



EUROPEAN UNION



# EU MISSIONS

CANCER



## Summary report of the young cancer survivors workshop, 15 December 2023

### 1. Introduction

Under the Quality-of-Life objective, the Cancer Mission has launched a new dialogue with young cancer survivors, to better understand their specific needs and challenges and to co-create initiatives that will help addressing them.

Since January 2023, a series of workshops (11-12 January, 6 February and 26 May) have been held with a group of about 70 young cancer patients and survivors from all over Europe to discuss unmet needs and challenges faced during and after cancer treatment, as an input for future priorities of the Cancer Mission.

Among the challenges reported, emphasis was placed on **mental health** and the importance of ensuring **quality psychosocial support**, both during and after treatment, when **late effects** (fatigue, chronic pain, infertility, disabilities, fear of relapse, secondary cancers, etc.) hugely impact survivors' lives. **Transition from childhood to adult care** (but also transition from hospital to home care), and more generally follow-up care, together with continuity in education and access to quality information were listed as areas where inequities and inequalities hit the most, both from the perspective of young cancer survivors and caregivers.

One of the aspects strongly voiced by participants, concerned the **management of adolescent and young adult (AYA) cancer patients**. Because of their particular age group, being neither children nor adults, care provided in healthcare systems is often suboptimal, not targeted to their specific needs and challenges, such as age-specific supportive care, fertility counselling, appropriate psychological support, education and career development, body image, sexuality and relationships, alcohol/substance abuse etc. The importance to invest in research and innovation, to i) develop more effective and specific treatments for AYA cancers, to ii) better understand late effects and develop approaches to better cope with them, were identified as main priorities.

The dialogue has been instrumental for:

- The organisation of the conference “*Addressing the needs of young cancer survivors*” held on 7 February 2023;

- The organisation of a thematic session “*Boosting mental health of young cancer survivors*” held at the European Health Forum Gastein on 26 September 2023;
- The inclusion of a topic in the 2024 EU4Health Annual Work programme to support an exploratory study on the provision of AYA care in the EU;
- The development of targeted promotion/awareness raising material, including videos (e.g. testimonials of young cancer survivors), articles (e.g. Horizon Europe magazine) etc;
- The inclusion of a proposal to develop a platform for young cancer survivors as a flagship initiative of the EC communication on a *Comprehensive approach to mental health*.

More concrete outcomes are in the making (e.g. support for research on late-effects in AYA cancer).

## 2. Objectives and Outline of the programme

One year since the inception of the dialogue, the workshop in December aimed to provide an opportunity to take stock of progress made in 2023 and discuss future priorities, with a group of young cancer survivors in their capacity of representatives of EU youth cancer patients/survivors organisations<sup>1</sup> as well as representatives of relevant EU funded initiatives/projects<sup>2</sup>.



The workshop built on the outcomes of previous workshops and consisted of an introductory session, where each organisation and project as well as DG RTD and DG SANTE provided an update on progress, setting the scene for the thematic discussions.

<sup>1</sup> Childhood Cancer International Europe; Youth Cancer Europe; SIOPE;

<sup>2</sup> EU-CAYAS-NET; PanCare follow-up; OACCUs

The moderated thematic discussions in the afternoon, revolved around two main topics:

1. Better work together
2. Better outreach local communities



Thematic discussions were moderated by Amanda Drury, Cancer Mission Board Member, together with staff of the Cancer Mission secretariat.

Details on the main theme of each thematic discussion and guiding questions shared with participants ahead of the workshop are available in Annex.

### 3. Main points and recommendations from the afternoon discussions

#### TOPIC 1: Better work together

**Communication and information sharing** were highlighted as two crucial elements to ensure effective cooperation among stakeholders.

The continuous development and fine-tuning of policies that address the needs of specific groups of cancer patients is crucial. Participants praised the direct engagement approach that the Cancer Mission is implementing with young cancer survivors, as an effective mechanism to promote dialogue and boost cooperation. It is an example of how the EU can make a difference by promoting policy making driven by the needs of different communities.

The group called for more meetings, alternating between in presence and virtual formats (more accessible), but also broadening participation, by bringing together different stakeholders' groups, to discuss around specific thematic priorities.

Effective collaboration requires **coordination**, which the Cancer Mission is currently providing (the Cancer Mission was defined as the "superglue", to bring different groups working on common issues together and steer discussion). It was suggested to establish a coordination committee, bringing together representatives of the different groups, DG RTD and DG SANTE.



Yet this would have an impact on resources, an aspect not to be underestimated, considering that sustainability, including **financial sustainability** remains a concern for patients and survivors organisations.

The importance of making the dialogue a **joint endeavour** (e.g., in setting the agenda, hosting meetings, define priorities etc) was also highlighted, to boost overall commitment.

**Information sharing** should be seen as a bidirectional process, from the EC to stakeholders and the other way around. A system should be developed (e.g., a joint platform) to ensure effective communication and information sharing between the different groups and stakeholders.

Information available on the Cancer Mission implementation and its interplay with the Europe's Beating Cancer Plan is rather scattered. Limited information is available on funded projects, their achievements or impact, as well as on what has been achieved through the dialogue with young cancer survivors. The group called for more transparency: more and better information would help **improving complementarity and reduce duplication**.

