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Summary report of the young cancer survivor workshops, 6 February 2023

1. Introduction

On 11 and 12 January 2023, the European Commission Directorate-General for Research and Innovation¹ organised online workshops, which brought together around 70 young cancer survivors, patients, parents, and caregivers, to discuss unmet needs and challenges faced during and after cancer treatment. Most of the 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 a representative of a patient organisation.

The online workshops were clustered around 4 main areas:

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

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 etc.) often have a huge impact on 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 **inequity and inequalities** hit the most, both from the perspective of young cancer survivors and caregivers. Participants highlighted the importance to invest in **research and innovation**, to i) develop more effective and specific treatments for childhood and adolescents and young adults (AYA) cancers, to ii) better understand late effects – too often neglected also by healthcare professionals – and iii) develop approaches to cope with them. Participants also stressed the importance to involve young cancer patients

¹ The workshop was organised with the support of projects funded by the EU4 Health Programme to create an EU Network for Young Cancer Survivors: OACCU 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).

and survivors in the design and implementation of clinical studies/trials and to ensure that research results are easily accessible and properly disseminated.

As a follow-up, **a workshop was organised in Brussels on 6 February** with the same group of stakeholders, which aimed to deepen discussion on the most prominent issues raised during the online workshops and prepare for the conference “*Addressing the needs of young cancer survivors*”, which took place in Brussels on 7 February 2023. Workshops and conference are citizens engagement activities of the [EU Mission on Cancer](#)².

2. Objectives and Outline of the programme

Objectives

By bringing people together, the onsite 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 network opportunities, facilitating long-term collaboration.

The on-site workshop built on the outcomes of the online workshops and consisted of three parallel sessions:

- Policy actions to address survivorship (physical and mental health issues, return to work/ education, needs of parents)
- Inequalities for Childhood and Adolescent Cancer Survivors (co-led by the WHO)
- Research actions to address survivorship (research needs, involvement of patients/ survivors in research activities).

Each parallel session was moderated by a Cancer Mission Board Member. The WHO co-moderated the session on “Inequalities for Childhood and Adolescent Cancer Survivors”.

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.

Following a brief introduction by the European Commission Cancer Mission secretariat to welcome participants and explain the scope and format of the workshop, short presentations were delivered on: 1. the study which will deliver the blueprint of the **European Cancer Patient Digital Centre**; 2. the project **Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe**.

Participants were then split in three groups for the parallel thematic sessions. The day concluded with a walking dinner, which provided additional opportunities for networking.

3. Main points and recommendations from the discussions

Policy actions to address survivorship (Moderator: Amanda Drury, Cancer Mission Board Member)

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

This session focused on the challenges that young cancer patients, their parents and caregivers face when transitioning from active cancer care to a different care setting. More specifically participants were asked to focus on:

- Transition from hospital to home care;
- Transition from paediatric to adult care;
- Transition from active treatment to follow-up care.

Psychological and social challenges during treatment or remission were also discussed.

Transition from hospital to home care

Main issues:

- Participants reported lack of advice and **tailored support** to parents in transitioning to home. All of a sudden parents become full-time caregivers, often unprepared, lacking skills and knowledge.
- Also, there is a general lack of understanding by people that while returning home from hospital is a reason to rejoice, it does not imply that the fight against cancer is over. This is often cause of frustration and distress.
- Patients/parents experience a serious **lack of psychosocial support** to deal with their situation (sense of guilt, fear of relapse; deal with mortality etc)
- **Peer-support** is extremely beneficial during this delicate phase and peer-support mechanisms are available. Yet very often healthcare professionals are either unaware or not interested and therefore unable to provide information about available options.
- Once at home, if health challenges arise there is also **lack of information/clarity** as to where help should be sought (GP, oncologist?)

Transition from paediatric to adult care

Main issues:

- Participants reported a general **lack of standardised follow-up care** between different healthcare professionals, but also between different health care systems across regions, and countries.
- Participants also referred to **lack of knowledge among healthcare professionals** about the patients' conditions, which causes worry and lack of confidence among patients and families.
- The **centralisation of care** puts limits on patients' lives, often limiting where they can live, study or work because their treatment is only provided in one specific place/region/country.

Transition from active treatment to follow-up care

Main Issues:

- Participants reported **lack of infrastructure**, disparities within and between countries in the way patients are referred to specialists or in the thoroughness of follow-up care;
- Similarly, **standard protocols for practitioners** for follow-up care are not available;
- **Limited access to medical records** limits the effectiveness of follow-up care. Participants reported;
- There is **lack of information and limited knowledge about late-effects**, which limits follow-up care.

