

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

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*EU4Health Programme*

## **Sustainability Strategy, including Evaluation Report**

Deliverable No: D6.3

WP: WP6

Task: Task 6.7 Sustainability planning



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## Version History

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Full Name	Short Name	Number	Role
CHILDHOOD CANCER INTERNATIONAL	CCI Europe	1	Coordinator
FUNDATIA YOUTH CANCER EUROPE	YCE	2	Beneficiary
SIOP EUROPE	SIOPE	3	Beneficiary
PANCARE	PANCARE	4	Beneficiary
PRINSES MAXIMA CENTRUM VOOR KINDERONCOLOGIE BV	PMC	5	Beneficiary
PAGALBOS ONKOLOGINIAMS LIGONIAMS ASOCIACIJA	POLA	6	Beneficiary
FUNDACIO PRIVADA PER A LA RECERCA I LA DOCENCIA SANT JOAN DE DEU	FSJD	7	Beneficiary
HOSPITAL SANT JOAN DE DEU	HSJD	7.1	Affiliated Entity
MEDIZINISCHE UNIVERSITAET WIEN	MUW	8	Beneficiary
PINTAIL LTD	PT	9	Beneficiary
SURVIVORS ÖSTERREICH - KINDER-KREBS-ÜBERLEBENDEN-INITIATIVE	SurvivorsAT	10	Associated Partner
Fondation d'Utilité Publique KickCancer	KickCancer	11	Associated Partner
Assosiation Heart for children with cancer	AHCC	14	Associated Partner
ASSOCIATION CHILDREN WITH ONCOHEMATOLOGIC DISEASES	ACOD	15	Associated Partner
Krijesnica - udruuga za pomoc djeci i obiteljima suocenim s malignim bolestima	Krijesnica	16	Associated Partner
Spolecne k usmevu, z.s.	SkU	17	Associated Partner
FAKULTNI NEMOCNICE U SV. ANNY V BRNE	ICRC	18	Associated Partner
DEUTSCHE KINDERKREBSSTIFTUNG DER DEUTSCHE LEUKAMIE-FORSCHUNGSHILFE AKTION FÜR KREBSKRANKE KINDER E.V. STIFTUNG	DLFH/DKS	19	Associated Partner

NGO KARKINAKI AWARENESS FOR CHILDHOOD AND ADOLESCENT CANCER	KARKINAKI	20	Associated Partner
YouCan Cancer Support Network Ireland CLG	YouCan	21	Associated Partner
CanTeen Ireland	CanTeen Ireland	23	Associated Partner
FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI	INT	24	Associated Partner
Vereniging Kinderkanker Nederland	VKN	25	Associated Partner
Fundacja Pani Ani	FPA	26	Associated Partner
Asociatia Obsteasca Filiala din Republica Moldova a Asociatiei Little People Romania	ALPMD	27	Associated Partner
Asociatia Little People Romania	Little People	28	Associated Partner
ASSOCIATION OF CHILDHOOD CANCER PARENT, GUARDIAN, CHILDREN AND FRIENDS Chika Boca	CB&MladiCe	29	Associated Partner
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Federación Española de Padres de Niños con Cáncer	FEPNC	31	Associated Partner
SMILE n.o.	SMILE	32	Associated Partner
Detom s rakovinou, n. o	DR	33	Associated Partner
Foundation Little knight	LITTLEKNIGHT_SI	34	Associated Partner
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ACREDITAR - Associação de pais e amigos de crianças com cancro	ACREDITAR	38	Associated Partner
EUROPEAN ONCOLOGY NURSING SOCIETY	EONS	39	Associated Partner
Fondatioun Kriibskrank Kanner	Fondatioun.lu	41	Associated Partner
Sano	Sano	42	Associated Partner
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 D6.3 ‘Sustainability Strategy, including Evaluation Report’ details the sustainability planning exercises carried out during the project and presents the Sustainability Strategy for the European Network of Youth Cancer Survivors. It also includes an evaluation of the events and other elements of the project, with a view to ensuring continuous growth and improvement of the network’s activities based on learnings from the network operation.

During the project, network members focused on activities across three main project themes identified as priorities by young cancer survivors themselves (Quality of Life, Adolescent and Young Adult (AYA) Care and Equality (Equity), Diversity and Inclusion (EDI)<sup>1</sup>). The Sustainability Strategy of the network seeks to ensure that the expected impacts of the project are achieved by continued dissemination of project results, as well as to set the stage for future activities to continue advancing the targeted actions and initiatives created during the project, necessary to benefit the quality of life of young cancer survivors. The strategy also lays out how the community created during the EU-CAYAS-NET project will be sustained into the future, under various potential levels of funding. Finally, future activities in new areas to further improve the lives of young cancer survivors are detailed, which build on the work carried out to date in this project and in other national and European initiatives.

## 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 focuses 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.

Work described in this report demonstrates how the Network has achieved the project objective to plan for sustainability of the Network and Platform post-project. This report describes the sustainability planning exercises carried out during the project and presents the Sustainability Strategy for the European Network of Youth Cancer Survivors. It also includes an evaluation of the events and other elements of the project, with a view to ensuring continuous growth and improvement of the network’s activities based on learnings from the network operation.

