

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

*Grant Agreement No. 101056918*

*EU4Health Programme*

## **Train-the-Trainer concept for HCPs on education & career support for survivors**

Deliverable No: 3.2

WP: 3

Task: 3.3.6 Develop Train-the-Trainer concept



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## Version History

Version	Date	Description
V0.0	24 June 2024	Quality Assurance review by PT
V0.1	12 Jul 2024	Updated version for Coordinator review/approval
V1.0	26.07.2024	Final version submitted to EU4Health

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SIOP EUROPE	SIOPE	3	Beneficiary
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## **Train-the-Trainer concept for HCPs on education & career support for survivors**

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## 1 Executive Summary

Childhood, adolescent and young adult (CAYA) cancer has a disruptive impact on education and career pathways, both during and after treatment (e.g. Vetsch et al, 2018; Nicklin et al, 2021; Foster et al., 2021). Cancer treatment leads to more frequent involuntary absences from school (from primary school to university, depending on age) or the workplace. At the same time, schools and workplaces are often unaware of the needs associated with the disease and treatment. Furthermore, there is usually a lack of knowledge about what additional support can be offered.

After treatment, returning to school, training or work or, depending on age, even starting school or work can be a major challenge. On the one hand, it can be socially and emotionally exhausting to reconnect after a long absence. Sometimes this can even lead to discrimination at school or in the workplace due to the difference between survivors and their peers who do not have the disease. On the other hand, the long-term effects of the disease or treatment can make it difficult to regain previous levels of ability, performance and stress tolerance. Cognitive, emotional or social late effects can sometimes occur many years after the disease/treatment, which can then lead to "setbacks" for CAYA cancer survivors. In any case, these late effects can lead to a need for additional support or the requirement to change to a different educational or career path - some may no longer be possible at all.

To minimise this disruptive impact on education and career pathways, a *Train-the-Trainer concept for Healthcare Professionals (HCPs) on education and career support* has been developed following a systematic review of the literature and desktop search of existing materials, as well as the results of two focus groups on the topic. The original target group of the training concept has been expanded to people who want to set up education or career support in their institutions or organisations or who want to create awareness in their area, in addition to HCPs. The concept developed and key milestones of the development and piloting phase are presented in the following report.

The *EU-CAYAS-NET Train-the-Trainer* concept is tailored to the needs of CAYA cancer survivors and aims to equip participants with the necessary knowledge, attitude and skills to deepen their knowledge and be able to disseminate knowledge or build educational and career support in their national/local structures.

The final version is available for download on the EU-CAYAS-NET Platform.<sup>1</sup>

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<sup>1</sup> LINK – Blog Post [Enhancing Survivorship: EU-CAYAS-NET Quality of Life Initiatives - BeatCancer](#)

## 2 Introduction & Background

Educational and employment outcomes have a significant impact on the quality of life of childhood, adolescent and young adult cancer survivors (CAYA). Devine et al. (2022) report that survivors were more likely to have lower educational achievement and more likely to be unemployed than comparative populations. A primary diagnosis of a central nervous system tumour and experiencing late effects proved to be risk factors. The authors recommended therefore that health care professionals (HCPs) be aware of the risk of educational and employment problems, implement regular surveillance, and refer survivors to specialists if problems are identified. Thompson et al. (2015) also recommend in their standard of care on the topic of school support that paediatric oncology programmes should identify a team member with the necessary knowledge and skills to coordinate communication between the patient/family, school and treatment team. Moreover, a handful of intervention studies have analysed further factors that lead to an improvement in participation in education and working life (e.g. Braun et al., 2023; Dax et al., 2021).

However, the implementation of these or similar recommendations in the follow-up of young people living with or beyond cancer is still in its infancy. There is a clear discrepancy between the existing standards of care and the actual implementation in the follow-up-care of CAYA cancer survivors. This point was very clear in the results of the online survey of survivors conducted during EU-CAYAS-NET (Task 3.2.2.), where the need for support around education and career was stated as being significantly greater than the support experienced.

