

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

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Report on the Ambassador Programme

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SIOP EUROPE	SIOPE	3	Beneficiary
PANCARE	PANCARE	4	Beneficiary
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PAGALBOS ONKOLOGINIAMS LIGONIAMS ASOCIACIJA	POLA	6	Beneficiary
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Sano	Sano	42	Associated Partner
Childhood Cancer Foundation	CCIRL	43	Associated Partner

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1 Executive Summary

EU-CAYAS-NET is a project led by patient advocates under one of the Flagship Initiatives of Europe's Beating Cancer Plan to build a "European Network of Youth Cancer Survivors" and to create a knowledge centre and interactive Platform for social networking.

In early 2023, EU-CAYAS-NET launched the **Youth Cancer Survivor Ambassador Programme**. Ambassadors are youth cancer survivors participating in the network who communicate the project objectives and disseminate the project results to stakeholders in their Member State. They are an integral part of EU-CAYAS-NET and participate in project activities, such as Peer Visits, Guidelines Workshops, focus group discussions, etc. They also contribute to the Equality, Diversity and Inclusion (EDI) Programme Development and share project resources within their own countries. Network Ambassadors also connect the network with new survivors and other stakeholders to build the community and generally promote the project.

This deliverable is a report on the Ambassador event held in Brussels on 9th February 2023, as well as describing future planned activities. The hybrid Ambassador event consisted of an introduction to EU-CAYAS-NET and the Network Platform/Discord community, interviews with patient advocates and round table/break-out sessions. The workshop concluded with a round-up of the round table/break-out sessions and information about the next steps in the Ambassador selection process. Out of 80 candidates who completed an Expression of Interest, 62 took part in the Ambassador event. 27 countries were represented, including 20 Member States.

As of 30 May 2023, 40 youth cancer survivors from 22 European countries (representing 18 Member States) have agreed to be Ambassadors for the European Network of Youth Cancer Survivors. A further recruitment round is planned before the next Ambassador event at the end of November 2023, before which Ambassador candidates from the nine Member States not yet represented will be sought.

EU-CAYAS-NET Ambassadors are now a visible focal point through which communication about survivorship can be managed at the national level, providing a link between European and national activities. Ambassadors will be active at national/international events and at the policy level, as well as invite survivors to the Discord community and make potential future Ambassadors aware of the project. Social and health care professionals and policymakers can also now benefit from our pool of dedicated Ambassadors and survivors from across Europe, who can be called upon for future consultations.

2 Introduction & Background

EU-CAYAS-NET is a project led by patient advocates under one of the Flagship Initiatives of Europe's Beating Cancer Plan to build a "European Network of Youth Cancer Survivors" and to create a knowledge centre and interactive Platform for social networking. Leading organisations from 18 countries active in the field will map resources for young cancer patients, survivors and their caregivers, create new European guidelines and empower cancer survivors to advocate for their rights and needs.

EU-CAYAS-NET fosters social networking, peer-support, knowledge-exchange, and will improve:

- the quality of life of survivors - including mental health, education & career support, follow-up care and transition from paediatric to adult health care,
- the care for adolescents and young adults (AYA) with cancer, as well as
- Equality, Diversity and Inclusion (EDI) along the whole treatment and survivorship trajectory.

The Network Platform (beatcancer.eu) is an interactive hub where survivors can get answers to questions, share with like-minded people and, last but not least, have fun. It is a safe place to share, learn and grow. The network welcomes everyone dealing with childhood and adolescent cancer. This includes not only cancer patients, survivors and their caregivers, but also stakeholders from healthcare, research or policy.

As part of Task 1.6, EU-CAYAS-NET has launched the **Youth Cancer Survivor Ambassador Programme**. Ambassadors are survivors participating in the network who communicate the project objectives and disseminate the project results to stakeholders in their Member State. CCI Europe and YCE equip Ambassadors with the skills to communicate to a broad range of stakeholders, as they are recruited on a rolling basis over the project. Ambassadors are recruited from within the networks of CCI Europe and YCE, as well as other Beneficiaries and Associated Partners.

Selected network Ambassadors are an integral part of EU-CAYAS-NET. Based on their interests, Ambassadors will be invited to:

- participate in Peer Visit activities, guidelines workshops (see chapter 5), focus group discussions, etc., together with healthcare professionals and representatives of other stakeholder groups related to Quality of Life (WP3) and Adolescents and Young Adult (AYA) care (WP4) and share the developed resources within their own countries (guidelines, toolkits, position papers, etc.), and
- contribute to the Equality, Diversity and Inclusion (EDI) Programme Development (WP5), participate in EDI training and share the EDI Toolkit within their own countries.

Network ambassadors are also to connecting the network with new survivors and other stakeholders to build the community (WP2) and generally promote the project (WP6).