## 3 Approach

Sustainability planning has been a core activity of the network under WP6, led by CCI Europe and Youth Cancer Europe, the two major umbrella organisations representing young cancer survivors across Europe. CCI Europe is a survivor and parent organisation for childhood and adolescent cancer uniting 66 member organisations in 33 European countries, and with international links to Childhood Cancer International (CCI), who represent member organisations from 93 countries globally. Youth Cancer Europe is a pan-European patient organisation representing survivors of cancer aged 18 – 39 from 31

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<sup>1</sup> 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.

European countries, with strong international links to Jovenes Contra el Cancer representing 11 Latin American countries, Stupid Cancer in the US and Canteen in Australia.

The main activities undertaken to develop the Sustainability Strategy under WP6 included the following:

- CCI Europe and Youth Cancer Europe facilitated two sustainability workshops during the project (M13, M19) during plenary meetings, where Beneficiaries and Associated Partners were asked to provide their thoughts on the network outputs from EU-CAYAS-NET and the next steps needed to achieve maximum impact from the work carried out to date, future priority areas and what activities were essential to maintaining the vibrant and collaborative community built during the project. Beneficiaries and Associated Partners were also asked to identify any national public funding or private funding that could be leveraged to support the network in future. Consideration was also given to non-financial factors essential for sustainability, such as maintaining engagement and how to ensure continued use of outputs of the project (such as the training programmes developed).
- Costing exercises were undertaken, using costs from the project as a guide, to establish the financial resources that would be required to continue operation of the network and the Platform. Different scenarios with different resource levels were developed and shared at the Sustainability Workshops.
- Sustainability planning was also a regular agenda item on the Management Team meetings (WP1), where identification of future European and national opportunities for funding was a key activity.<sup>2</sup>

The outputs of the workshops were reviewed by CCI Europe and Youth Cancer Europe to develop the strategy, which was shared with all Beneficiaries and Associated Partners for feedback. The final version of the Sustainability Strategy is presented in this report. In addition, the Sustainability Strategy was launched publicly at the Closing Event in the final month of the project, where achievements of the project were celebrated.

Evaluation of network activities was an on-going process throughout the project, including tracking progress versus indicators in the Grant Agreement.

## 4 Results

### 4.1 Sustainability Workshop, M13

The first Sustainability Workshop was held during the virtual plenary meeting on 28 September 2023 (M13), which was open to all Beneficiaries and Associated Partners. The agenda for the session included the following sessions:

- Our Vision for the Network – what do we want the legacy of the project to be?,
- What is the Network currently? – how was it defined in the call text? how have we defined it in EU-CAYAS-NET? how do we want to define it after EU-CAYAS-NET?,
- Prioritisation Activity – what 3 – 5 activities would you like to see maintained? what 3 – 5 new activities would you like to see?,

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<sup>2</sup> For example, the call topic *CR-g-24-45 Call for proposals on EU Network of Youth Cancer Survivors* under the EU4Health programme was identified as a potential source of funding to continue operation and growth of the network.

- Break-out Sessions – to discuss results of Prioritisation Activity,
- Overview of 3 Potential Scenarios for the Platform – Maintain only, Maintain with some Extension, Maintain with Extension, and
- Recap and Closing.

#### 4.1.1 Our Vision for the Network

Key elements of legacy identified by participants included strengthening the patient advocacy voice of many CAYAs, building a strong Community/Network (with peer support, collaboration, friendship), acting to effect positive changes for the community (in care, mental health, etc.) and acting as a knowledge source for the community and other stakeholders (Knowledge Hub, with resources, on the Platform).

#### What do we want the legacy of the project to be?

Wordcloud Poll 97 responses 30 participants



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# Our VISION for the European Network of Youth Cancer Survivors



Wouldn't it be fantastic if the European Network of Youth Cancer Survivors in the next 5 years will....

Be a Europe-wide network with an international, community and resources

Continue to grow and reach more people

A permanent, well-known institution for all CAYA cancer survivors

Still exist, be even bigger

Still gather together

Continue to grow as a community

Be a network known by all AYA cancer survivors

The community is still alive and thriving, maybe with more in person events

Be a community of 10 000+ (patients / survivors / carers / HCPs)

Still exist! :D

Grow and still exist

Still growing and advocating for a better life for survivors in Europe

Have a long contact list of e-mails

Bring this to a global program. A CAYAs network on every continent! Like CCI

Would be remembered as a nice memory

but hopefully not only as a memory, but still going on!

We've made name as the network and that survivors are able to find us very easy. That we don't have to prove ourselves anymore!

Be a name that every major decision maker in EU level knows about

Be a reference in the CAYA cancer community (healthcare professionals, patients, survivors, patient organizations, etc.)

Achieve global recognition and support

Be a significant change and impact maker to influence policies and impact quality of life of survivors

Be an active player in EU advocacy events/topics

Network recommendations turned into actual health policies

Would have continuous high level funding by the EU

Provide representation & active Ambassadors across Europe (and beyond) who are actively involved on shaping the agenda on national & European level

Through the current outputs still continue to make an impact on European policy in 5 years...

Be a place where every survivor has a place and ability to contribute in terms of their strengths/talents

Give added & meaningful value to the CAYAs & their loved ones

Have kept the involvement of healthcare professionals

Help create and support strong national survivor groups

Continue with the support and involvement of parents, carers and families

Have regular (once a year) big happening / conference / with workshops & getting together & shaping the network further

Be a real resource for everyone and everything that is needed (knowledge, awareness, community, policy, care etc.)