For this reason, a *Train-the-Trainer concept for HCPs on education and career support* was developed following a systematic review of the literature and desktop search of existing materials (Tasks 3.3.1 and 3.3.2), as well as accounting for the results of two focus groups on the topic of "Identifying gaps in career support programmes" (Task 3.3.3.) (Figure 1). The concept was precisely tailored to the needs of CAYA cancer survivors and equips the participants being trained with the necessary knowledge, attitude and skills to deepen their understanding and be able to disseminate knowledge or build up education and career support in their national/local structures. Once developed, the *Train-the-Trainer concept* was tested and evaluated as part of the EU-CAYAS-NET project. The finalised concept (in English) was then made available for download on the Platform.<sup>1</sup>

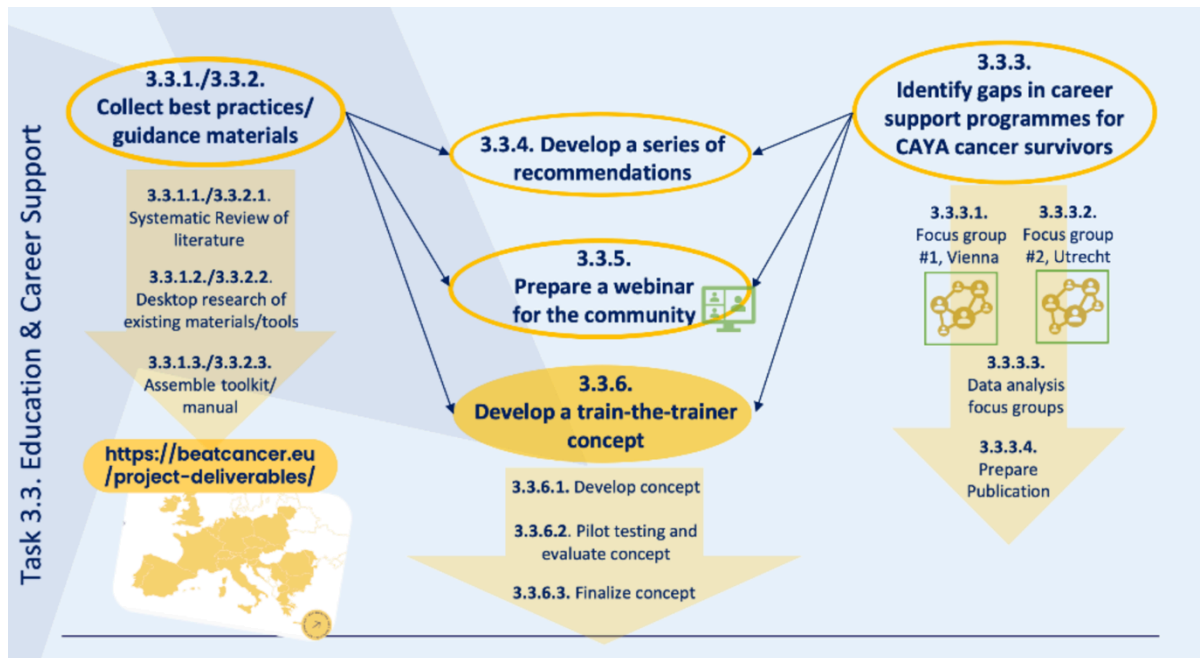


Figure 1. Overview of all subtasks of Task 3.3 Education and Career support that fed into the development of the Train-the-Trainer concept.

### 3 Approach

Beneficiaries CCI-E, MUV and PMC were involved in Task 3.3 Education and Career Support. All activities were carried out using a co-leading approach (involving co-leadership by patient advocates and HCPs), in order to always take into account both stakeholder perspectives.