This deliverable is a report on the half-day Ambassador event held in Brussels on 9th February 2023 (M6), which was part of the selection and training process for Ambassadors. The report includes the meeting agenda, meeting list, presentations, feedback questionnaire and a description of the event outcomes. In addition, the report details future planned activities.

3 Approach

3.1 Ambassador Expressions of Interest, Preparation for Ambassador/Advocacy Workshop

3.1.1 Development of recruitment materials (CCI-E, YCE)

Planning for the Ambassador programme started at the Kick-off Meeting with a consensus-building exercise focused on defining the role of Ambassador, brainstorming appropriate criteria candidates should fulfil and considering what training might be required (Figure 1). An Ambassador Working Group, composed of eight young people with lived experience of cancer, was formed to develop an

application process, define the final criteria and draft Terms of Reference. Three co-leaders volunteered to lead the process.

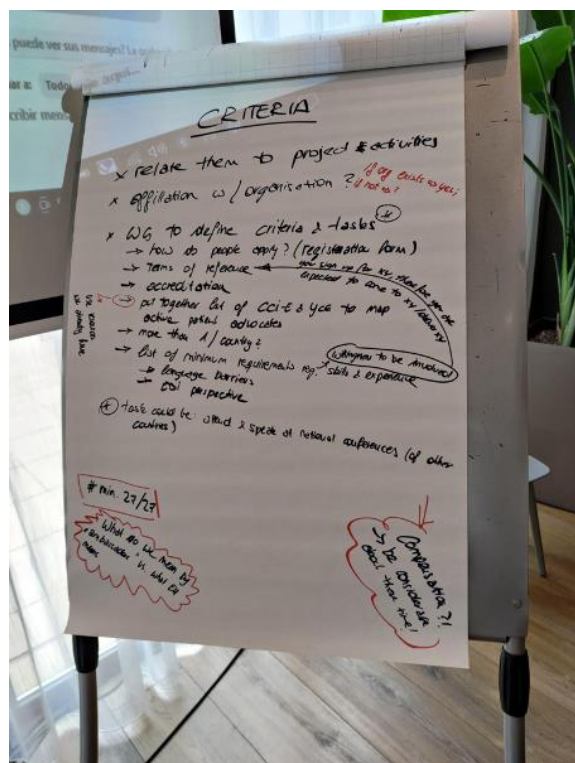


Figure 1 Brainstorming criteria for Ambassadors, Kick-off Meeting

The Ambassador Working Group co-leaders drafted criteria and Terms of Reference over M2 - M3, which were circulated to the full Working Group for review and comment. An updated draft was circulated to the Management Team for review. A meeting convened with the Working Group Core Leaders and members of the Management Team in M4 to launch the recruitment of Ambassadors. A selection panel of four young survivors from CCI Europe, YCE and PMC was appointed at this meeting.

Materials and strategies were developed to recruit Ambassadors and inform them about their role in the project and beyond (Appendix 1). In addition, potential candidates from the diverse organizations were identified for an invitation to become an Ambassador, and channels through which potential applicants could be recruited were identified.

Ambassador requirements:

An Ambassador:

- should be between 18-39 years of age,
- have been treated or be in treatment for cancer between the ages of 0 – 39 years,
- should be able to think and reflect upon the aims of the European Network of Youth Cancer Survivors from a lived experience point of view,
- be willing to speak about the activities of the European Network of Youth Cancer Survivors at external events and share related posts on social media,
- have at least an intermediate level in speaking, writing and reading in English, and
- preferably be involved in a national/regional network and willing to advocate nationally.

Ambassador commitment:

The EU-CAYAS-NET project runs until August 2024 and will include a number of events covering a broad range of topics. Ambassadors will be invited to attend all events and will be given priority when participants are selected. However, Ambassadors are not expected to attend all events.

Ambassadors will also be invited to attend additional in-person and online meetings, such as focus group discussions. Again, attendance is optional, but Ambassadors will be given priority when participants are selected.

3.1.2 Collection of Expressions of Interest for Ambassadors (CCI-E, YCE + BEN/APs)

Beneficiaries and Associated Partners were provided with a link to an Expression of Interest form online and asked to share widely with their survivor communities and via social media. The form included contact information, affiliation (if any), nationality, etc. (Table 1). 79 potential candidates (55 female, 16 male, 8 not specified) from all over Europe completed an Expression of Interest form (29 nationalities, 25 countries of residence).

