EUROPEAN UNION

EU MISSIONS CANCER

Summary report of the young cancer survivor workshops, 26 May2023

1. Introduction

The Cancer Mission aims to strengthen the links between patient needs/survivors needs, and the direction of public health policy and research. Under the Quality-of-Life objective, the Cancer Mission has launched a dialogue with young cancer survivors, to better understand their specific needs and challenges and to co-create initiatives that will help addressing these.

On 11 and 12 January 2023 online and on 6 February onsite, about 70 young cancer patients and survivors from all over Europe as well as a few caregivers attended workshops to discuss unmet needs and challenges faced during and after cancer treatment. Discussions were clustered around 4 main areas:

Life after cancer

Caring for children with cancer

Involvement in research and late effects

Inequalities in access to care

Outcomes of the workshops fed the conference “Addressing the needs of young cancer survivors”, held on 7 February 2023, which was the first big public event since the launch of the Cancer Mission. Workshops and conference are citizens engagement activities of the EU Mission on Cancer[1].

---

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

Among the issues reported by participants, 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. Each year, more than 150,000 people in Europe and over 1.2 million worldwide, are diagnosed with AYA cancer. Cancer represents a substantial cause of death in this population group. Outcomes are often poorer than in younger (or older) patients with the same type of cancers, due to the different biological features of their tumours, which limit specificity and sensitivity to available therapies. 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.

Participants also highlighted 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.

2. Objectives and Outline of the programme

Objectives

The follow-up workshop on 26 May was organised in a hybrid format. The workshop aimed to strengthen engagement with young cancer patients, survivors, and caregivers from across the EU and beyond, and give voice to their unmet needs, challenges but also to successful and inspirational approaches and initiatives. It also aimed to create new networking opportunities, with a view to facilitate long-term collaboration.

More specifically, the workshop created an opportunity to exchange with experts and young cancer survivors on the issue of management of AYA cancer patients, as well as on the understanding and management of late effects of treatments. The meeting was an opportunity to identify gaps and test ideas for new initiatives which the Cancer Mission is currently developing.

The workshop built on the outcomes of previous workshops and consisted of a plenary session in the morning and group discussions in the afternoon.

During the morning session, experts, representatives of excellent initiatives and projects (PANCARE, SmartCare, ECPDC, EUonQoL, SIOPE, EORTC, OACCUs etc.) set the scene, shared their experience and animated the discussion, which continued throughout the networking lunch.

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

1. Understanding and managing late effects in AYA cancer
2. Provision of AYA services and care

Each session was moderated by a Cancer Mission Board Member and/or EC staff.

An outline of the programme, including details on the main theme of each parallel session and guiding questions shared with participants ahead of the workshop is available in Annex.

3. Main points and recommendations from the afternoon discussions

TOPIC 1: Understand and manage AYA's late-effects

What challenges did you experience due to late effect of your treatment?

- Participants reported to experience a number of late effects, ranging from eating disorders, chronic pain, disabilities, extreme frailty and fatigue, anaemia, muscle cramps, infertility, mental health disorders etc.
- While some of these effects are reported to be common across different types of cancers (fatigue, chronic pain, mental struggles, infertility), others (e.g. frailty of the bones) are linked to specific treatments;
- Both from the psychological and physical standpoints, dealing with late effects proves in most cases harder than dealing with the primary treatment. There is often a feeling of being left behind, an (in)ability to socialise, and disrupted working patterns. Coping with permanent disabilities is extremely challenging.
- Many participants indicated to have never received information on possible late-effects from their doctors, neither before nor during treatment. In addition, transitioning from paediatric and/or oncologic care to general care, creates an additional layer of complication in the management of symptoms that sometimes appear long after the treatment has been completed.
- In fact, in most cases, general practitioners are unaware of late effects and therefore not able to manage them properly. Patients are treated for the symptoms without their cancer history being taken properly into account.
- Strong emphasis was placed on fertility. Some participants reported that limited or no information was provided to them about the long-term effects of treatment on fertility and how this can affect patients, including psychologically. In some countries there are no clear guidelines, for example on fertility preservation. Also in some countries there is no clear legislation on related issues, such as adoption or the use of surrogate mothers.