Be a hub for cancer information understood by mass media

AYAs working in education in society: programs for universities and schools

Be the biggest hub for cancer related resources

Provide advocacy tools / sessions for AYA survivors and patient advocates

AYAs designing programs to implement in hospitals next to healthcare professionals

Be the first source of information for all those who want to learn

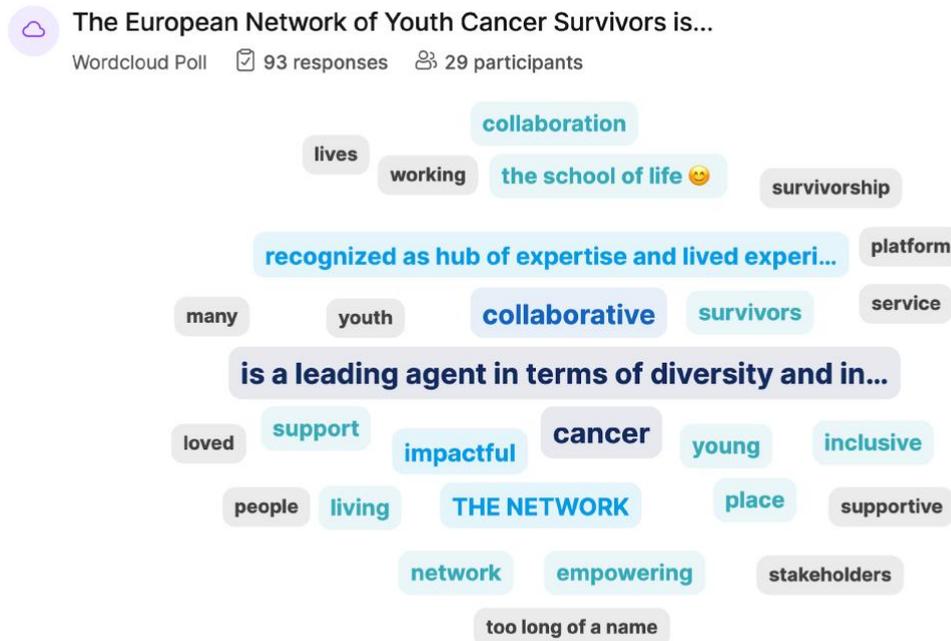
Still be a valuable resource for survivors, their supporters and health care professionals

Be a fixed point of contact for everyone and contact with a community and for healthcare professionals seeking patient representatives to be part of their work (e.g., care or research) by representing the needs of the community



#### 4.1.2 What is the Network?

Participants were keen to see the Network as a recognised hub of expertise and lived experience with an impactful Platform and network of people that supports and empowers all young cancer survivors, offers specific services that are useful and acts as a leading agent in terms of equity, diversity and inclusion.



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#### 4.1.3 Prioritisation

In terms of existing network activities, workshop participants wanted to see the following activities continue:

- **COMMUNITY/EVENTS** (including fun activities, such as gaming nights, etc.) to create a strong independent network of survivors that stay engaged and are empowered to become advocates for change,
- **PLATFORM** with Knowledge Hub (resources) that is kept lively and active (requiring some level of Platform management)
- **WEBINARS** to continue as an easy and sustainable way of information sharing and training,
- **EDUCATION/TRAINING**, and
- **PARTICIPATION IN RESEARCH**.

In terms of new activities, workshop participants wanted to see the following activities:

- **NETWORK APP**, combined with digital pass
- **PODCASTS** to complement webinars as a way to reach the community,
- **CONNECTION with other patient advocacy groups and networks** to find synergies (e.g. WECAN),

- **CONFERENCES** to see the Network incorporated in already existing conferences (SIOPE/CCI-E, PanCare, ESMO, ECCO) and to present EU-CAYAS-NET also outside of Europe, regular meetings with healthcare professionals,
- **TWINNING PROGRAMMES:** to increase the national and regional level of engagement (including in local languages), increase the number of interactive regional events and projects, and provide support in implementing the results from the project (ideally with a dedicated team from the network),
- **EDUCATION & SKILLS DEVELOPMENT** in Public Patient Involvement and Engagement (PPIE) for patient advocates to improve their advocacy skills (e.g. how to use ChatGPT/AI for patient advocacy, how to use tools like Canva, Miro etc., how to design to improve your publications, how to approach stakeholders, how to enlarge local outreach/strengthen your voice, how to do national patient advocacy, how to make your national survivors group work, etc.) and for healthcare professionals to better facilitate and deliver PPIE,
- **CANCER PREVENTION/LIFESTYLE** as a new theme for network activities,
- **PHARMA** as an untapped partner/stakeholder, and
- **JOB MARKET** with jobs that are survivors-inclusive e.g. from European patient advocate institutions, NGOs etc.

## 4.2 Sustainability Workshop, M19

The second Sustainability Workshop was held during the hybrid plenary meeting 11.- 12 March 2024 (M19), which was open to all Beneficiaries and Associated Partners. The agenda for the session included the following sessions:

- Bridging the funding gap (including discussion of future funding opportunities and how to keep the network active & visible post-project),
- Discussion (including break-out sessions) of how the Network can deliver on the three areas identified at the first Sustainability Workshop:
  - Realising the vision of the Network as the first source for cancer information, understandable by the lay public, as the biggest hub for cancer-related resources,
  - Maintaining the Network as a fixed point of contact for survivors seeking knowledge and contact with a community, and
  - Ensuring the Network is also a place for health care professionals seeking patient representatives to be part of their work.