Table 1 Ambassador candidate characteristics

Ambassador Characteristics	Number
Age at cancer onset (years)	0 - 41
Cancer type	
Acute lymphoblastic leukemia (ALL)	8
Acute myeloid Leukemia (AML)	4
Brain tumours	3
Breast cancer	3
Burkitts Lymphoma	1
Cholangiocarcinoma	1
Ewing sarcoma	3
Germ cell tumour	1
B Cell Lymphoma	1
T-Cell lymphoma	1
Hodgkin lymphoma	13
Langerhans Cell Histocytosis	1
IPT-like FDCE	1
Systemic mastocytosis	1
Malignant Rhabdoid Tumour (MRT)	1
Neuroendocrine tumour	1
Neuroblastoma	1
Non-Hodgkin lymphoma	7
Osteosarcoma	3
Rhabdomyosarcoma	2
Sarcoma	2
Small cells ovarian cancer	1
Spinal Astrocytoma	1
Testicular cancer	1
Thyroid cancer	1
Wilms Tumour	2
Not specified	14
Nationality	
Armenia	1
Austria	4
Azerbaijan	1

Ambassador Characteristics	Number
Belgium	3
Bulgaria	1
Costa Rica	1
Croatia	1
Cyprus	1
Czech Republic	2
Finland	3
France	1
Germany	2
Greece	2
Ireland	7
Israel	2
Italy	3
Lithuania	2
Luxemburg	2
Macedonia	2
Moldova	2
Montenegro	1
Netherlands	20
Poland	2
Portugal	4
Romania	3
Spain	1
Sweden	1
Switzerland	2
United Kingdom	1

3.1.3 Preparation for Ambassador/Advocacy Workshop, 9th February 2023

The hybrid Ambassador/Advocacy Workshop was planned for 9th February 2023. As the workshop was directly after the in-person Peer Visit Training conducted by WP4 on 8th February 2023, Ambassador candidates attending the Peer Visit Training were invited to attend the workshop in person. All other candidates were invited to attend the workshop via Discord. An agenda was developed by CCI Europe and YCE. Details about the event were also uploaded to the Platform by POLA (<https://beatcancer.eu/event/ambassador-advocacy-workshop-eu-cayas-net/>).

4 Results

4.1 Report on the Ambassador/Advocacy Workshop

The hybrid Ambassador/Advocacy Workshop was held in Brussels on 9th February 2023 at the NH Collection Brussels Centre Hotel and online via Discord. The agenda (Appendix 2) included an introduction of EU-CAYAS-NET (Appendix 3), the Network Platform/Discord Community and patient advocacy (including interviews with survivors on issues such as the "Right to be forgotten" and the setting of "Cancer Plan Priorities" in specific EU countries). These introductory sessions were followed by round table/break-out sessions. The workshop concluded with a round-up of the round table/break-out sessions and information about the next steps in the Ambassador selection process.

Out of 80 candidates who completed an Expression of Interest, 62 took part in the Ambassador/Advocacy Workshop in Brussels in February 2023.¹ 16 candidates participated online and 46 joined in person. 27 countries were represented, including 20 Member States (Table 2). Therefore, the project has exceeded the indicator of 40 participants in the Ambassador training by M6 (Project Objective 1).

Table 2 Ambassador/Advocacy Workshop– Representation by Country

Country of Birth/Passport	Country of Residence
Armenia	Armenia
Austria	Austria
Belgium	Belgium
Bulgaria	Bulgaria
Costa Rica	Netherlands
Croatia	Croatia
Cyprus	Cyprus
Czech Republic	Czech Republic
Finland	Finland
France	France
Germany	Germany
Greece	Greece
Ireland	Ireland
Italy	Italy
Lithuania	Lithuania
Luxemburg	Luxemburg
Macedonia	Macedonia
Moldova	Romania
Montenegro	Montenegro
The Netherlands	The Netherlands
Poland	Poland

¹ As this is a Public report, the names of attendees are not included as not all candidates were selected/accepted Ambassador positions. The names of those candidates that became Ambassadors are available on the Ambassador page of the Network Platform as they have consented to being publicly identified as Ambassadors (<https://beatcancer.eu/de/community/>).

Country of Birth/Passport	Country of Residence
Portugal	Portugal
Romania	Romania
Romania	United Kingdom
Spain	United Kingdom
Sweden	Sweden
Switzerland	Switzerland
United Kingdom	Sweden

For the round table/breakout sessions, Ambassador candidates were divided into four groups (three in-person and one online). The workshop organisers had assigned participants to groups in advance to ensure a mix of different countries and backgrounds in each group. Each group was moderated by a survivor involved in the project from CCI Europe, YCE or PMC. The topics listed in the agenda were discussed and the respective suggestions and reflections were recorded in Miro by a nominated notetaker from CCI Europe, YCE or Pintail. Based on the key messages captured in Miro, a breakout session report was created after the workshop that systematically compiled the suggestions for the different topics. These suggestions were reviewed by the Management Team and will be incorporated in the Ambassador programme, where appropriate.

After the event, an online feedback questionnaire was distributed, including multiple choice questions and fields for free text responses, and 23 responses (22 in-person attendees, 1 online attendee) were received Table 3. All respondents indicated they would attend another EU-CAYAS-NET event. Overall, the feedback was positive and there were useful suggestions for areas where additional support and training are needed, as well as for the organisation of future Ambassador meetings.