Where do you think there are gaps in our understanding of late-effects that targeted research could help addressing?

- In general, participants considered that research on long-term follow-up of late effects remains rather limited. This would be however essential to support policy actions to improve the management of late effects.
- For some types of late effects very little is known. Often these symptoms are not even recognised as late effects, as their link with the cancer treatment remains poorly understood. A systematic review of onset of late effects by cancer type and treatment would be needed.

- The majority of participants experience more than one late effect. In particular, fertility, mental health and fatigue are often interconnected. These symptoms should be studied with a holistic approach.
- Specifically on fertility, more research is needed to better understand the impact of treatment on fertility and define more effective strategies for fertility preservation.
- More effort should also go into improving the understanding of psychosocial aspects linked to late effects. This would require more involvement of human sciences to investigate quality of life, and participation of all stakeholders, including patients in research projects.

Do you think more research efforts should go into developing better strategies for the management of late effects (e.g. what features should the best management practices have? What do you think is needed to identify, create or mainstream best practices in management of late effect? Etc.)

- Participants considered important to create a “care conscience”, both in doctors and patients, about the importance of following late effects in cancer survivors.
- This can be achieved through targeted education, which should address both healthcare workers and patients.
- For patients and caregivers, the goal should be to ensure that they receive detailed information about the late effects they may experience, at every stage of the disease, including guidelines on how to identify these late-effects and strategies to manage them effectively (e.g. through sport, nutrition etc.).
- Participants considered also essential to invest in targeted training of health care professionals. Therapists/sport trainers/etc. should receive dedicated training on specific AYA needs, to be able to provide the best care (e.g. through sport activities).
- Providing dedicated infrastructure for mental health programmes, meetings/conferences to bring AYA’s together, online tools for AYA’s (podcasts, etc.) were also mentioned as important elements to improve the management of late effects in AYA patients and survivors.
- There is a clear need to establish multidisciplinary teams that would follow AYAs during the treatment, but also later as survivors.
- It is also essential to ensure efficient health data portability, to facilitate individual’s mobility (e.g. to work in a different place) as well as for follow-up care.

Can you share any good practice/experiences that you found particularly helpful?

- A good practice from Slovenia was reported: young adults have their regular check-ups in the oncological hospital, in a dedicated “late-effects” unit. The oncologist can refer the survivor to other services as needed. Every year patients receive clear instructions about the screening tests they must take.
- The PANCARE project[2] was also highlighted, which offers twinning with hospitals to develop long-term plans for survivorship, including management of late effects.

RECOMMENDATIONS

- Support an epidemiological, large cohort, long-term clinical study, which will help to identify and characterise late-effects in AYA.

---

[2] https://www.pancare.eu/

- Support research to predict the occurrence or relapse of late effects.
- Support research on fertility issues: this is not only about developing clinical guidelines (for example on counselling and preservation), it should also consider the psychosocial dimension of the matter (social effects, emotional well-being, how it affects patients in their integration to society or labour market etc.).

TOPIC 2: Provision of AYA services and care

What type of support is mostly needed/missing for the provision of quality AYA care (e.g. what type of support/services do you consider could be included in an optimal provision of services?)

