



EUROPEAN UNION



EU MISSIONS

CANCER



Summary report of the Young cancer survivor workshops

January 11-12, 2023

1. Introduction

On 11 and 12 January 2023, an online workshop organised at the initiative of the European Commission Directorate-General for Research and Innovation¹ took place, bringing together young cancer survivors, patients, parents and caregivers. A second workshop with the same group of participants will take place on 6 February, ahead of the conference “*Addressing the needs of young cancer survivors*”, planned in Brussels on 7 February 2023. The workshops and conference are activities of the [EU Mission on Cancer](#)².

Objectives

The workshops were meant to prepare for the conference, by collecting input directly from young cancer patients, survivors and caregivers from across the EU and beyond on their unmet needs, based on their personal experience. It also aimed to strengthen network opportunities, facilitating long-term collaboration and exchanges, including of good practice.

The workshop discussed four broad areas, each addressed in a dedicated parallel session:

- Life after cancer
- Caring for children with cancer
- Involvement in research and engagement
- Inequalities in access to care

¹ The workshop were organised with the support of projects funded by the EU4 Health Programme to create an EU Network for Young Cancer Survivors: OACCUs and EU-CAYAS-NET (CCI Europe, Youth Cancer Europe and fellow partners), as well as the World Health Organization Regional Office for Europe (WHO/Euro).

² The EU Mission on Cancer is an initiative under Horizon Europe, the EU framework programme for research & innovation (2021-2027).

The two-day workshop was joined by nearly 100 participants. Most of the registered participants were young cancer survivors and patients, while about one in ten were parents or caregivers of children who have/had cancer. About 1 in 3 participants also indicated that they were representative of a patient organisation.

2. Outline of the programme

Day 1 - Plenary

A plenary opening session kicked off the workshops with a brief introduction to the EU Mission on Cancer and clarifications about the purpose and structure of the workshops. One of the key objectives of the EU Mission on Cancer is to improve the quality of life and (follow-up) care of young cancer patients, survivors and their caregivers. Thanks to advances in early detection, effective therapies and supportive care, survival rates have increased dramatically. The number of cancer survivors is growing every year and is now estimated at over 12 million in Europe. This figure includes around 300 000 childhood cancer survivors, a number which is also expected to rise substantially in the years to come. While this is a reason for joy, survivors, their families and carers experience significant challenges. To better understand and address these challenges, the EU Mission on Cancer recognises that it essential to engage with young cancer patients and survivors, providing them with a space to voice their needs, directly contributing to shaping a future EU research and policy agenda that matters to them.

Four polling questions showed the countries where the participants were joining from, the age distribution, participants' relation to cancer, and their expectations for the workshop.

Then, the collective group was broken up into smaller groups for the different parallel sessions.

Day 1 - Parallel session 1, Life after cancer

This session was directed at people who have experienced cancer at a young age. A brief introduction summarised data from the literature on challenges that young cancer patients and survivors face during and after treatment. Before starting the discussion, participants were asked in a poll what topics they found most relevant to discuss regarding life after cancer. Mental health and late effects were the most mentioned; other aspects included fertility, follow-up care and discrimination.



During break-out sessions, participants discussed about challenges they encountered during and after treatment. Lack of psychosocial support was often mentioned, as well as the importance of having a support network of patients with people they could relate to. Participants referred to the sense of loneliness during treatment, in particular during the COVID pandemic, and difficulties in continuing with their education. Continuity of care, and in particular follow-up care, was also a central topic. Many also stressed that

it is not easy to find reliable quality information, especially about specific late effects of treatment. There is the feeling that healthcare professionals neglect that adolescents and young adults (AYA) have specific needs, and that research should focus more on the specificities of the AYA group, as compared to children or adult patients.

A detailed description of the challenges and needs is described in the section on Main challenges and needs.

Day 1 - Parallel session 2, Caring for young people with cancer

Six parents and/or caregivers of children who had/have cancer participated in this parallel session. They joined from Germany, Greece, Ireland, Portugal, Bulgaria and Spain.

Participants talked about follow-up care and transition, from the hospital setting to home, but also transition from childhood to adulthood. Caregivers also stressed the importance of maintaining good quality of life both during and after treatment, referring to school, traveling, family bonds as part of feeling well and living a good life. The overall wellbeing (physical and mental health care, nutrition etc) should be supported.