Table 3 Workshop Feedback

Question/Statement	Average Response (1 – poor, 5 - great)	Average Response (1 – strongly disagree, 5 strongly agree)
How was the Ambassador Training overall?	4.6	-
I found the content of the training easy to understand.	-	4.5
The training was relevant for me to understand more about the European Network of Youth Cancer Survivors and the role of Ambassadors in the project than I did before.	-	4.5
I understand what is expected from Ambassadors of the European Network of Youth Cancer Survivors project.	-	4.1
I feel ready to engage in the activities of the European Network of Youth Cancer Survivors.	-	4.3

I feel ready to speak about the activities of the European Network of Youth Cancer Survivors if needed.	-	4.1
I feel comfortable to share related posts of the project on social media.	-	4.4
The speakers delivered the information well.	-	4.5
The training was of the right length.	-	4.1
I know where to go to get further information.	-	4.0

4.2 Ambassador Selection

Prior to the Ambassador/Advocacy Workshop, an Ambassador Selection Committee consisting of survivors and patient advocates CCI Europe, YCE and PMC was established. The committee met several times to evaluate candidates for their suitability to join the Ambassador programme, based on their background, patient history, and participation in the workshop. Each selection committee member chaired one of the break-out sessions to assist with the selection process. One candidate was refused by the committee due to a lack of proficiency in English. The committee also conducted follow-up interviews where at least two Ambassador committee members were present with four candidates (where further information was needed). Of those interviewed, three were subsequently included in the programme and one was postponed due to high stress arising from on-going/recently completed cancer treatment. Six candidates refused further participation themselves following the workshop due to lack of time or concerns about being publicly included on the Network Platform or social media.

The 54 remaining Ambassador candidates were then officially invited to become EU-CAYAS-NET Ambassadors (Appendix 4). Those who responded to this official invitation with a confirmation of interest, received a Terms of Reference document specifically developed for this Ambassador programme to be filled in and signed (Appendix 5).

4.3 Current Status of the Ambassador Programme

As of 30 May 2023, 40 youth cancer survivors from 22 European countries (representing 18 Member States) have agreed to be Ambassadors for the European Network of Youth Cancer Survivors (Figure 2). Therefore, the project has exceeded the indicator of 10 Ambassadors, with a minor delay from M6 to M9 (Project Objective 1). Those who have not yet submitted signed Terms of Reference or have submitted incomplete terms are reminded at regular intervals that their input is pending. In addition, a further recruitment round is planned before the next Ambassador event at the end of November 2023 (M16). The project is well on the way to meeting the next indicator of 27 Ambassadors from 27 EU Member States by M24 (Project Objective 1).

The Ambassadors (name, country of residence, cancer type, short bio and picture) can be found on the Network Platform (<https://beatcancer.eu/community/>). The site will be regularly updated as more Ambassadors formally join.



Figure 2 Ambassadors, as presented at the first EU-CAYAS-NET webinar (30th May 2023)

Task 2.6 originally planned to deliver 3-monthly updates on project activities to the Ambassadors. However, a more dynamic approach with live updates has been undertaken instead through a dedicated Ambassador channel on the Discord communication platform (Figure 3) created in mid-April 2023 (M8). In this channel, Ambassadors can exchange information with each other, as well as receive regular updates on project activities. The channel is also used for announcements on any Ambassador-relevant.

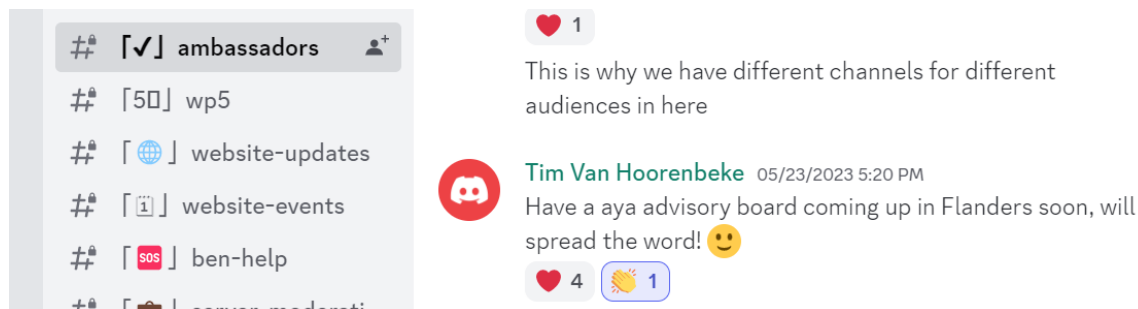


Figure 3 Screenshot of the Ambassador channel in Discord

Topics and announcements in the channel to date have included:

- Promotion of RTD-SANTE-CANCER MISSION Workshop & three Communications Activities,
- Information on the European Musculo-Skeletal Oncology Society Congress (where an EU-CAYAS-NET Ambassador was keynote speaker),
- An invitation to provide testimonials for the EU-CAYAS-NET communication campaign during the Cancer Survivors' Week in June 2023,
- An invitation to register for first EU-CAYAS-Net webinar (30th May 2023) and request to share with the wider community, and
- An announcement that the Ambassadors will be featured on the Network Platform (19th May 2023).