### 4.2.1 Network as the first source for cancer information

The main outcomes of this breakout session are summarised below:

- Include the public into collecting resources for the Platform (form or similar where Platform visitors can submit resources),
- Include non-text information material (videos, podcasts, infographics) alongside text materials on the Platform,
- Keep information (resources) on the Platform up-to-date,
- Provide suggestions for visitors to related resources on the Platform,
- Identify topic specific resources from Discord,
- Develop and deliver education series (i.e. online course modules),
- Seek celebrity endorsements for the network (cold outreach to every A-level celebrity),

- Produce documentaries on cancer journeys/experiences (high-quality, long-form) to share via the Platform and network,
- Connect with national cancer organisations, support groups to generate a map/directory for the Platform,
- Funnel people to Discord and newsletter from the landing page of the Platform (collect emails and contact info),
- Create tags for target groups (healthcare professional, Survivors) and pre-validate the target group when they enter the resources page on the Platform, and
- Communication committee with all the Beneficiaries and encourage more engagement from Associated Partners.

#### **4.2.2 Maintaining the Network as a fixed point of contact for survivors**

The participants of this breakout session identified two main focal areas: Platform optimisation and social media communications. Specifically, they identified the following points of importance:

- **Optimise Platform and Discord for accessibility:**
  - Discord can be used to reduce the pressure on the Platform for communication.
  - Make easier to reach and more accessible – for example, reduce the number of channels on Discord so not overwhelming.
  - Foster sense of “you’re already in the group”.
  - Drive connection, support and community.
  - Explore how to connect offline community existing in regional communities to the network via Discord.
- **Make social media communication more attractive:**
  - Provide adjustable information, wording and messaging depending on the target audience.
  - Improve the ‘why’ on network messaging.
  - Deliver sessions on topics of interest to the community (e.g. sexuality, mental health).
  - Use social media take overs.
  - Collaborate more with healthcare institutions and professionals.

#### **4.2.3 Network also as a place for health care professionals**

For the participants in this breakout session, education was seen as key to change the mindsets of healthcare professionals with a view to changing the perception of survivors as recipients of services to collaborators. Improvements to PPIE were seen as a main goal following EU-CAYAS-NET. Key next steps were seen as below:

- First, identify and monitor what training is already out there (e.g. pilot training in PPIE).
- Accreditation is important for uptake and recognition. Include as stakeholders bodies that give certifications (ECCO, ESMO, ESO) and consider specialties outside oncology (such as nutrition, psychology, healthy lifestyle).
- Develop training (such as e-learning modules) that target patient advocates and young healthcare professionals (including students and not only pediatric oncologists but other specialties). Explore Europe-wide curriculum that includes patient advocates.

- Healthcare Professional Ambassadors could be useful, playing a similar role as the existing EU-CAYAS-NET Ambassadors to reach other healthcare stakeholders. HCPs often don't have the same concept of PPIE or don't know about it – as Ambassadors, patient advocates and healthcare professionals could work together on alignment.

A second theme in this session was the importance of ensuring that the results of the EU-CAYAS-NET project are implemented across Europe (for example, guidelines, standards, recommendations). Consideration should be given to how to strengthen collaborations with the network and local organisations so that results can be put into practice at national level. Furthermore, best practice clinics can investigate what is working well and what not, and share this with the community. To increase the reach, a Europe-wide curriculum could be developed based on the project results with pilot testing, experience exchange, peer visits, twinning projects, etc.

### 4.3 Sustainability Strategy - continuation of the network via YARN

The EU-CAYAS-NET project (2022–2025) made a significant contribution to the European childhood and youth cancer community by creating a structured network for young survivors, their families, and healthcare professionals, supported by a comprehensive Platform and active Community on Discord. The project results<sup>3</sup> demonstrate the value of connecting youth cancer survivors across borders and elevating their voices in policy and practice. With the launch of **YARN (Youth Cancer Network)**, described below) in July 2025 under the EU4Health programme, and building directly on the foundations of EU-CAYAS-NET and OACCU<sup>4</sup>, there is now the opportunity to ensure that the outcomes of EU-CAYAS-NET become part of a lasting European framework for childhood, adolescent and young adult (CAYA) cancer survivorship, as well as continue the work of the network for additional years.

A sustainability strategy begins with governance. One of EU-CAYAS-NET's flagship innovations, the Ambassador Programme, has already empowered survivors to act as peer leaders and advocates. Under YARN, this will be formalised through the establishment of a **Youth Cancer Council** that has a permanent role in guiding YARN project priorities, representing survivor interests, and advising on EU and national policies. This council will ensure that survivor leadership is embedded in the very structure of the network as it continues into the future.

Digital infrastructure is another cornerstone of sustainability. EU-CAYAS-NET successfully piloted an online Platform and Knowledge Centre with a wealth of resources, but these need long-term hosting, regular updates, and dedicated support. YARN provides the framework to consolidate these tools into a sustainable, multilingual digital hub. This hub will serve as a peer-support community, a repository of guidelines and training materials, and a communication channel with policymakers and the wider public. Ensuring the Platform's continuity beyond 2028 (when YARN ends) will require financial planning—potentially blending EU funding with support from national health agencies, NGOs, and philanthropic partners.