#### 3.1 Development of the Train-the-Trainer concept

The Train-the-Trainer concept was developed based on the results of activities carried out in Task 3.3 Education and Career Support (Figure 1), including:

- systematic search of literature,
- desktop research of existing support materials/tools,
- toolkit for education and career support,<sup>2</sup>
- recommendations developed as a result of the research within the project and presented in the form of Pocket Cards,<sup>3</sup>
- educational webinar on Education and Career Support hosted by EU-CAYAS-NET,<sup>4</sup> and
- analysis of the results of the focus groups on gaps in career support programmes.

From a didactic point of view, the action learning approach was chosen, which includes a combination of expert knowledge, concrete experience and reflection. In practice, this means that in addition to imparting knowledge, skills, materials and best practice models in the training, there is also room for self-reflection to delve deeper into the subject matter and better understand possible areas of action and problems through self-awareness. Sufficient time was also planned during the training for an exchange of experience, (e.g. to identify successful national best practice models and for trainees to learn from each other).

<sup>2</sup> [Supporting Educational and Career Pathways for AYA Cancer Survivors - BeatCancer](#)

<sup>3</sup> [Pocket Cards for Mental Health Awareness and Guidance for Cancer Patients and Beyond - BeatCancer](#)

<sup>4</sup> <https://www.youtube.com/watch?v=09oa7bVfggs>

The training was designed to be delivered over two half-days and follow-up appointments for supervision and exchange were also included in the concept.

### 3.2 Pilot testing and evaluating of the Train-the-Trainer concept

For the testing and evaluation phase, potentially interested participants were invited via the project Platform (including Discord) and via the project social media channels. The invitation was addressed to people who already work in the field of education and career support with young people living with or beyond cancer, but also to those who want to develop something in this area or those who are interested and want to raise awareness (Figure 2). The invitation was intentionally distributed widely to see who has the greatest need for the training programme.



30 participants from 16 countries took part in the face-to-face pilot-training in Vienna (12 – 13 Mar 2024) (Table 1, Figure 3).



Figure 3. Face-to-face pilot training event in Vienna



**Table 1. Countries of participants at the Train-the-Trainer event**

Country	# Participants
Austria	3
Bosnia	1
Bulgaria	2
Croatia	1
Czech Republic	2
Germany	1
Greece	3
Ireland	2
Luxembourg	1
Macedonia	1
Moldova	1
Netherlands	2
Poland	6
Portugal	2
Slovenia	1
Sweden	1

Amongst the participants, there was only one person who was already working as a trainer in this field, 11 participants offering education/career support in their institution, 10 participants with a desire to build up education/career support in their country, 5 participants interested in the topic and 3 participants attending the training for other reasons. When asked about their experience in education and career support at the start of the training, 75.9% rated themselves between 1 and 3 on a scale of 1 (beginner) to 10 (expert). The majority of participants stated that their reason for attending the training was to expand their knowledge and skills, to learn from the experiences of others and to inform themselves on how to set up an education and career support programme in their setting.

The agenda alternated between theoretical input, group work, role play and group discussion. Plenty of time was allocated for feedback to be able to learn from the testing to optimise the final version of the *Train-the-Trainer concept*.

At the end of the training, participants were asked for feedback on the pilot. Fortunately, the average learning gain reported was 9.6 (*Have you learnt something new?* 1 (not at all) - 10 (a lot)). The participants rated their expertise after the training at an average of 7.6 (scale from 1 (beginner) to 10 (expert)). The most helpful elements mentioned were: resources & materials, exchange of experiences, group discussions, networking. Almost all participants would have liked the training to have lasted longer.

### **3.3 Finalising the Train-the-Trainer concept**

Following the pilot testing, the *Train-the-Trainer Concept* was revised in line with the results and feedback from the pilot and is presented in the Results section.