4.4 Future activities

Through various publicity efforts in WP6 and through the recruitment of potential new candidates by the Ambassadors themselves, several additional Ambassador candidates have expressed interest. If the necessary criteria are met, these candidates, those who could not attend the first training event, as well as those who are additionally selected by the Ambassador Selection Committee, will be invited to the 2-Day Ambassador Networking & Guideline Workshop event in Vienna that will take place from 23rd to 25th November 2023. The event will be coupled with a workshop on patient advocate involvement in survivorship guidelines.

5 Impact & Conclusion

With the launch of the EU-CAYAS-NET Ambassador programme, activities to promote improved survivorship under the three project themes have begun to make an impact. EU-CAYAS-NET Ambassadors are now a visible focal point through which communication about survivorship is managed at the national level, providing a link between European and national activities. Ambassadors are continuously asked not only to be active at national and international events and on the policy level, but also to make new potential Ambassadors aware of the project, to invite them to the communication platform (Discord).

Social and health care professionals and policymakers can also now benefit from our pool of dedicated Ambassadors and survivors from across Europe, who can be called upon for future consultations. In one specific example and as part of our cooperation, surveys from the project OACCUs (<https://oac-connect.eu/>) have been shared with Ambassadors and they have been invited to a number of OACCUs events and activities.

6 Appendices

6.1 Appendix 1. Ambassador Programme Description



What is the European Network of Youth Cancer Survivors?

The European Network of Youth Cancer Survivors (EU-CAYAS-NET) is a project co-funded by the European Union's EU4Health programme that aims to improve the quality of life of childhood, adolescent and young adult (CAYA) cancer survivors through meaningful social networking among individuals with lived experience of cancer, as well as social and health professionals active in cancer prevention and care across the European Union.

The network will bring together a wide spectrum of stakeholders and create an online Platform to support the promotion of targeted actions and initiatives, covering areas which are of demonstrated benefit to the quality of life of young people affected by cancer. The focus will be on three themes identified by young people with lived experience throughout Europe:

- 1) Quality of Life,
- 2) Adolescent and Young Adult Cancer Care, and
- 3) Equity, Diversity and Inclusion.

What will the European Network of Youth Cancer Survivors do?

Young people with a lived experience of cancer will lead a collaborative approach involving diverse stakeholders to identify targeted actions and initiatives to be promoted via the network and Platform. Activities will include: Peer Visits, Network meetings, Training, Virtual co-working, Social media campaigns, Webinars, and Policy recommendations and other national/international policy events.

The activities will build on previous and on-going initiatives, such as European Reference Networks (ERN) PaedCan and Horizon 2020/Horizon Europe projects.

The project will help deliver on Europe's Beating Cancer Plan Flagship initiatives such as the "Knowledge Centre on Cancer" and "EU Network of National Comprehensive Cancer Centres". EU-CAYAS-NET will also address many objectives of the EU4Health programme, including health promotion and reduced disease burden, reducing health inequalities and improving access to care, improving patient/survivor rights, and more.

In addition to delivering an EU-wide digital Platform informed by research as well as stakeholder engagement, EU-CAYAS-NET will also directly contribute to reducing health inequalities, improving access to care and resources, and promoting young patients' and survivors' rights.

What is the Ambassador Programme?

During the project, at least 27 Ambassadors will be recruited to actively link the European network to national communities.

Who can become an Ambassador?

You will:

- be between 18-39 years of age,
- have been treated or be in treatment for cancer between the ages of 0 - 39 years,
- be able to think and reflect upon the aims of the European Network of Youth Cancer Survivors from a lived experience point of view,
- be willing to speak about the activities of the European Network of Youth Cancer Survivors at external events and share related posts on social media,
- have at least an intermediate level in speaking, writing and reading in English, and
- preferably be involved in a national/regional network and willing to advocate nationally.

What's in it for you?

You will join an enthusiastic European community dedicated to improving the quality of life of CAYA cancer survivors!

- You can develop skills and knowledge.
- You will be offered the opportunity to participate in topic-specific training.
- You will actively participate in a network on a European level.
- You will be able to travel to various events across Europe.

Travel and accommodation costs for Ambassadors participating in project events will be covered. The time spent to participate will not be covered.

What is the time commitment?

The EU-CAYAS-NET project runs until August 2024 and will include a number of events covering a broad range of topics. Ambassadors will be invited to attend all events and will be given priority when participants are selected. However, Ambassadors are not expected to attend all events. There will be four in-person events (approx. 16 business days in total) and four online events (approx. four business days).

Ambassadors will also be invited to attend additional in-person and online research meetings, such as focus group discussions. Again, attendance is optional but Ambassadors will be given priority when participants are selected.

How can I learn more?