Policy embedding is equally critical. The standards and recommendations developed by EU-CAYAS-NET—on psychosocial care, equitable access, and smooth transitions from paediatric to adult care—

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<sup>3</sup> Available on the Platform: <https://beatcancer.eu/project-deliverables/>

<sup>4</sup> <https://oac-connect.eu/>

will be further converted into practical resources, such as toolkits, checklists, and certification schemes that healthcare systems can adopt at national and regional level. YARN’s partnerships, including organisations like EUREGHA, provide a pathway to integrate these outputs into regional health strategies and cancer plans. By doing so, the network’s achievements should outlast individual projects and become part of routine practice in survivorship care.

Sustainability also requires capacity building. The deliverables of EU-CAYAS-NET can be scaled into training modules and e-learning courses for healthcare providers and survivor organisations. A “train-the-trainer” approach will allow national organizations and survivor groups to adapt materials to their contexts, ensuring wide and lasting dissemination. This decentralised model strengthens ownership across Europe and reduces dependence on a central coordinating body.

Public awareness and visibility will play an important role in maintaining momentum. Through YARN, the network has set ambitious outreach targets, aiming to reach tens of millions of citizens via media, podcasts, events, and education initiatives. By linking survivor voices with European awareness campaigns, such as the European Week Against Cancer, the movement can establish itself as the recognised voice of young cancer survivors in Europe. This visibility not only strengthens advocacy but also makes the case for continued investment.

Finally, a robust system of evaluation and adaptation model is needed. YARN has committed to ongoing quality assurance and impact measurement, which will allow the network to demonstrate tangible benefits—such as improved access to psychosocial care, increased survivor engagement, and strengthened policy alignment. Collecting feedback directly from survivors will ensure that the network remains responsive to evolving needs and is not simply reproducing outdated solutions.

In summary, the sustainability of EU-CAYAS-NET lies in its transformation from a project with a limited duration into a permanent European ecosystem for young cancer survivors. Through YARN, this can be achieved by embedding survivor leadership in governance, securing the digital platform, mainstreaming standards into policy and practice, diversifying funding, building scalable training programmes, expanding outreach, and maintaining a strong evidence base. If these elements are implemented strategically, the youth cancer survivor movement in Europe will thrive, shaping healthcare, policy, and public understanding for years to come.

## **4.4 Evaluation Report**

The EU-CAYAS-NET project has been a real success, as evidenced by achievement of the indicators detailed below.

### **4.4.1 Metrics**

The network has achieved the following indicators from the call topic:

- number of events, meetings and discussions organised
  - 1 Kick-off Meeting (M1, Barcelona)
  - 4 General Assembly Meeting (M6, Brussels/hybrid; M13, online; M19, Vienna/hybrid; M24, Cluj-Napoca/hybrid)
  - 3 Ambassador Events (M6, Brussels/hybrid; M15, Vienna; M34, Vienna),
  - 12 webinars on topics relevant to the Network in Quality of Life, AYA Care and EDI,

- 16 Community Discussions for Peer Support on Discord,
- 9 Community Events featuring Associated Partners,
- 1 Peer Visit Training Event (M6, Brussels)
- 6 Peer Visits (3 for Quality of Life, M8 & M10 (Utrecht, Barcelona, Vienna); 4 for AYA Care, M9, M10 & M11 (Milan, Amsterdam, Ghent)
- 1 Workshop on Transition (M8, online),
- 1 Consensus Workshop on the Design of PLAIN materials (M23),
- 2 Workshops on Education & Career Support (M11, Vienna; M14 in Utrecht),
- 1 Train-the-trainer Event on Education & Career Support in Vienna (M19),
- 1 workshop on Quality of Life at 2025 CCI Europe annual meeting (M33),
- 1 AYA Online Roundtable (M16),
- 1 EDI Policy Event in Brussels (M19),
- 3 EDI Training Events in Cluj-Napoca (M22),
- 4 webinars on EDI (M30 - M33),
- 1 Inclusivity Training in Tomosoara (M28),
- 1 High Level Inclusivity Roundtable (M31),
- 1 Equity, Diversity & Inclusion in Cancer Care Stakeholder Forum (M34),
- 3 Policy Events in Austria (M22), Lithuania (M21) and Spain (M22),
- 1 national Symposium in Austria (M22, Surviving Survival),
- 3 Regional Events in Sarajevo (M12), Zagreb (M22) and Bratislava (M22),
- 1 Closing Event in Cluj-Napoca (M24).
- number of documents produced for information and dissemination
  - 3 core project communication materials (Leaflet, Postcard, Overview Poster)(translated into 11 languages),
  - 1 Overview Powerpoint presentation for use by BEN + Associated Partners,
  - 13 publications on Quality of Life available on the Platform, including a White Paper on ‘Optimizing Quality of Life after Youth Cancer’,
  - 1 Position Paper on ‘Recommendation and Implementation Roadmap for Minimum Standards of Specialist Adolescent and Young Adult (AYA) Cancer Care Units’,
  - 1 White Paper on ‘Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe’,
  - 1 ‘Equity, Diversity and Inclusion Principles in Cancer Care Train-the-Trainer Toolkit’, and
  - More than 570 resources on the Platform, with more than 200 network articles available in nine European languages (<https://beatcancer.eu/resources/>).
- number of initiatives supported
  - 6 DG RTD/DG Sante events attended by network representatives,
  - 1 EU Mission Cancer: Young Cancer Survivor Workshop attended by network representatives,
  - 1 national Survivors Event supported in Bosnia,
  - 45 PLAIN language brochures (initiated in PanCareFollowUp, PanCareSurPass projects) optimised,
  - 2 World Cancer Day Events in Brussels (2024, 2025),

- 1 DG RTD co-organised event to promote the Cancer Mission at Expo25 in Osaka, Japan, and
- 2 national/regional events (policy event for German-speaking countries in Austria, Romanian Parliament for the National Day of Cancer Survivors).