## 4 Results

In the following sections, the *EU-CAYAS-NET Train-the-Trainer concept on Education and Career Support* developed and evaluated during the project is presented. The programme and the training materials (in English) are available for download as a package on the Platform.<sup>1</sup>

### 4.1 Overview of the training content and modules

#### EU-CAYAS-NET TRAIN-THE-TRAINER ON EDUCATION AND CAREER SUPPORT

##### Target group:

- People already working in the field of education & career support
- Anyone who wants to set up something in this field
- Anyone who is interested and wants to work to increase awareness in this field

##### Recommended duration:

- 1,5 days face-to-face training
- Online follow-up sessions and supervision

##### Training lead:

- Co-lead patient advocate & healthcare professional (desirable: from psychology or social work background)

##### Modules:

<p><b>Module 1:</b> Welcome: Teambuilding and introduction to the training</p> <p><b>Module 2:</b> Impact of CAYA Cancer on education and work: challenges &amp; protective factors</p> <p><b>Module 3:</b> Personal factors: Reflection on education- and work-related strengths and weaknesses</p> <p><b>Module 4:</b> Environmental factors: Analysis of school and workplace conditions &amp; social network</p> <p><b>Module 5:</b> Environmental factors: Finances and legal framework</p> <p><b>Module 6:</b> Specific support options</p> <p><b>Module 7:</b> EU-CAYAS-NET recommendations for career support</p> <p><b>Module 8:</b> Guidance aspects - Communication &amp; attitude</p> <p><b>Module 9:</b> Closing summary, follow-up sessions, evaluation</p>
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<p><b>Module 1:</b> Welcome: Teambuilding and introduction to the training</p>
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##### Goal:

- (1) Getting to know each other, building trust within the group; assessing the level of expertise and experience in the group; clarifying expectations
- (2) Overview of the training programme, presentation of the methodology

**Method:** (1) Group work, (2) Theoretical input

**Material:** Flipchart, sticky notes

**Module 2: Background: Impact of CAYA Cancer on education and work: challenges & protective factors**

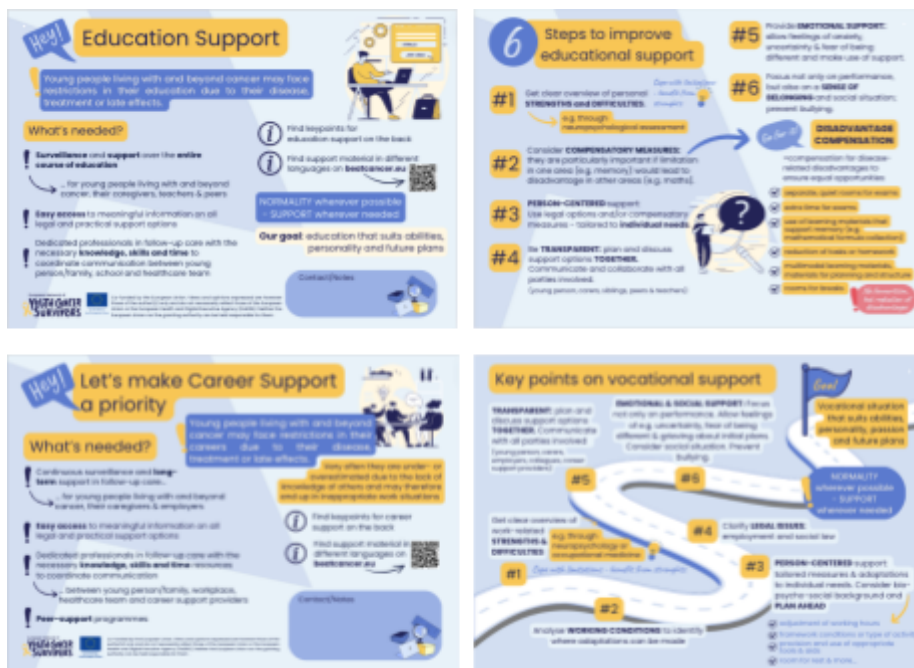
**Goal:** Broaden background knowledge to...