Recommendations and good practices:

- Getting in touch with local survivor groups help reassure people

- The case of respite care (e.g. care provided in hospice services to allow family some time away from caregiving) in Germany was highlighted: patients can receive respite care in twin care facilities in Switzerland and Austria for four weeks to give a chance for the parents to have a break
- The different steps of the care pathway could be split between routine check-ups and specialised treatments.
- General practitioners should be given time to equip themselves with the necessary knowledge to deal with patients' needs;
- Establish a system to ensure that patients are informed about who they should contact for help, and there should be more focus on providing psychosocial support not only during but also after treatment.
- National social and care programmes should provide support for side/late effects of treatment. These might include: rehabilitation, transition (from hospital) to private and professional lives – for some patients this means after hospitalisation and end of treatment, for others this means living while on maintenance therapy for many years to come, for cancer 'survivors' (cancer patients in remission, on maintenance therapy, cured former patients).
- The International Late Effects of Childhood Cancer Guideline Harmonization Group, IGHG, was mentioned as an example of a successful international initiative, focused on the optimization of care for childhood, adolescent & young adult cancer survivors. A link to the [International Guideline Harmonisation Group was shared with participants.](#)
- Youth networks offer a unique resource to highlight disparities that exist between the quality of care offered in different regions/countries.

Inequalities for Childhood and Adolescent Cancer Survivors (Moderators: Eleni Tolma, Cancer Mission Board Member; Allison Ekberg, WHO Regional Office Europe)

A Cancer care pathway involves several stages, from presentation of symptoms to diagnosis, treatment, and follow-up. Despite huge progress in cancer care, inequalities exist in the provision of cancer care, which can significantly impact outcomes. This session focused on inequalities during and after treatment. More specifically participants were asked to discuss:

- Childhood cancer care pathways to reduce inequalities (care, transition, information):
- Lifetime burden of inequalities (rights/benefits, reproductive issues, long-term care needs, mental health, education, job market/career, cancer survivors vs other patients/survivors)

Childhood cancer care pathways to reduce inequalities (care, transition, information):

Main issues:

- In terms of care offered, both during and after treatment, many participants reported that limited attention was given to their young age. **Healthcare professionals often lack skills in how to interact and communicate with young patients**, who have different needs than adults.
- Also, there are **differences between children, adolescents, or young adults**, which are often neglected by healthcare systems.
- There is **limited cooperation between medical specialties** (surgeons, oncologists...), which further complicate access to and quality of care offered.
- Many participants reported **limited understanding/knowledge by general practitioners**, who have often limited knowledge of cancer, symptoms, or later side effects of treatment.
- One of the most prominent issues discussed was **provision of psychological support**, which most participant reported as suboptimal or absent, both at the time of diagnosis, during treatment, and after treatment, when it would be much needed as fear of relapse, having to deal with

debilitating long-term side effects, coping with reintegration into society etc create huge burden on patients/survivors.

- Setting up proper psychosocial care and making it available to cancer patients throughout the cancer continuum is essential.
- In many hospitals, provision of psychological support is available; yet **psychologists very often lack knowledge/skills to deal with oncological patients**.
- In most countries, provision of follow-up psychosocial care is not covered by social security, and related **cost** fall on patients. Also **stigma** both on cancer and psychosocial needs remain very high.
- More should be done to **increase cancer awareness**. Cancer patients should have access to complete information about their disease, and what they will face through the treatment.

Lifetime burden of inequalities (rights/benefits, reproductive issues, long-term care needs, mental health, education, job market/career, cancer survivors vs other patients/survivors)

Main issues:

- The notion of young cancer survivors is relatively new. Thanks to advances in early detection, effective therapies and supportive care, survival rates have increased dramatically. Yet **health systems are not prepared to accommodate the needs of cancer survivors**, even less the needs of young cancer survivors.
- Also in many countries, once treatment is over healthcare systems no longer recognize you as a patient, despite long-term disabilities. This triggers a number of issues, including the fact that certain treatments are no longer provided free of charge.
- There is **limited literature available on survivorship**. Cancer registries are incomplete. This includes also **limited literature on late effects** for different cancer types. Many participants reported to have received from their oncologist limited or no information on late effects (fatigue, chronic pain, brain fog etc), including on their management, being therefore completely unprepared.
- **Fertility remains a major concern**. In most countries, young patients cannot make any informed choice (sometime also due to the young age). Options are not discussed, as the only concern is to treat cancer, without really considering what will come next.
- **Cancer plans in MS include limited focus on young cancers**, compared to other types of cancer.
- **Cross-border healthcare remains suboptimal**; when treatment is delivered in a different country, language can represent a barrier.
- More in general having to move to a different place to be treated is very burdensome. **Portability of health records** should be improved; also better data sharing between hospitals should be ensured.