A detailed description of the challenges and needs is described in the section on Main challenges and needs.

Day 2 - Parallel session 3, Research

After a brief recap of what was discussed in the sessions of the previous day, a short introduction of the main challenges in research relevant for childhood and AYA cancer patients, prompted a number of priorities to facilitate the discussions. These included:

- Research to improve understanding of childhood and AYA cancers.
- Research for the development of new, more-effective, and safer treatments.
- Survivorship research, targeting the long-term effects of cancer and treatments, including psycho-social aspects
- Infrastructures (e.g. including for data collection and sharing) to enable researchers, clinicians etc to access better resources and services.

What topics regarding 'involvement in research on childhood cancer and late effects' are most relevant to you? It can also be the main topics you want to discuss with other cancer patients and survivors in



A poll asked participants to highlight what topics they found most relevant. Mental health, fertility, and fatigue were amongst the most listed topics, which were then followed-up in the break-out discussions. Participants voiced the importance to enhance efforts to develop more effective, less toxic treatments for childhood and AYA cancers, as well as more research to better understand the late effects of cancer and treatments as well as development of tools and strategies to better cope with them. Involvement of young cancer patients in the

design and implementation of research studies was also identified as needing more attention.

A detailed description of the challenges and needs is described in the section on Main challenges and needs.

Day 2 - Parallel session 4, Inequalities (co-led by WHO)

The WHO team presented an overview of ongoing work to address inequalities in cancer care. They pointed to the [The Global Initiative for Childhood Cancer](#) which aims to increase access to care, via patient-centred efforts, to establish a global quality framework via health systems centred efforts and to integrate

childhood cancer into national policies and programmes, via policy centred efforts. Participants also received more information about a recent WHO Europe Report on Childhood Cancer Inequalities across Europe, which provided insights on the level of Inequalities across countries in childhood cancer incidence/mortality/survival rates/survivorship follow-up care.

Following the opening presentation participants were split into two breakout rooms. They discussed inequalities based on their own experience.

A detailed description of the challenges and needs is described in the section on Main challenges and needs.

3. Main challenges and needs as mentioned across sessions

Main issues & good practices summarised

- **Support**
 - o Mental health, psychosocial support and peer support are important and deserve more attention, should be available for all children and caregivers
 - o Siblings and family members need more support
- **Financial aspects**
- **Continuity of quality education for patients**
 - o Educate the educators about (hidden) disabilities
 - o Network of teachers that help students to continue learning
- **Transition & follow-up care**
 - o There needs to be more attention on transition from paediatric to adult care
 - o More education for healthcare professionals, particularly for follow-up care
 - o Facilitate follow-up care throughout Europe; more standardization
- **Access to quality information for patients and caregivers**
- Involvement in research, lack of information about research
 - o Ensure input from young people, especially for uptake on digital tools
 - o Improve communication about research projects and networks
 - o More research into late effects and approaches to better cope with them
- Exercise, music, traveling can help make people feel better
- More collaboration between healthcare professionals, pediatricians, adulthood doctors, parents and patient organisations needed

Psychosocial support

Participants strongly emphasised the importance of psychosocial support. Some participants reported that they were never asked about their mental health, during nor after treatment. Many participants reported that mental struggles sometime even increase after the treatment, because of the side effects, including chronic pain and fatigue. Mental support is therefore crucial not only during treatment but also after that. But support by a psychologist or psychiatrist is not easy to get and it can be very expensive.

Psychosocial support is needed not only for the patients themselves, but for the whole family, both to parents and siblings. While to some extent such support is available in some countries, participants argued that there should be a standard and it should be integrated in all stages of the cancer continuum. For example, participants from Ireland and Portugal mentioned that psychosocial support is provided through

non-profit support centres and not through the hospital. In Greece there are no psychologists in hospitals, unless it is a hospital dedicated to mental health.

Recommendations & good practices:

- Good practice: Rehabilitation therapy after chemotherapy, in which patient and family can spend extended periods in contact with nature has proven very useful.
- Recommendation: Ensure that mental care becomes available and accessible for all young patients, siblings and caregivers in all EU Member States.