- enable differentiated, individualized and effective support,
- avoid underestimation or overestimation,
- avoid insecurity and fear of the topic.

**Method:** theoretical input

**Material/Content:**

- Disease- or treatment-related physical, psychological and social late effects; protective factors
- Contextual factors that influence participation in education and employment (see e.g. Davis et al., 2022)
- Normative and non-normative developmental tasks for children, adolescents and young adults
- Key points for education and career support (Figure 4 and download materials on the Platform<sup>3</sup>). The Pocket Cards on education and career support were developed under Task 3.2.1 in a working group consisting of HCPs and patient advocates, and then agreed via a Delphi survey and several consensus meetings.



**Figure 4. Key points on Education and Career Support**

**Module 3: Personal factors: Reflection on education- and work-related strengths and weaknesses**

**Goal:**

Through self-reflection and by analysing one's own education- or job-related strengths and weaknesses, the aim is to experience how important it is to know one's own strengths and weaknesses to find a suitable education or job, particularly in the case of late effects; Realising what can be a relevant strength in the context of education or job.

**Method:** Self-Reflection/Partner Interview (Figure 5 and download materials on and download materials on the Platform<sup>2</sup>)

**Partner-Interview - Self-Reflection**  
Train-the-trainer Education & Career Support

Which strengths are helpful in your training/job? Which strengths can you make use of?

Are there strengths that you cannot realise in your job/training? That nobody knows about?

general, disease-related or unrelated

Enthusiasm, Loyalty, Creativity, Empathy, Team spirit, Memory, Problem solving, Hearing, Load capacity, Organisation, Flexibility, Language, Forward-thinking, Processing speed, Endurance, Logical thinking, Mathematical skills, Accuracy, Organisation, Attention, Multi-tasking, manual skills, Communication, Stress resistance, ...and many more...

What weaknesses do you have, that sometimes make your job/training difficult?

What exactly happens? How do you deal with the situation?

Do your colleagues know your strengths or weaknesses better?

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**Module 4: Environmental factors: Analysis of school and workplace conditions & social network**

**Goal:** Analyse education & working conditions: facilitators and hindering factors; Raising awareness that environmental factors have a major influence on school/job performance and consequently must be analysed in detail and consequently very often adapted.

**Method:** Group work: *What can be hindering factors in the school or work context?*

**Material:** Flipchart paper, sticky notes

**Module 5: Environmental factors: Finances and legal framework**

**Goal:** Broaden knowledge about legal and financial regulations and challenges in the educational- or work-context

**Method:** Theoretical input; Group discussion and collection of national best practice models

**Material:** Flipchart paper, sticky notes

**Module 6: Specific support options**

**Goal:** Learn about and discuss specific support measures and best practice models

**Method:** Theoretical input; Group work: *Specific support options in the work context*

**Material:** Worksheets that deal with various possible limitations/impairments, e.g. chronic fatigue (see Figure 6 and download materials on the Platform<sup>2</sup>) or memory deficits and how to deal with them (*How can the respective limitation/impairment be recognised? How can targeted support be provided?*). Task: Create respective checklists for the work context.

**Reduced resilience/chronic fatigue**

How do I recognize it? <input checked="" type="checkbox"/>	What can I do? <input checked="" type="checkbox"/>
<input type="checkbox"/> Difficulty getting to school on time	<input type="checkbox"/> Gradual integration: Initially, the pupil returns to school for a reduced number of hours, which is gradually increased (with regeneration); preferred attendance of main subjects and favorite subjects; alternation of strenuous/less strenuous lessons; e.g. starting school only at the second or third lesson
<input type="checkbox"/> Severe tiredness and exhaustion, which increases as the school day goes on	<input type="checkbox"/> If necessary, maintain the reduction in lessons in the event of persistently reduced resilience
<input type="checkbox"/> Lack of motivation	<input type="checkbox"/> Individual form of task setting/ performance review/assessment
<input type="checkbox"/> Increased irritability	<input type="checkbox"/> Individual organization of breaks
<input type="checkbox"/> Impaired concentration or memory difficulties	<input type="checkbox"/> Allow eating and drinking in the event of a severe "drop in energy" (by prior arrangement), e.g. chewing gum has been shown to increase alertness in the short term
<input type="checkbox"/> Frequent confusion	<input type="checkbox"/> Enabling movement units and other activating measures
<input type="checkbox"/> Slower working style	
<input type="checkbox"/> Less interaction with classmates	
<input type="checkbox"/> Decreased appetite	