Recommendations and good practices

- Increase investment in education and training for healthcare professionals on youth cancer. There should be a medical specialty for cancer survivors – from treatment to everyday life
- Increase investment into psychosocial support (camps, being with survivors, understanding late effects...). If the transition is good, a survivor will be able to integrate better to society and “give back” to it more.
- Arts and sport can be beneficial for cancer patients for improving mental health.
- **Involving survivors** to share their experience with peers going through the same situations has proven very beneficial. **EU-CAYAS-NET** was referred as an example of successful initiative implemented at EU level.
- In Vienna a **mentorship program has been developed**, through which **survivors are trained** to help next patients.

- Investments are needed to define guidelines for the characterization and management of late effects (e.g. through nutrition, sport, etc).
- Create conditions to ensure that patients reporting/feedback feeds into healthcare practice (e.g., how should diagnoses be addressed in medical setting, what is important for a patient etc.).

Research actions to address survivorship (moderator Ana Toledo Chávarri, Cancer Mission Board Member)

Involvement of young cancer patients/survivors in research

Main issues:

- There is **limited involvement of young cancer patients/survivors in clinical research**. Very often young cancer patients are excluded, either because they not fit the inclusion criteria (e.g., trials are designed for older survivors) or because of the strict legal requirements for the participation of minors in trials, which sometime has a deterrent effect.
- Beside enrolment in clinical trials, participants also insisted on the importance of **involving young cancer patients in the design phase**, which should be done systematically.
- Also, many reported that even when participating in trials, **limited information is then provided to participants on outcomes**. Better communication of results should be ensured.
- More in general targeted communication and better dissemination of research results is needed. **Scientific literature should be made more accessible to non-specialists**.
- **Collection of data on severity of side-effects** should be improved. On the one side, the questionnaires used by healthcare professionals to collect data are often outdated. On the other hand, as side effects are not reported directly by patients, but rather by doctors, “perception” is distorted. **Long-term/late effects are not systematically tracked**.
- Healthcare professionals should be better trained on how to interact and inform young patients.

Late effects and survivors' quality of life

Main issues:

- Main long-term effects reported: Chronic fatigue, chronic pain, long-term memory loss, fertility issues, disabilities, (e.g. amputation, limited mobility/coordination following brain surgery,..); frailty (e.g. osteopenia, osteoporosis, cardiovascular side-effects, brain fog, frail mental health – ‘looking good, beautiful at the outside but struggling at inside’), mental health (due to all or one/few of the above side-effects).
- Focus has been rather on short-term, acute effects, but with progress in cancer treatments and increasing survival rates, there is a need to **better understand chronic or late effects of treatment**.
- More research is needed on **late/long-term effects, including to support the development of guidelines/strategies to better management** them (long-term maintenance therapy, and combination with comorbidities).
- **Fertility issues** due to aggressive treatments was highlighted as a late effect of major concern. Participants stressed the necessity to ensure better understanding and better management of the problem. Limited information is provided to parents and patients for them to make an informed choice, and this despite the fact that very often such choice does not exist as cancers are too aggressive and life-threatening.
- More **research on transition** is needed, for example on the impact survivor ship has on mental health. This is particularly important after treatment, during the remission phase, when patients eventually start fully realising the impact cancer is having on their lives.
- More in general research efforts should be increased to better understand how cancer and treatments affect **mental health**. Having cancer at an adult age, when your life is already settled,

is different than living with cancer at young age, when all of sudden your life is halted and you get disconnected from everything.

- Research efforts/investments targeting the **development of specific, less toxic treatments for childhood and AYA cancers** is rather limited, compared for example to other types of cancer, such as breast or colorectal cancer. Over the past 20 years only 4 treatments specific for childhood cancer have been approved.
- This also reflects limited interest from pharmaceutical companies, as childhood and AYA cancers are rare.