Peer support

It is important to be able to count on peer support, a network of survivors or caregivers to share time with. Survivorship demands a cancer family. “We need to be around peers to feel understood.”

But there is a sense of a lack of networks where survivors and/or caregivers can contact each other and share common experiences. Many survivors and parents experienced a sense of loneliness while going through treatment.

Recommendations & good practices:

- Good Practices: In Portugal, the organisation *Acreditar* has a network of volunteers who visit patients during treatment and share experiences. An organisation in Bulgaria arranges for cancer survivors to visit hospitalised cancer patients every week.
- Good practice: A survivor has organised workshops for teenagers after cancer, where they can meet each other and talk and work on themselves, for example on boosting confidence and mental health.
- Good practice: In Belgium, an organisation developed an AYA pathway. Pilot project with specialised team for AYA care at hospital in Ghent, which will be implemented in 6 hospitals in Belgium. Written by AYA, involved in policy making. The EU Commissioner for Health Stella Kyriakides has visited a the pilot project, link to the visit: https://twitter.com/SKyriakidesEU/status/1546813309395079173?ref_src=twsrc%5Etfw
- Recommendation: Young cancer patients should be treated in centres for young people only, and not in general hospitals. In this context, the Princess Maxima Centre (Netherlands), the Medical University of Vienna (Austria) or the FSJD in Barcelona (Spain) were mentioned as example of centres providing dedicated AYA care (transition, long-term follow up).

Support with daily life (finances, recreation, work)

From the perspective of caregivers, such support would be essential to coping with other responsibilities (care for other children, work, household) or give them some time for leisure. Time can be a problem, especially for single parents, who might have to quit their (paid) job to take care of their children. Single parents especially talked about the high financial burden and all responsibilities weighing on them as the only caregivers. It was suggested that parents/caregivers should receive financial support – “not a lot, but enough not to worry about money” – to bring some relief as they take care of their children. Financial and social support should also be given to young people as they navigate the job market, grapple with loss of income, and ongoing health expenditures.

Participants agreed that support from social workers can really help to learn about your rights and to navigate the bureaucratic maze, to know and secure entitlements for young people and adolescents.

Participants also reported that in many cases they were confronted with healthcare professionals that had limited understanding of the challenges of patients, survivors and their families.

Recommendations & good practices:

- Good practice: In Portugal, a social innovation project provides recreational and physical activities at home for children with cancer, as well as nannies for the caregivers. It is a pilot project which will last 18 months. 28 families are included in the project, impact evaluation is being done by the university – the scientific results will be available at the end.
- Good practice: Luxembourg, since childhood cancers are not treated in the country, but across the border in France, Germany and Belgium, support comes from two parent organisations that provide psychologists, therapies for the whole family, homework assistants.
- Good practice: In Greece a patient organisation is now running educational groups with some doctors and parents, where healthcare professionals are educating families about survivorship, what they should take care of, what they should know, and in return doctors are also learning about the experiences from families.

Education

Participants experienced challenges in access education/continuing their education journey while undergoing treatment. This for some has meant being at home without school for long periods of time.

There is no support system for students in universities and high schools when they go into treatment. Similarly, it is often not possible for children to attend school when in treatment. There is a need for understanding (from schools) that children are not always capable to follow their studies. Educators are often not aware of the (hidden) disabilities that prevent children from participating in education. Children, adolescents and young adults should be able to participate in school's activities. Sometimes, technology can help.

Recommendations & best practices:

- Good practice: In Germany, to ensure continuity in education, a young cancer patients was provided by the hospital with an avatar, so that he could join classes online.
- Recommendation: Create a network of teachers able to help these students continue learning. The NGO "Bednet" based in Belgium works on this issue.

Healthcare professionals and access to care

Several participants, particularly from small countries, reported limited availability of competent medical staff, equipment and medication, or transportation. Access to treatment relies too often on connections or self-funding. Ethnic minorities in particular face discrimination and cultural, religious, language, and economic barriers.

Recommendations & best practices:

- Recommendation: For rare conditions, the EU should consider creating a support mechanism to transfer patients across EU countries, depending on availability of treatments.

Follow-up care and transition

Transition from childhood to adolescence to young adulthood brings many changes and challenges, including changes in the type of care patients receive and where they can access it. The burden of a lifetime of follow-up care is complicated by this phase in life.