Have a question? Reach out to us at office@ccieurope.eu.

How do I apply?

The first group of Ambassadors will be selected in January 2023, but the programme will remain open for applications throughout 2023. You can complete your application online [here](#) at any time.

6.2 Appendix 2. Agenda - Ambassador/Advocacy Workshop

AGENDA

In person: NH Collection Brussels Centre Hotel, Boulevard Adolphe Max, 7, Brussels

Online (via discord): For those attending online, the meeting will be held on discord.

If you are not already on discord, you will need to first create an account: <https://discord.com/>

Then you can join the meeting here: <https://discord.gg/55FXSxmsEC>

Everyone: Join us on the beatcancer discord community!

You will learn more about it at the event.

<https://discord.gg/vJT3nbCd6m>

Questions? Don't hesitate to contact us at office@ccieurope.eu !

Time (CET)	Topic	Speaker(s)
8.45 – 9.00	Registration & Welcome	
9.00 – 9.20	Welcome & Brief Introduction Round	Carina Schneider (CCI Europe)
9.20 – 9.40	What is the European Network of Youth Cancer Survivors? What is the role of Ambassadors?	Carina Schneider (CCI Europe)
9.40 – 10.00	What is the Network Platform? How can it be used by youth cancer survivors?	Šarūnas Narbutas (POLA) Simonas Petkevičius (POLA)
10.00 – 10.30	General Intro to Advocacy (5 min) Experience Transferring Advocacy Success from EU to Member States • Right to be forgotten – Portugal (10 min) • Cancer Plan priorities – Romania (10 min) Q & A (5 min)	Carina Schneider (CCI Europe) Right to Be Forgotten: Tiago da Costa (interviewee), Jaap den Hartogh (interviewer) Cancer Plan Priorities: Victor Girbu, (interviewee), Katie Rivzi (interviewer)
10.30 – 10.45	BREAK	



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Time (CET)	Topic	Speaker(s)
10.45 – 11.45	Round Table/Break-out Sessions (3 groups + online) 1. What kind of support do you need to be a successful Ambassador? 2. What are some possible first steps you can take in your home country as an Ambassador? 3. Overall, how do you think EU-CAYAS-NET should communicate to attract more young people from across Europe?	Led by Ambassador Selection Panel Q 1: Jaap den Hartogh (PMC) Q 2: Andrea Ruano (YCE) Q 3: Colette Ryan (YCE) Online, Q1 – 3: Carina Schneider (CCI Europe)
11.45 – 12.00	Summary of break-out Sessions	Jaap, Andrea, Colette, Carina
12.00 – 12.15	Next Steps and Wrap-up	Carina Schneider (CCI Europe) Šarūnas Narbutas (POLA)
12.15	LUNCH	



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6.3 Appendix 3. Slides - Ambassador/Advocacy Workshop



The slide features a light blue background with abstract geometric shapes in shades of blue and white. The European Network of Youth Cancer Survivors logo is positioned in the upper right. The title 'Ambassador Training' is prominently displayed in a large, bold, dark blue font. Below the title, the date and location are specified. A small European Union flag logo is accompanied by a disclaimer text. The agenda is presented as a numbered list with yellow markers.

European Network of
**YOUTH CANCER
SURVIVORS**

Ambassador Training

9th February 2023, Brussels
Carina, Jaap, Colette

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What's expecting you today

1. EU-CAYAS-NET Ambassadors
2. Role of Ambassadors
3. Recruitment
4. The Network Platform
5. Advocacy
6. Ambassadorship – Break-Out Sessions
7. Summary of Break-Out Sessions
8. Wrap up

European Network of Youth Cancer Survivors

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EU-CAYAS-NET Ambassadors

Starting the activities of the Network through ad hoc missions/webinars/workshop, with the direct involvement of EU Network delegates and 'Ambassadors'.

WP1 will also launch the **Youth Cancer Survivor Ambassador programme**. Ambassadors will be survivors participating in the network who communicate the project objectives and disseminate the project results to stakeholders in their Member State. CCI Europe and YCE will train Ambassadors to equip them with the skills to communicate to a broad range of stakeholders, as they are recruited on a rolling basis over the project. Three-monthly updates on project activities will be generated by the Stakeholder Core Group, which will include recommended national level actions that will be coordinated at network level. Ambassadors will be recruited from within the networks of CCI Europe and YCE, as well as other Beneficiaries and Associated Partners (10 by M6, 27 by M18).

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Rule #1: What you put into the proposal...

... you have to implement after the Kick-Off.

- Set-Up of „task force“ to define
 - the **role** of ambassadors
 - **criteria** for becoming ambassadors
 - **selection** process
 - **Opt-in** and **opt-out** possibilities

Huge thank you to Jaap, Colette, Magda, Hannah, Elena, Andrea, Ana T. & Sónia!