Collaborations with other EU-funded projects were also on-going throughout the project (e.g. Joint Action on European Networks, Strong AYA, SmartCare), as well as other EU initiatives (e.g. European Network of Teenage and Young Adult Cancer (ENTYAC)).

- number of participants (people or entities)
  - 129 members in Full Network mailing list (Beneficiaries + Associated Partners),
  - 765 members in the wider community on Discord, and
  - 55 Ambassadors from 20 Member States (29 countries in total).
- number of participants (Member State, other countries or international organisations)
  - 38 European countries in the consortium across BEN + APs and the networks of CCI Europe, YCE, PanCare and SIOP Europe) representing 27 EU Member States + 11 non-EU countries.
  - Additionally, CCI Europe has strong links with international umbrella organisation Childhood Cancer International and SIOP Europe with the International Society of Pediatric Oncology (SIOP).
- number of stakeholders/associations participating per country and field
  - Involvement of major European organisations representing **survivors** - CCI Europe, representing 66 organisations in 33 European countries and Youth Cancer Europe (YCE), with members from 31 countries.
  - **Survivors/caregivers** represented by 3 beneficiary organisations representing 38 countries and 25 Associated Partners from 21 countries.
  - **Healthcare professionals** represented by 5 Beneficiary/Affiliated entities from 5 countries, 3 Associated Partners from 3 countries and wider involvement through SIOP Europe members in 35 countries.

Below are action-level indicators:

- # network participants (baseline = 0; target = 50 by M6, 150 by M24 from 27 EU Member States)
  - 129 members of the Full Network (Beneficiaries + Associated Partners, representing 38 European countries from the consortium and the networks of CCI Europe, YCE, PanCare and SIOP Europe).
  - The network community on Discord grew to 765 members by M34, well exceeding the target of 150 members.
- # of Youth Cancer Survivor Ambassadors (baseline = 0; target = 10 by M6, 27 by M24 from 27 EU Member States)
  - 5 Ambassadors from 20 Member States (29 countries in total). In spite of targeted efforts to reach non-represented Member States (Cyprus, Estonia, France, Hungary, Italy, Malta and Slovenia), it was not possible to reach the target of 27 Member States. However, the total number of Ambassadors exceeded the target, with representation from 27 countries.
- First version of the Platform publicly available by M4
  - The first version of the Platform was launched by M4.

- # visitors/month (baseline = 0; target = 2,500 by M12, 5,000 by M24)
  - By the end of the project, there were 66,000 visitors/month, exceeding the target.
- # visits by country/month (baseline = 0; target = 12 by M6, 27 by M24, 40 by M34)
  - By the end of the project, there were visitors to the Platform from 255 territories and countries, exceeding the M34 target.
- # peer support sessions (target = 300 by M12, 1,000 by M24)
  - The total number of peer support sessions was 1,055 by M24, which includes 275 sessions from the peer-to-peer support application in Discord, 190 sessions from peer support events, and 590 peer-to-peer support sessions from Discord community channels. By M34, there were 1,822 sessions in total, including sessions from peer support events (385 sessions), peer-to-peer support application in Discord (276 sessions) and peer support sessions from the Discord community channels (1,161 sessions).
- # publications incl. reports on Platform and position papers (baseline = 0; target = 6 by M24)
  - As of M34, 13 publications are available on the Platform.<sup>5</sup>
- # downloads of (WP3) published materials from the Platform (baseline = 0; target = average 200/document by M24)
  - By M34, WP3 materials published on the Platform had an average of 323 downloads/document.
- # of countries represented in mental health & psychosocial care survey (baseline = 0, target = 27 by M14)
  - As of the end of the survey in April 2024 (M20), responses were received from 24 countries, falling 3 countries short of the target. Although the target of 27 countries was not met, information on mental health & psychosocial care has been collected from all Member States over the course of the project via other means.

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<sup>5</sup>Pocket Card Set for Mental Health & Psychosocial Care (<https://beatcancer.eu/resources/mental-health/brochure/pocket-cards-for-mental-health-awareness-and-guidance/>),

Map of Education and Career Material Around Europe (<https://beatcancer.eu/project-deliverables/>),

Vienna Declaration on Mental Health and Psychosocial Care, <https://beatcancer.eu/event/surviving-survival-symposium-zur-mental-en-gesundheit-nach-kindekrebs/>

D3.2 'Train-the-Trainer concept for HCPs on education & career support for survivors' (<https://beatcancer.eu/wp-content/uploads/2024/07/EU-CAYAS-NET-D3.2-submission-26Jul2024.pdf>),

Vilnius Declaration on Transition of Care (<https://beatcancer.eu/resources/transition/publication/vilnius-declaration-on-transition-from-pediatric-to-adult-cancer-care/>), and

Barcelona Declaration on LTFU care (<https://beatcancer.eu/event/policy-event-improving-the-long-term-follow-up-care-for-young-cancer-survivors/>)

EU-CAYAS-NET Quality of Life White Paper ([https://beatcancer.eu/wp-content/uploads/2024/07/EU-CAYAS-NET\\_Quality-of-Life\\_White\\_Paper.pdf](https://beatcancer.eu/wp-content/uploads/2024/07/EU-CAYAS-NET_Quality-of-Life_White_Paper.pdf)),

