Meeting (2024)	Conferences	Research EU Industry, Specific end user	communities, Institutions, business partners, communities	Task 6.4 Presentation of EDI and AYA recommendations (ESMO meeting attracted global audience of 34,000 participants, clinicians, researchers, patient advocates, journalists, global healthcare leaders)	Delivered
Item on eQuoL project website	Other	Citizens, Specific end user Civil society		Task 6.4, To raise awareness of and promote the EDI Policy Paper from EU-CAYAS-NET	Delivered

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
Pediatric Neurooncology Science Slam 2024	Meetings	Research communities		Task 6.4, EU-CAYAS-NET results from WP3 were shared and Pocket Cards were distributed.	Delivered
56th SIOP Congress/30th CCI Conference	Conferences	Research communities, Citizens, National Specific end user communities, Innovators, Civil society	communities, authorities,	EU-CAYAS-NET was presented at 56th Annual SIOP Congress/30th CCI Annual International Conference (Oct 2024, Honolulu, USA)	Delivered
Presentation at conference (psychosocial), 2024	Conferences	Research Specific end user communities, Local Civil society	communities, authorities,	Task 6.4 Presentation, Psychosocial care for children and adolescents, Special needs and support regarding psychosocial health for children and adolescents (Apr 2024)	Delivered
Onkologiebeirat Austria	Meetings	Specific end user communities		EU-CAYAS-NET was presented at Onkologiebeirat Austria March 2025, Vienna	Delivered
Presentation at SIOP-E AYA Course 2023	Education and training events	Research Specific end user communities	communities,	Task 6.4 - Presentation at SIOP-E AYA Course (Sep 2023) - Psychosocial issues for adolescent and young adult cancer patients/survivors. Interdisciplinary audience (psychology, medicine, social work)	Delivered
Presentation, EU4H Integration & Impact Conference	Collaboration with EU-funded projects	Research EU Citizens, National Specific end user communities, Local Regional Civil society	communities, Institutions, authorities,	Task 6.4 Quality of Life results presented by CCI Europe and MUW at the Integration and Impact Initiative for Health Conference (organised by EU4Health Integration and Impact Initiative), Dec 2024	Delivered

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
EDI, AYA Pocket Cards - Youth Policy Dialogue	Meetings	EU National Specific end user communities, Local Regional authorities	Institutions, authorities, communities, authorities, authorities	Task 6.4, Presentation of EDI and AYA Pocket Cards at the Youth Policy Dialogue with EU Commissioner for Health and Animal Welfare, Oliver Várhelyi	Delivered
Austrotransplant meeting	Meetings	National Specific end user communities	authorities, communities	EU-CAYAS-NET was presented at the Austrotransplant meeting in Oct 2024, Salzburg, Austria	Delivered
Presentation at PanCare meeting 2024	Meetings	Research Citizens, National Specific end user communities, Local Regional Civil society	communities, authorities, authorities, authorities, society	Task 6.4 Presentation of Transition Guideline developed under EU-CAYAS-NET by PMC and update from EU-CAYAS-NET by PanCare at the 30th PanCare meeting (Sep 2024)	Delivered
Training at MUW paediatric clinic, 2024	Education and training events	Research Specific end user communities	communities, communities	Task 6.4 - Presentation of the project/network to all those who work at the paediatric clinic of the Medical University Vienna (including psychologists, medicals, social workers, scientists).	Delivered
Austrian Mission Action Group Cancer Meeting	Meetings	National Specific end user communities	authorities, communities	EU-CAYAS-NET was presented at the Austrian Mission Action Group Cancer Meeting Dec 2024, Vienna, Austria	Delivered
EDI, AYA Pocket Cards at HaDEA Project Showcase	Meetings	EU Specific end user communities	Institutions, communities	Task 6.4, AYA and EDI Pocket Cards disseminated at HaDEA project showcase	Delivered
Training on Participatory Research, 2024	Education and training events	Research Specific end user communities	communities, communities	Task 6.4 - EU-CAYAS-NET presented as an good example of participatory research to all psychologists and scientists of the Medical University Vienna (April 2024).	Delivered