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What's the role of an Ambassador? (Version 1.0, Feb 9th 2023)



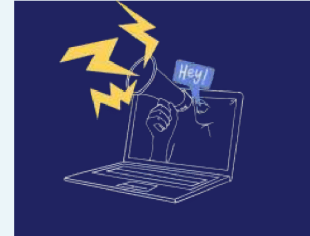
Network updates: attend project meetings, incl. three-monthly virtual BEN & AP meetings & hybrid six-monthly project meetings held at locations around Europe.



Co-Creation of project outcomes: invited to attend focus groups reg. Quality of Life, AYA, EDI and other internal network meetings.



Network: invited to public network events.



Please do note

The **level of participation** in these internal meetings and public network events will be determined by each Ambassador, **according to their available time, area of expertise and national priorities.**



Travel and accommodation costs for Ambassadors participating in EU-CAYAS-NET events **will be covered.** The **time spent to participate will not be covered.** Selected Ambassadors will receive an agreement that provides details on remuneration.

Ambassadorship Criteria

An Ambassador ...

- ... is/was **treated for cancer between** the ages of **0–39** and can be **in or out of treatment**.
- ... is preferably **involved in a national/regional network** and **willing to advocate**.
- ... is able to **think and reflect** upon the aims of this **project from a lived experience** point of view.
- ... has at least an **intermediate level** in speaking, writing and reading in **English**.
- ... is **willing to speak** about the activities of the European Network of Youth Cancer Survivors at **external events and share related posts on social media** (did I hear someone say Discord?...)

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Recruitment Procedure or: How to find Ambassadors

- 1 Kick-Off Meeting, Sept 2022
 - 1st round of recruitment via existing patient advocates from CCI-E and YCE
- 2 Recruitment of new Ambassadors via AP
 - 2nd round of recruitment via Expression of Interest Dec 2022
 - Ambassador Training, Brussels Feb 9th
- 3 Expansion of network
 - Reaching out to countries not covered yet

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How will I know if I will be an Ambassador?



Decision on official ambassadors will be made after the Ambassador Training

Written notification will be sent until end of Feb



Confirmation by the selected participants to accept / not accept invitation

- Acceptance is not mandatory! There is always the possibility to opt out along the way.



Selected Ambassadors will receive written Agreement for participating in Ambassador programme

You can decide!

After being selected to be an official EU-CAYAS-NET Ambassador, Ambassador Candidates / Confirmed Ambassador can opt out any time.

(Not that we want you to, though ;-)



4 • Network Platform

1. Sarunas & Simonas, POLA, WP2

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5 • Patient Advocacy



1. About Patient Advocacy
2. What's Patient Advocacy for you?

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6 • Advocacy – How to translate EU Policy into national context

1. Right to be forgotten – Portugal. Tiago
2. Cancer Plan priorities – Romania. Victor

Interviews by Jaap & Katie

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**Enjoy the break!
See you in 15 minutes.**

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7 • Ambassadorship – Break-out session

1. What kind of support do you need to be a successful Ambassador? – Jaap
2. What are some possible first steps you can take in your home country as an Ambassador? – Andrea
3. Overall, how do you think EU-CAYAS-NET should communicate to attract more young people from across Europe? – Colette
4. Online Group, all three questions – Carina

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Break-out groups

- Group Leaders & Notetakers move every 15 minutes
- Notetakers will take notes in Miro
- In Wrap up session group leaders will present for their questions based on miro

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Next steps



- Decision on official ambassadors will be made
- Written notification will be sent until end of Feb
- Confirmation by the selected participants to accept / not accept invitation
 - Acceptance is not mandatory! There is always the possibility to opt out along the way.
- Selected Ambassadors will receive written Agreement for participating in Ambassador programme
- Selected Ambassadors will be enrolled in Platform (Discord) activities
- Outreach to unrepresented countries to expand coverage of the Network

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EU-CAYAS-NET is a project, co-funded by the European Commission, which unites leading organisations from 18 countries active in the childhood and youth cancer field to map the existing resources that are helpful to young cancer patients, survivors and their caregivers, to create new European guidelines and empower cancer survivors to advocate for their rights and needs.

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Thank you!

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Follow us on social media



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 Instagram

 YouTube

 Twitter

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6.4 Appendix 4. Invitation Email

Subject: You are invited to become an Ambassador for EU-CAYAS-NET

Dear [name],

Thank you very much for your interest in becoming an Ambassador for EU-CAYAS-NET. **We are extremely happy to inform you that your candidacy has now been accepted!** Please confirm that you are still interested in being an Ambassador.

As such, you will be listed on the Network Platform as EU-CAYAS-NET Ambassador, will be a link between the project and what's going on in your country, and you will be engaged in regular updates, communications and activities of the project. 😊

What are the next steps?