Transitioning from paediatric to adult care is difficult; it is important that caregivers get more support during this period. Moving from paediatric care means moving to (and sometimes having to find) another doctor, in most cases an oncologist. It can also mean that costs that were covered before are not covered anymore. Children also need to be prepared for the transition.

This is only possible if there is a place for follow-up care, and if healthcare professionals themselves are familiar with the organisation of (follow-up) care. It is necessary to have paediatric cancer survivor follow-up care, which is often not available. But in adult medicine, follow-up care is even more elusive, with some participants feeling “left alone” after the treatment phase is over. The continuity of care between treatment and after treatment differs greatly amongst countries. In most countries, adults see an oncologist periodically, but many survivors need specialised follow-up care, and once they leave the paediatric system, this becomes dispersed across the medical specialities and difficult to access.

Participants reported that it is difficult to find reliable quality information or knowledge, for example about late effects, palliative care, re-vaccination. Especially after therapy, when follow-up care is very spread out, there might not be an opportunity to ask the treating oncologist. There is a lack of knowledge amongst GPs and other non-specialised doctors regarding how to directly deal with cancer patients.

Access to full medical records by patients has been also reported as sub-optimal.

Parents/caregivers stressed the importance to engage more in discussions on how care and life for young cancer survivors can be improved. Networks such as CCI and Pancare were praised for their work in providing good information.

Health care systems hugely differ across EU countries.

Recommendations & best practices:

- Good practice: In Italy survivors get a survivorship passport, which might be helpful to have in all EU countries.
- Recommendation: There should be a gradual system for young patients spanning across their lifetime and which is adapted to their care needs across their lives.
- Recommendation: There should be a strong follow-up program for physical care, with specialists from different specialties.
- Recommendation: Transition of care from paediatric to adult care should receive more attention (e.g. through dedicated conferences)
- Recommendation: Parents and patient should get a treatment summary outlining their care plan and medical history.

Research: involvement, information

Participants insisted on the importance of involving more young cancer patients in the design and implementation of clinical studies. There is not enough information and no communication about ongoing research and results. Patients, survivors and caregivers have to actively look for ongoing research programmes/projects, as also healthcare providers often lack information. Even when participating in clinical studies, many participants reported that they receive no information on outcomes. Clear guidelines and protocols for participants in clinical studies/trials should be developed.

Some participants referred to the importance to invest in research infrastructures, ensuring equal/fair access across the EU.

One participant mentioned for example that genetic testing for BRCA mutation should be more accessible to prevent mastectomies or other surgeries later.

Communication between all levels (patients between themselves, with doctors, researchers) should also be improved. There is also a sense of lack of involvement of patients in the development of resources for patients, such as mobile phone apps. But getting input from young people can help with uptake on digital tools.

Recommendations & good practices:

- Recommendation: Invest more in research targeting mental health and late effects.
- Recommendation: Make EU guidelines for involvement of people under 18 in research and clinical trials.

Fertility

Despite having an enormous impact on their lives, several of the young people whose fertility was affected felt there was not enough support for them on this issue. One participant tried to break the discomfort surrounding it by talking about it on his social media channel. He had to decide as a child whether he wanted to preserve his sperm and have it used for research involving animal testing to maintain a small chance of having children. It was hard to decide that as a child.

Another barrier can be the legislation about assisted reproduction in certain countries. For example, in Italy only married women qualify for this. It is not possible to use the oocytes with someone who is not a husband in Italy. There can also be differences between support for cancer patients in related to “other” patients, for instance with coverage for hormonal treatment. Another issue of access is the costs of reproductive treatments, which are very high and often not covered by health insurance schemes.

What is next?

Participants welcomed the workshop and expressed eagerness to continue engaging in the future. Participants appreciated the possibility to connect with peers from their age group.

As one participant put it: “there is a lot to be done, I am glad we are doing this together.”

The pre-conference event takes place on 6 February 2023. The conference Addressing needs of Young Cancer Survivors takes place on 7 February 2023. All participants who have expressed interest in participating have been contacted to arrange for their participant and travel. For more information: <https://research-innovation-community.ec.europa.eu/events/6KlqT7zlxUlzJx0APfF06i/overview>