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**Module 7: EU-CAYAS-NET recommendations for career support**

**Goal:** Learn about EU-CAYAS-NET recommendations for career support

**Method:** Theoretical input; Group Discussion

**Material:** Pocket Cards (Figure 7 and download materials on the Platform<sup>3</sup>)

**Module 8: Guidance aspects - Communication & attitude**

**Goal:** Learning about the basic principles of communication with young people with or beyond cancer; developing communication skills and an appropriate attitude through self-reflection

**Method:** Theoretical input; Role play “Respect feelings”; Group discussion

**Material:** Pocket Cards (Figure 7 and download materials on the Platform<sup>3</sup>; the Pocket Cards on were developed under Task 3.2.1 in a working group consisting of HCPs and patient advocates and agreed in a Delphi survey and several consensus meetings); Guidelines on communication about serious matters

**Talking with young people about serious matters**

Communication about difficult topics is not something that can be avoided, but the approach and attitude can make a difference.

- #1 BE AT EYE LEVEL**  
Physically and symbolically.
- #2 APPRECIATE**  
Show willingness to enter the young persons world, try to accept their reality as they see it and hear their fears and their losses as they feel them. Appreciate their points of view - don't judge or underestimate them.
- #3 INVOLVE**  
Give young people a voice: Talk TO, not ABOUT them! Encourage age-appropriate, active participation.
- #4 LISTEN**  
Listen carefully: WHAT is being said HOW? Especially at untypical times & unexpected places.
- #5 ADAPT LANGUAGE**  
Use gentle & careful language oriented to the DEVELOPMENTAL STAGE of the young person. Consider both verbal & non-verbal communication. e.g. eye contact, personal space.
- #6 RESPECT EMOTIONS**  
Take emotions seriously. Name emotions, respect them, don't minimize.

Find more information on [youthcancer.eu](https://www.youthcancer.eu)

**Talking with young people about serious matters**

- #7 BE SINCERE**  
Young people expect honest answers to honest questions in order to build trust.
- #8 SHOW OPENNESS**  
Signal that all questions are good & welcome. Be open to discuss difficult topics instead of making them taboo. Pay attention to small signals.
- #9 ORIENT YOURSELF TO QUESTIONS**  
Be guided by questions from the young people. They naturally seek the amount of information that is right for them in order to feel safe. Don't over- or underchallenge.
- #10 GIVE SPACE & TIME**  
Offer a protected, age-appropriate environment. Consider attention span and give time to process. Schedule multiple sequential conversations.
- #11 USE TOOLS**  
Provide books, drawings, applications, visual models, etc. to encourage understanding and processing in order to support informed and shared decision making.
- #12 PLAN & ACT**  
Discuss concrete next steps & plan together to ensure self-efficacy. Give confidence & security.
- #13 INVOLVE FAMILY & SOCIAL NETWORK**  
Family or the social network can be a valuable source of support during difficult conversations.

It is okay to be overwhelmed and look for help when communicating.

Find more information on [youthcancer.eu](https://www.youthcancer.eu)

**Hey!** Before engaging in a conversation with people living with and beyond cancer, ask yourself...

- How am I feeling today? Am I capable to support?
- What is my role in this person's life?
- What does that imply for the conversation?
- What does this person expect from me?
- If it was me, what would I want from this conversation?
- What do I know (or think I know) about this diagnosis?
- What kind of question can I ask? Do I need to ask that?