- Participants considered that AYAs are neither children nor adults. What works for other age groups may not work for AYAs.
- In most countries, AYAs are treated in paediatric facilities, which is sub-optimal.
- Participants referred to the “right to be forgotten” regulation, an example of important progress made, which however remains unevenly applied across countries.
- The psychosocial dimension of living with and beyond cancer should receive more attention. More emphasis should be put for example on supporting survivors to regain the lifestyle they had before cancer, to ensure a smooth transition to return to work, or school.
- The notion of disability should also be properly considered. Cancer patients should be declared disabled persons at the moment they are diagnosed with cancer, and not only after the treatment. As disabled cancer patients, AYAs would have access to rehabilitation and other social and financial benefits. In this respect, many participants indicated that genetic tests should be freely available to cancer patients in all EU countries.
- In addition, specific screening tests for late effects should also become available in the hospital setting.
- Many participants highlighted the complexity of accessing their health records. As survivors, collecting their medical history proves often extremely complex.

What should be improved and how?

- Transitioning from paediatric care to adult care was reported as a major issue. Suddenly, survivors are thrown into a new reality, with no guidance nor support.
- Participants stressed the importance to ensure the provision of AYA-dedicated care and services in hospitals. These should include provision of follow-up care for late effects.
- Healthcare should be holistic and patient-oriented. This also implies that communication and tools for information exchange between specialists are available/improved.
- Programmes to support survivors re-entering school or the job market should be developed.
- Participants advocated for changes in legislations, to ensure that in each EU Member State patients/survivors can have instant access to their medical history.
- Provision of personalised long-term care plans should become a standard procedure.
- Mental health support and access to mental health services should become an integral part of such long-term plans.
- Many participants agreed that as AYAs, they should be empowered to have a say in medical decisions that impact their lives (e.g. choice of treatment, questions linked to fertility etc.).

Where do you think EU support could make a difference?

- The issue of inequalities across EU countries on the provision and quality of AYA care was discussed. Participants agreed that the EU could play a role in ensuring a level-playing field.
- The EU could also have an important role in mapping the provision of AYA services across the EU and showcase best practices, supporting also peer-learning.
- Participants also agreed that the EU has an important role to play in the implementation of the “right to be forgotten” regulation.

RECOMMENDATIONS:

- Promote the establishment of dedicated “late-effects units/department in hospitals or cancer care facilities. This should include multidisciplinary teams that would follow AYAs throughout the cancer continuum, both as patients and later as survivors.

Next steps

As announced at the workshop, the outcomes of the discussions will be used to fine-tune upcoming cancer R&I and policy actions.

A follow-up workshop in the last quarter of the year is also being considered. Participants expressed their interest and availability to contribute to shaping the agenda of the next workshop and host the event.

Topics and guiding questions

	THEMATIC SESSION 1	THEMATIC SESSION 2
Theme of the session	**Understanding and managing late effects in AYA cancer**	**Provision of AYA services and care**
Short description of the topics to discuss	Because of recently acquired knowledge and novel therapies of AYA cancers, the gaps have increased in our understanding and management of known and unknown late-effects (increased COVID sensitivity with immunosuppression, organ and skin alteration including infertility, mental health such as body image or stress in facing tumour relapse monitoring, chronic pain, handicap etc) of AYA cancers and related treatments, which warrant more targeted research on AYA cancer survivorship.	Because of their particular age group, care provided to AYA patients is often suboptimal, not targeted to their specific needs and challenges (e.g. age-specific supportive care, fertility counselling, psychological support, education and career development etc.) In addition, AYAs do not have the same health seeking behaviour as adults, making provision of prevention & care services even more complex.
Guiding questions	1. What challenges did you experience due to late effect of your treatment? 2. Where do you think there are gaps in our understanding of late-effects that targeted research could help addressing? 3. Do you think more research effort should go into developing better strategies for the management of late-effects (e.g. what features should the best management practices have? What do you think is needed to identify, create or mainstream best practices in management of late effect? Etc) 4. Can you share any good practice/experiences that you found particularly helpful	1. What type of support is mostly needed/missing for the provision of quality AYA care (e.g. what type of support/services do you consider could be included in an optimal provision of services?) 2. What should be improved and how? 3. Can you share any good practice/experiences that you found particularly helpful (e.g. What support/services did you appreciate the most in your itinerary of care?) 4. Where do you think EU support could make a difference?