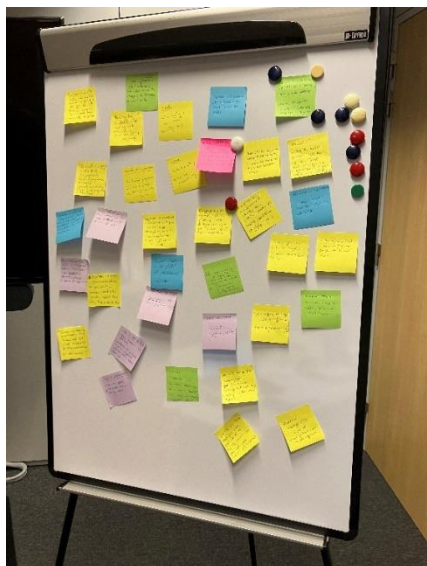
The Cancer Mission informed that a new website is in the making, which will be much more focused on implementation and address many of the concerns raised.

Participants also pled to continue supporting **research relevant for the CAYA group**, ensuring meaningful involvement of young cancer patients and survivors (beyond dissemination).

## TOPIC 2: Enhance outreach to local communities

There was general consensus that widening outreach to local communities is a shared priority, yet rather challenging.

Often there is **reluctance from young cancer patients/ survivors** to engage. One of the reasons is that engaging in such activities is rather time-consuming and not compensated. Participants would have to take leave from their job or studies, which in the long run is not sustainable.



Language and cultural barriers were also mentioned.

A proposal was made to develop a mechanism to provide more financial support for small-scale, local initiatives, going beyond the large national or international gathering.

In addition, a centralised communication platform accessible to all, including local organisations, could improve inclusion and outreach. Complementing it, a program for staff exchange, both for healthcare professionals and for those engaged in patient organisations, could aid the exchange of good practices and the alignment of service offers.

Emphasis was placed also on **minority groups** and **disadvantaged people**, as particularly hard to reach. The group pled **also for more research to better know/understand such group**, an essential step to facilitate their integration and engagement.

Both EU-CAYAS-NET and OACCUs referred to their **ambassador programmes**, as a great way to boost outreach to and participation of local communities. Ambassadors could be actively involved in collecting experiences, ideas, challenges of local communities to be taken into consideration when developing new

policies and funding schemes. Yet more support is needed to expand those programmes and improve their sustainability.

Different groups referred to the extensive effort that is already being put into ensuring continuous engagement with local patients, parents and survivors organisations. Healthcare institutions could play a central role as meeting point and source of information for young cancer survivors, beyond online resources. Also, information (and education) addressed at the non-medical professionals that work with young cancer survivors (including school/university teachers, vocational trainers, social services, insurance officers etc) could lead to societal change.

To see a meaningful impact, it is essential to bring also care managers, administrators, charities etc into the discussion, to push **survivorship and the provision of survivorship services** higher up in their agendas.

Many considered that the ongoing **Echos** project<sup>3</sup> could play an important role in facilitating this dialogue at national/regional and local level.

Participants also called for better mapping services/hospitals at EU level that provide dedicated services for AYA patients and survivors. The EC reminded participants that the 2024 EU4Health AWP includes a topic for a study to map provision of AYA care in the EU, to identify best practices and gaps/barriers.

The study is also expected to produce recommendations for action.

## Next steps

The Cancer Mission secretariat will draw a plan for 2024 and beyond to further structure and develop the dialogue with young cancer survivors that started in 2023.



<sup>3</sup> <https://cancermissionhubs.eu/>

## Topics and guiding questions

	THEMATIC SESSION 1	THEMATIC SESSION 2
Theme of the session	Better work together	Better outreach local communities
Short description of the topics to discuss	<p>Under the Quality of Life objective, the Cancer Mission has launched in 2023 a dialogue with young cancer survivors, to better understand challenges faced during and after cancer treatment, and to co-create initiatives that will help address such challenges.</p> <p>The dialogue has been instrumental for the inclusion of a proposal to develop a platform for young cancer survivors to boost mental health, as a flagship initiative of the EC communication on a Comprehensive approach to mental health. It also allowed to identify specific issues to be addressed through research.</p> <p>Looking ahead, it has become essential to better structure the dialogue, including by ensuring better complementarity with other ongoing initiatives and stakeholders sharing similar objectives, ultimately fostering synergies.</p>	<p>1 in 3 persons in the EU will be affected by cancer; the Cancer Mission aims to ensure that citizens are never left out of sight, for example by strengthening the links between patients and survivors needs, and the direction of public health policy and research.</p> <p>Citizens engagement is therefore key to the Cancer Mission approach, aiming to build trustful dialogues with and providing direct feedback from and to citizens on the EU cancer activities and policies.</p> <p>Building on ongoing work with young cancer patients and survivors, a need has been recognised to broaden its engagement, better reaching out to local communities.</p>
Guiding questions	<ol style="list-style-type: none"> <li>1. How can we improve communication to better support collaboration?</li> <li>2. What common goals/shared objectives would you define?</li> <li>3. What challenges/gaps do you see?</li> <li>4. Where do you think EU support could make a difference?</li> </ol>	<ol style="list-style-type: none"> <li>1. What do you see as most challenging in engaging with local communities?</li> <li>2. What would you consider the main goal of engaging with local communities?</li> <li>3. Can you share any good practice or unsuccessful experience?</li> <li>4. Where do you think EU support could make a difference?</li> </ol>