Recommendations for Mental Health & Psychosocial Care After CAYA Cancer – Standard, Not Luxury ([https://beatcancer.eu/wp-content/uploads/2024/10/EU-CAYAS-NET-D3.1\\_readyforupload.pdf](https://beatcancer.eu/wp-content/uploads/2024/10/EU-CAYAS-NET-D3.1_readyforupload.pdf)),

Report on Career Support for young people living with and beyond cancer (<https://beatcancer.eu/wp-content/uploads/2024/07/Career-Support-Report.pdf>),

Recommendations for Transition of Care for childhood and adolescent cancer survivors (<https://beatcancer.eu/wp-content/uploads/2024/08/Summaries-of-Transition-Guideline-EN.pdf>),

Recommendations for LTFU Care to be Seen as the Last Step of Successful Cancer Treatment (<https://beatcancer.eu/wp-content/uploads/2024/07/EU-CAYAS-NET-D3.4-submission-05Nov2024.pdf>),

Roadmap for Optimal Long-Term Survivorship Care (<https://beatcancer.eu/wp-content/uploads/2024/07/EU-CAYAS-NET-D3.4-submission-05Nov2024.pdf>), and

A Guide to Talking with Survivors About Late Effects ([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](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)).

Furthermore, the data generated by the survey is sufficient for evidence-based conclusions on Mental Health & Psychosocial Care in Europe.

- Consensus Group Discussion participants (baseline = 0, target = 20 by M6, 40 by M15)
  - 15 participants attended the first consensus group meeting in the second reporting period (M17) and 12 participants attended the second consensus group meeting in this reporting period (M20) for a total of 27 participants in attendance at the meetings. While the target of 40 participants was not achieved at the meetings, many additional people participated in feedback rounds via review of online documentation. For example, interdisciplinary HCPs (e.g. in MUV from medicine & neuropsychology) gave feedback on the joint standard of care, which will enhance the quality of the finalised standard of care. Overall, there will be more than 40 participants involved in the consensus process, via meetings and other means of feedback on the joint standard of care.
- Focus Group Discussions on Education & Career Support (target = 40 by M10, 85 by M24)
  - Two focus groups were held by M13 with 10 participants in total. While this was below the target, the information collected was extensive and no further focus groups were deemed necessary. As reported in the second reporting period, questions on career support were included in the survey on mental health and psychosocial care in place of additional focus groups.
- # Train-the-trainer participants for education & career support (baseline = 0, target 30 by M24)
  - The Train-the-Trainer workshop was held in Vienna (M19) with 30 participants from 16 countries, meeting the indicator.
- Indicator: # workshop participants on transition (baseline = 0, target = 20 by M8)
  - The workshop was held as planned in M8, with 14 participants. 19 participants expressed their interest in advance, however due to last-minute cancellations only 14 were able to attend. Even though the indicator was not reached, the outcomes from the discussion were very informative.
- 64 of participants involved in peer visit activities for Transition (baseline = 0, target = 55 from at least 10 countries by M18)
  - 64 unique Peer Visitors participated across the three visited sites, representing 16 countries, exceeding the indicator.
- 1 Transition Guideline (scientific paper) by M26
  - 1 Transition Guideline accepted to Lancet Oncology by M34.
- # of countries represented in Long-Term Follow-Up care survey (baseline = 0, target = 27 by M10)
  - After the closing of the survey, 24 countries were represented in the survey; information was gathered directly for the missing countries to create an as complete as possible overview of the situation of long-term follow-up care in Europe.
- # of participants involved in peer visit activities for Long-Term Follow-Up (baseline = 0, target = 55 from at least 10 countries by M18)
  - 64 unique Peer Visitors participated across the three visited sites, representing 16 countries, exceeding the indicator.
- # participants from at least 15 countries participating in peer visit methodology training (to support peer visit activities in WP3 & WP4) (baseline = 0, target = 50 from 15 countries by M11)
  - 64 participants from 19 countries attended the training event held in Brussels in