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
15th CCI Europe Conference	Conferences	Research Citizens, National Specific end user Regional Civil society	communities, authorities, communities, authorities,	Task 6.4, EU-CAYAS-NET was featured as a Project in the Spotlight and hosted a session '34 months of EU-CAYAS-NET: Showcasing outcomes to improve Quality of Life for CAYA Cancer Survivors'	Delivered
Panel discussion, World Cancer Day 2025	Meetings	Research EU Citizens, National Specific end user Local Regional Civil society	communities, Institutions, authorities, communities, authorities, authorities,	Task 6.4 - CCI Europe participated in panel discussion at World Cancer Day 2025: HaDEA project showcase, 04 Feb 2025 (Reducing inequalities and improving quality of life of cancer patients, survivors)	Delivered
Youth Policy Dialogue with Commissioner Oliver	Meetings	EU Citizens, Specific end user Civil society	Institutions, communities,	Task 6.4, Cancer survivors met with European Commissioner Olivér Várhelyi to discuss how EU health policies can better support patients on World Cancer Day 2025.	Delivered
EU4Health Integration and Impact Initiative - 2024	Meetings	Research EU Citizens, Specific end user Civil society	communities, Institutions, communities,	Task 6.4, CCI Europe and MUW participated in the session 'Quality of life of Pediatric Cancer Survivors'	Delivered
e-QuoL e-mail	Collaboration with EU-funded projects	Research Specific end user	communities, communities	Task 6.4, E-QuoL sent an email to their consortium partners where they mentioned EU-CAYAS-NET, incl. link to eQuoL website where they disseminated EU-CAYAS-NET.	Delivered
Prinses Maxima Research Meeting	Meetings	Research	communities	Results of work to develop a guideline on transition (WP3) presented to the PMC research community	Delivered

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
EDI Policy Paper on Oncodaily blog	Other	Citizens, Civil society		Task 6.4, To raise awareness and promote the EDI Policy Paper; Article can be found here - https://oncodaily.com/insight/98087	Delivered
EDI items on partner channels	Other	Research, Citizens, Specific end user communities, Civil society	communities,	Task 6.4, CCI Europe, SIOE Europe featured EDI recommendations, events on their websites, social media channels	Delivered
MELODIC GA Meeting	Meetings	Research, Industry, Specific end user communities	communities, business partners,	Task 6.4, EU-CAYAS-NET was presented at the MELODIC project General Assembly Meeting	Delivered
EDI, AYA Pocket Cards - AIOM/AIEOP WG	Conferences	Industry, Specific end user communities	business partners,	Task 6.4, EDI, AYA Pocket Cards presented at the AIOM/AIEOP Working Group	Delivered
Article on europa-uomo.org	Other	Citizens		Task 6.4, Article raised awareness about the EDI Train-the-Trainer Toolkit and recommendations for EDI Cancer Care from Policy Paper.	Delivered
5 Ways to Reduce Cancer Care Inequalities, Europe	Meetings	EU, Industry, National authorities	Institutions, business partners,	Task 6.4, Call to Action: 5 Ways to Reduce Cancer Care Inequalities in Europe by Cancer Patients Europe - CPE at a high-level event at the European Parliament hosted by MEP Tomislav Sokol.	Delivered
Presentation at ÖPSAPOH meeting, 2024	Meetings	Research communities		Task 6.4 Presentation (17 Apr 2024) of awareness materials (MH pocket cards) at the networking meeting of supporting organisations for employees in the psychosocial field in Austria.	Delivered
MELODIC LinkedIn post, EDI webinar	Other	Citizens, Specific end user communities, Civil society		Task 6.4, Promote the EDI Webinar; Post can be found here - https://www.linkedin.com/posts/melodiceu_webinar-when-circumstances-decide-socioeconomic-activity	Delivered
OncoDaily blog posts	Other	Citizens, Specific end user communities, Civil society		Task 6.4, Three OncoDaily blog posts to promote EDI webinar (oncodaily.com/blog/youth-cancer-europe-272818 , oncodaily.com/blog/carmen-monge-montero291274 , oncodaily.com/blog/april-dorenbosch-291475)	Delivered

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
Austrian Society, Pediatrics & Adolescent Medicine	Meetings	Research Specific end user communities, Local authorities	communities,	Task 6.4, Presentation at Austrian Society for Pediatrics and Adolescent Medicine meeting, Mental Health and Psychosocial Care results from EU-CAYAS-NET (Oct 2024)	Delivered
5th National Scientific Forum, Romanian Y. Oncol.	Meetings	Specific end user communities		Task 6.4, YCE shared EU-CAYAS-NET results at the Adolescent and Young Adult session at the 5th National Scientific Forum of the Romanian Young Oncologists	Delivered
MELODIC website news item	Other	Citizens, Specific end user communities, Civil society		Task 6.4, Blog on MELODIC project website about project Webinar: "When Circumstances Decide: Socioeconomic Status and Cancer Inequities in Europe"	Delivered
Presentation at 3rd Vienna Pediatric Brain Tumor..	Conferences	Research National Specific end user communities, Local Regional Civil society	communities, authorities, authorities,	Task 6.4 'PanCare PLAIN language summaries for childhood, adolescent and young adult cancer survivors...' and 'EU-CAYAS NET - A European network of young people with...' (18-19 Apr 2024)	Delivered
Presentation at SIOP-E/CCI-E conference	Conferences	Research Specific end user communities	communities,	Task 6.4 - dissemination of results at conferences/meetings 'EUCAYAS-NET: Sneak Peak on Education and Career Support Outcomes' presented at 4th Annual SIOP-E meeting, in partnership with CCI-E	Delivered
Presentation at PanCare Annual Meeting, Ghent	Conferences	Research Specific end user communities	communities,	Task 6.4 - oral presentation by PMC of the structure, aims, benefits and outcomes of Peer Visits organised on long-term follow-up and transition (WP3)	Delivered
PNO Science Slam	Meetings	Research communities		Task 6.4 Dissemination - Science Slam within the <UW paediatric neuro-oncology team to provide information about ongoing projects and research	Delivered
Presentation of network, survivor video premiere	Meetings	Research Specific end user communities	communities,	Task 6.4 - oral presentation for dissemination of EU-CAYAS-NET at survivor video premiere event at PMC	Delivered