- To formalise our agreement and your future involvement as an Ambassador, you will soon receive from us the **Terms of Reference to be signed**.
- The selected **candidates will be made visible** on the network platform, and, if appropriate, on other occasions (communications of ambassador events on Social Media etc.). Your contact details (name, organization, country, picture etc.) will be obtained as part of the Terms of Reference.
- If your **Discord handle** is different from your actual name, **please let us know your exact Discord handle**, so we can mark you as an Ambassador in Discord. Only if you are marked as Ambassador can we add you to the respective Discord Channel. 😊
- **Save the date:** The next Ambassador training will take place in the first week of December 2023 in Vienna.

A list of resources for Ambassadors will be developed based on the results from the workshop in Brussels. Thank you once again for your valuable contributions!

Furthermore, additional interactive activities will be offered during the entire duration of the project, and plans will be co-created with you about how the Ambassador program can continue to run beyond the duration of this project (which ends in September 2024).

We are looking forward to building the European Network of Youth Cancer Survivors with you!

Kind regards,
Barbara
on behalf of the EU-CAYAS-NET Ambassador Selection Panel



beatcancer.eu

6.5 Appendix 5. Ambassador Terms of Reference



Terms of Reference EU-CAYAS-NET Ambassadors

1 Objectives of the Project

EU-CAYAS-NET will improve the quality of life of childhood, adolescent and young adult cancer survivors through improved social networking and the use of a platform to improve the links amongst individuals, patients, cancer survivors, and social and health professionals active in cancer prevention and care across the EU. The network will focus on areas which are of demonstrated benefit to the quality of life of young cancer survivors. The focus will be on three themes identified by young survivors throughout Europe as most important for equitable, lifelong care (Quality of Life, Adolescent and Young Adult care, Equality, Diversity and Inclusion).

2 Role of Ambassadors

The project includes Ambassadors, who are young people with lived experience of cancer participating in the network to communicate the project objectives and disseminate the project results to stakeholders in their Member State. Ambassadors will be recruited from within the networks of CCI Europe and Youth Cancer Europe, as well as from other Beneficiaries and Associated Partners.

3 Activities

CCI Europe and Youth Cancer Europe will train Ambassadors to equip them with the skills to communicate to a broad range of stakeholders, as they are recruited on a rolling basis over the project.

Regular updates (whenever required, at least twice a year) on project activities will be provided for the Ambassadors by the stakeholder core group, the group of representatives of stakeholders directly involved in delivering the project as beneficiaries. The updates will also include recommended national level actions for Ambassadors that will be coordinated at network level.



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Ambassadors will be expected to attend project meetings, including three-monthly virtual meetings with representatives from all Beneficiaries and Associated Partners and hybrid six-monthly project meetings (online or in-person) held at locations around Europe.

As part of the thematic work in Quality of Life, Adolescent and Young Adult Care, Equality Diversity and Inclusion, Ambassadors may also be invited to attend focus groups and other internal network meetings. They will also be invited to public network events. The level of participation in these internal meetings and public network events will be determined by each Ambassador, according to their available time, area of expertise and national priorities.

Travel and subsistence costs for Ambassadors will be reimbursed by a beneficiary upon prior agreement. Time spent at the respective activities will not be reimbursed.

4 Visibility

To give visibility to the Ambassadors, they will be shown on the virtual platform (<https://beatcancer.eu/>)

To have your biography and photo uploaded to the network website, please complete the following information and send both the completed and signed form plus a recent profile picture via an email to info@beatcancer.eu:

1. Name, surname _____
- 2 Country of residence _____
3. Date of birth _____
4. Occupation / profession _____
5. Type of cancer _____
6. 1-3 sentences about you



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You can ask your biography and / or picture to be updated at any time by sending an email to info@beatcancer.eu titled "Updated biography of [your Name, Surname]".

5 Resources

Ambassadors will have access to resources that enables them to give information about the network, to advocate for improvement (e.g. leaflet, templates for presentations , instructions on how the project should be presented etc.).

6 Commitment

As an Ambassador I understand that:

- My first term as an Ambassador is 18 months. After the term expires, I can express my interest to be an Ambassador for another term. The number of terms is not limited.
- I am free to resign from the role of being an Ambassador at any moment in time by sending an email to info@beatcancer.eu, titled "Ambassador Resignation by [your Name, Surname]".
- I am expected to dedicate at least four hours per month to the activities of the European Network of Youth Cancer Survivors.
- I am expected to share social media posts about the European Network of Youth Cancer Survivors on Facebook, Instagram, Twitter and/or LinkedIn to the extent that I agree with the content and think it is worth disseminating.
- In order to help grow the community of the European Network of Youth Cancer Survivors I am expected to invite at least five young people (aged 18-39) with lived experience of cancer to the "beatcancer" discord server within one month of signing this document.
- I am expected to promote activities of the European Network of Youth Cancer Survivors at national level, including, but not limited to being interviewed by journalists and/or attending events related to patient advocacy.



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7 Confidentiality

Ambassadors shall not disclose any information, which is clearly identified as “confidential” about EU-CAYAS-NET project or participants to third parties.

Date

Signature



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