- # participants involved in peer visit activities for AYA Care (baseline = 0, target = 30 from 15 countries by M11)
  - 30 participants from 16 countries were involved in Peer Visit activities by M11.
- 1 Specialist AYA Units Minimum Standards position paper by M22
  - The Specialist AYA Units Minimum Standards position paper was launched at a webinar in M22, with the related deliverable (D4.1) submitted in M23 (Jul 2024) following translation of the deliverable results into eight European languages.
- 25 countries represented in EDI Online Survey for minority groups (baseline = 0, target = 8 by M10)
  - 25 countries were represented in the EDI Online Survey for minority groups by M14, exceeding the target number. There was a minor delay in completion of the survey, but the data was collected in sufficient time to avoid delays to subsequent tasks.
- # institutions audited by EDI Survey for HCPs (baseline = 0, target = 20 by M10)
  - 77 submissions were received by M15. In error, the survey did not collect information on the institution of the respondent. However, a broad coverage of institution types was represented, including publicly funded hospitals/clinics/institutions (33%), university, medical school or residency (27%), children's hospital, special ATA clinic, adult settings, etc. (26%), and academia (19%). The survey was delayed but results were still available in time to feed into related tasks in WP5.
- 1 EDI Policy Recommendations by M22
  - The EDI Policy Recommendations were launched at the EDI Policy event in M19, with the related deliverable (D5.2) submitted in M23 (Jul 2024) following translation of the deliverable results into eight European languages.
- 59 participants trained via EDI “Train-the-trainer” programme (baseline = 0, target = 60 from at least 15 countries by M16)
  - The inclusivity training was delivered on M28 to 100 people living with and beyond cancer, including Roma community members (and other historical ethnic minorities) in Timisoara, Romania.
- # initiatives supported (baseline = 0, target = 10 by M24)
  - 6 DG RTD/DG Sante events attended by network representatives,
  - 1 EU Mission Cancer: Young Cancer Survivor Workshop attended by network representatives,
  - 1 national Survivors Event supported in Bosnia,
  - 45 PLAIN language brochures (initiated in PanCareFollowUp, PanCareSurPass projects) optimised,
  - 2 World Cancer Day Events in Brussels (2024, 2025),
  - 1 DG RTD co-organised event to promote the Cancer Mission at Expo25 in Osaka, Japan, and
  - 2 national/regional events (policy event for German-speaking countries in Austria, Romanian Parliament for the National Day of Cancer Survivors).
- 3 Regional Events - Survivors, healthcare professionals, policymakers (3 events with 50 participants/event)
  - The regional event in Bosnia had 49 participants, in Bratislava 35 participants and in Zagreb 52 participants.

- 2-Day Networking Event - Survivors (Ambassadors) from 27 EU Member States, at least 60 survivors from non-EU countries, Stakeholder Core group, general public, media (at least 60 participants in event)
  - 35 senior Ambassadors and 17 new Ambassadors participated in the 2-Day Networking Event (i.e. Ambassador Training 2 and Guideline Workshop). Together with other participants, 62 people in total attended the meeting. 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 additional countries.
- 3 National Policy Events - Survivors, healthcare professionals, policymakers, media (at least 30 participants/event), 3 events: in Lithuania, in Austria, in Spain
  - Three national Policy Events were held to communicate project results in Spain (47 participants), Lithuania (27 participants) and Austria (49 participants)).
- 4-day Closing Event in Romania - Survivors, general public, media (at least 170 participants)
  - The 4-day Closing Event took place in Cluj-Napoca, Romania, with 180 participants in attendance (168 in person and 12 online for the General Assembly). Participants covered 21 EU Member states and 10 non-member states, totalling 31 countries (60 participants were from Romania, 12 from Lithuania, 12 from the Netherlands, 9 from Poland, 9 from Austria, 8 from Ireland, 6 from Portugal, 6 from Hungary, 5 from Spain, 5 from Ukraine, 5 from Belgium, 4 from Croatia, 4 from Greece, 4 from Bulgaria, 4 from Finland, 3 from Slovenia, 3 from United Kingdom, 3 from Serbia, 3 from Italy, 2 from Bosnia and Herzegovina, 2 from North Macedonia, 2 from Germany, 1 from Republic of Moldova, 1 from France, 1 from Sweden, 1 from Armenia, 1 from Brazil, 1 from Canada, 1 from Czech Republic, 1 from the Philippines, 1 from Slovakia).
- # workshop participants for survivors involvement in guideline development & PPI (baseline = 0, target = 20 by M24)
  - The workshop was held as part of the 2-Day Networking Event in M15, attended by 62 people in total.

## 5 Impact & Conclusion

The results of WP6 make a considerable contribution to the overall progress and long-term impact of the EU-CAYAS-NET project. While the project as a whole aimed to establish and strengthen the European Network of Youth Cancer Survivors, WP6 ensured that the achievements would be widely communicated with the aim to have a long-lasting impact within and beyond the CAYA cancer community. By focusing on communication and dissemination via many available channels and events, WP6 amplified the reach of the project's outputs, ensuring that knowledge, tools, and insights generated through the network reached survivors, healthcare providers, researchers, and policymakers across Europe. This broad visibility supported the uptake of project results and

positioned the network as a reference point for initiatives addressing the needs of young cancer survivors.

The work of WP6 was anchored in the priorities identified by young cancer survivors themselves, making it very powerful. The three central themes—Quality of Life, Adolescent and Young Adult Care, and Equality, Diversity and Inclusion—guided the communication, dissemination, and sustainability efforts, ensuring that they were directly aligned with the issues that matter most to the community. This survivor-driven approach not only lends legitimacy to the project’s outputs but also strengthens engagement and ownership within the network, which is essential for lasting success. At the same time, WP6 looked beyond simply preserving what had been achieved to envision new areas of development. By linking EU-CAYAS-NET with national and European initiatives, the strategy opens pathways for growth, collaboration, and policy influence, thereby reinforcing the project’s role as a central hub in the field.

Equally important, WP6 placed sustainability at the heart of its activities. D6.3 presents a comprehensive sustainability strategy that provides a clear roadmap for how the network continues operating beyond the end of EU-CAYAS-NET and with the start of the follow-up project YARN (Youth Cancer Network). By embedding flexibility and forward planning, WP6 created the conditions for the community built during the project to thrive in the long term.

In this way, WP6 aimed to transform the EU-CAYAS-NET project from a time-restricted initiative into a long-lasting network with the potential to generate long-term impact. Through strategic communication, comprehensive dissemination, careful evaluation, and forward-looking sustainability planning, it ensured that the voices of young cancer survivors will continue to be heard and that concrete progress continues to be made in improving their quality of life across Europe.