**Key Takeaways**

- Be curious
- Be patient
- It is ok to not know what to say (and to express that openly)
- It is ok to ask a difficult question, but give the person the space to leave it unanswered
- Accept the persons experience, not what you think it is
- Try to be comfortable with silence, non-verbal communication can also be effective and comforting

Find more information on [youthcancer.eu](https://www.youthcancer.eu)

**Tips to improve communication**

Poor communication can affect decision-making, adherence to treatment, social relationships & mental health.

**What to say (DO'S)**

- Tailor communication**  
Consider individual age, cognitive development, social supports and trough all that, unique needs and abilities.
- Acknowledge emotions**  
Be empathic, but avoid excessive empathy.
- Support decision-making**  
Provide all information needed to make an informed decision.
- Be honest and transparent**  
Provide information in a constructive, helpful manner.

**What NOT to say (DON'T'S)**

- Blame**  
"What have you done to get cancer?"
- Compare**  
"You should be grateful at least you are alive!"
- Impose**  
"You should be grateful at least you are alive!"
- Label**  
"Fighter", "Hero" (There is no one-size-fits-all)
- Use toxic positivity**  
"Stop worrying, it's few months you will look completely better!"
- Depersonalise or minimize**  
"At least you did not have the most aggressive type of cancer!"

Find more information on [youthcancer.eu](https://www.youthcancer.eu)

**Module 9: Closing Summary, follow up, evaluation**

**Goal:**

- evaluation of training,
- discuss open questions,
- collect and make available content, that was generated in the training,
- ensure possibility of future collaboration/networking of the group (for all who want to join), and
- plan focus of next online follow-up sessions (e.g. supervision, open questions, exchange of best practice models, etc.)

**Method:** Group discussion

**Material:** Flipchart paper, sticky notes

## 5 Impact & Conclusion

The overall project revealed a great need for education and career support for CAYA cancer survivors, which cannot currently be adequately covered by the existing care structures almost anywhere. This was also demonstrated by the fact that there were many people who wanted to set up something in their national structures and very few who were working in this specific area were present during the pilot training. The need for specific support tailored to the needs of CAYA cancer survivors was confirmed once again, as general counselling approaches (without, for example, knowledge of the impact of cancer-related late effects) proved to be ineffective.

Various steps are now being taken with the concept and materials developed in the project:

1) The group of participants in the pilot training will continue to work together in online follow-up sessions. In this way, the participants will continue to develop from trainees to trainers for others. The material developed will be made available to them.

Furthermore, additional international best practice models for education and career support will be collected to learn from each other and to continue the respective health policy work. Moreover, the follow-up sessions will be used to work on concrete ways of setting up education and career support in their regions.

All of this will result in an updated, finetuned version of the train-the-trainer concept, which will also be scientifically tested for its effectiveness in the future.

2) Professional societies for HCPs (e.g. SIOP Europe or PanCare) will be informed about the now existing train-the-trainer concept on education and career support. Interested colleagues from e.g. SIOP Europe Psychosocial Working Group, SIOP Europe Brain Tumour Group Quality of Survival, but also national professional societies will be invited to a possible training course, which should be offered e.g. in connection with other meetings/educational courses of the professional societies. This will be communicated in the form of presentations at conferences, newsletters and via the project platform.

Interested persons can also contact the Medical University of Vienna ([eucayasnet@meduniwien.ac.at](mailto:eucayasnet@meduniwien.ac.at)) or CCI Europe ([office@ccieurope.eu](mailto:office@ccieurope.eu)).

**Sources:**



Braun, I., Friedrich, M., Morgenstern, L., Sender, A., Geue, K., Mehnert-Theuerkauf, A., & Leuteritz, K. (2023). Changes, challenges and support in work, education and finances of adolescent and young adult (AYA) cancer survivors: A qualitative study. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, 64, 102329. <https://doi.org/10.1016/j.ejon.2023.102329>

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