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
Presentation, CCI Europe/SIOP Europe meeting 2024	Conferences	Research Citizens, National Specific end user Local Regional Civil society	communities, authorities, communities, authorities, authorities,	Task 6.4 'EU-CAYAS-NET, Project in the Spotlight', Session: 'Accelerating Patient & Public Involvement and engagement: Easy as p(p)ie!', 'EU-CAYAS-NET in Improving quality of survivorship' (May 2024)	Delivered
Joint Action on European Networks of Expertise	Collaboration with EU-funded projects	Research EU Citizens, Industry, National Specific end user Civil society	communities, Institutions, business partners, authorities, communities,	Task 6.4 - dissemination EU-CAYAS-NET representative attended Joint Action on European Networks of Expertise (JANE) meetings (19 Jan 2023, 16 Feb 2023, 26 Apr 2023); one network domain is survivorship	Delivered
Strong AYA meetings	Collaboration with EU-funded projects	Research EU Citizens, National Specific end user Civil society	communities, Institutions, authorities, communities,	Task 6.4 - dissemination Strong AYA (GA No 101057482) meetings organised to harmonise activities in the AYA area to avoid overlap and duplication	Delivered
Presentation at 'Cancer and Family Planning'	Meetings	Research EU Industry, National Specific end user	communities, Institutions, business partners, authorities, communities	Task 6.4 Findings of patient-led research & advocacy work in area of AYA and fertility presented at 'Cancer and Family Planning' meeting in European Parliament, 28 Feb 2023	Delivered

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
Updates at ENTYAC meetings	Meetings	National Local Regional Civil society	authorities, authorities, authorities,	Task 6.4 Updates re: EU-CAYAS-NET progress and exploration of collaboration in AYA care at European Network of Teenage and Young Adult Cancer ENTYAC meetings 24 Nov 2022, 16 Feb 2023. 27 Mar 202	Delivered
SmartCare Kick-off	Collaboration with EU-funded projects	Research EU Citizens, Industry, business partners, National Specific end user communities, Civil society	communities, Institutions, National authorities, Specific end user communities, Civil society	Task 6.4 - dissemination EU-CAYAS-NET presented at kick-off meeting of EU4H SmartCare project in European Parliament, 28 Mar 2023	Delivered
Presentation at OAC Connect Us meeting	Collaboration with EU-funded projects	Research Citizens, Specific end user communities	communities,	Task 6.4 EU-CAYAS-NET was presented at OAC Connect Us meeting 30 Mar 2023; collaborative links established between the two survivor networks	Delivered
Presentation at 4th Annual SIOP-E Meeting	Conferences	Research National Specific end user communities, Regional authorities	communities, authorities,	Task 6.4 - Presentation 'Survivorship after a Brain Tumor' (May 2024) at 4th Annual SIOP-E Meeting	Delivered
Presentation at national event, LT, Apr 2024	Meetings	Citizens, Specific end user communities		Task 6.4 - Presentation of EU-CAYAS-NET results at Lithuanian young cancer survivors association "Onkojaunimas" ("Onkoyouth") (20 Apr 2024)	Delivered

Dissemination Activity Name	What? Type of dissemination activity	Who? Reached	Target audience	Why? Description of the objective(s) with reference to a specific project output	Status of the dissemination activity
World Cancer Day 2025: HaDEA project showcase	Meetings	Research EU Citizens, Local, National, Regional authorities, Specific end user communities, Innovators, Civil society	communities, Institutions, Regional	Task 6.4, CCI Europe and YCE represented EU-CAYAS-NET at the World Cancer Day 2025: HaDEA project showcase 'Fostering synergies to beat cancer: The impact of EU-funded projects'	Delivered
Presentation at national event, RO, Jun 2024	Meetings	Citizens, National Specific end user communities, Civil society	authorities, Regional	Task 6.4 Presentation of AYA recommendations at Romanian National Day of Cancer Survivors (01 June 2024)	Delivered
Presentations at SIOP Europe Summer School 2024	Education and training events	Research Specific end user communities	communities, Specific end user communities	Task 6.4 - SIOP Europe Summer School in Paediatric Haematology and Oncology (Jul 2024), 'Interactive sessions: Patient and parent communication'	Delivered