Recommendations and good practices

- Ensure better feedback-loop between research-patient-physicians;
- Set up a good framework for meaningful patient involvement in R&I. Patient provided example of an App paid for by crowdfunding, which allows instantaneous feedback for example on quality of life issues³ that seems to work well and could deliver real world data (RWD).
- Multidisciplinary approach, breaking silos, for the management of CAYA cancer patients and research was mentioned as best practice. The panel recommended setting a multidisciplinary CAYA cancer board in each country, which should include also tools and training to enable cancer survivors and parents/caregivers to speak out, raise awareness (most kids don't want or don't know how to speak out), long-term psychological and long-term social (education, right to be forgotten, financial, etc.) support AFTER treatment.
- Direct engagement of young cancer patients/survivors -as implemented through this event- with face-to-face discussion, is what is really needed. Surveys are often not clear or exhaustive; there is also survey fatigue.
- Side effects should be registered by patients themselves (on a scale from 1-10), not physicians. Patients have the 'lived experience', physicians do not. This already introduces bias. Literature shows that physicians tend to underreport side effects. Suggestion to change the way these measurements are done, e.g., use more precise (quantitative and qualitative) methods.
- Using patient panels and AYA patient board to respectively evaluate research pre-proposals and consult on new ideas to address AYA concerns, needs, side-effects.

Next steps

Outcomes of the workshop contributed to stir the panel discussions at the conference "*Addressing the needs of young cancer survivors*", which was held on 7 February 2023.

These engagements have created the basis for the establishment of a new dialogue between young cancer patients/survivors and the European Commission, through the Cancer Mission.

As announced at the conference and as immediate follow-up, a workshop will be organised in May 2023, to deepen discussions on some specific issues of survivorship, which will contribute to shaping upcoming cancer R&I and policy actions.

³ Know your CML App : <https://play.google.com/store/apps/details?id=com.cmladvocatesnetwork.knowyourcml&pli=1>

	SESSION 1	SESSION 2	SESSION 3
Theme of the session	Gaps in Policy actions to address survivorship	Inequalities for Childhood and Adolescent Cancer Survivors	Research actions to address survivorship (research needs, involvement of patients/survivors in research activities)
Short description of the topics to discuss	Life after cancer treatment can pose many challenges for young survivors. These include mental health problems, transition from paediatric to adult care, transition from oncological care to follow-up care etc.	Young cancer survivors reported substantial levels of inequalities within countries, between regions, or social groups with respect to many different aspects during their cancer treatment and follow-up care (e.g. services, information, continuity of education etc) , both in terms of access and quality.	Developing more specific, more effective and less toxic treatments as well as investing in research to better understand and manage adverse effects during and after treatments are major priorities for childhood and AYA cancer research. Young cancer patients and survivors voiced their strong interest but limited opportunities available for their direct involvement in the design and implementation of research studies (e.g. clinical trials). More emphasis should also placed on better divulgating outcomes of research.
Topics and guiding questions	<p>Topic 1: Transition:</p> <ol style="list-style-type: none"> 1. What challenges did you experience while transitioning from paediatric to adult care? 2. What challenges did you experience while transitioning from cancer treatment to follow-up care? 3. What challenges did you experience when transitioning from hospital to home care 4. Can you share any good practice/experiences that you found particularly helpful 	<p>Topic 1 Childhood cancer care pathways to reduce inequalities (care, transition, information):</p> <ol style="list-style-type: none"> 1. What challenges did you experience in terms of <ol style="list-style-type: none"> a. access to cancer care? b. during the transition? c. access to information? (before/during/after treatment) 2. What could be improved in terms of cancer care pathways? <ol style="list-style-type: none"> a. For access b. For transition c. For information 	<p>Topic 1: Involvement of young cancer patients/survivors in research:</p> <ol style="list-style-type: none"> 1. What roles do patients and survivors have in research projects and do you have any personal experience with this? 2. Can you share good examples/experiences based on your own involvement in research? <p>Topic 2: Late effects and survivors' quality of life</p> <ol style="list-style-type: none"> 1. What challenges did you experience due to late effect of your treatment?

	<p>Topic 2: Psychosocial aspects and mental health:</p> <ol style="list-style-type: none"> 5. What challenges did you experience during treatment, remission or after remission? 6. What type of information or support would you need now or could be of help for new patients and cancer survivors? 7. Can you share any good practice/experiences that you found particularly helpful 	<ol style="list-style-type: none"> 3. Can you share any good practice/experiences that you found particularly helpful? <p>Topic 2: Lifetime burden inequalities (Rights/benefits, reproductive issues, long-term care needs, mental health, education, job market/career, cancer survivors vs other patients/survivors):</p> <ol style="list-style-type: none"> 1. What challenges did you experience in terms of lifetime burden inequalities? 2. What type of support is mostly needed/missing? 3. What should be improved and how? 4. Can you share any good practice/experiences that you found particularly helpful? 	<ol style="list-style-type: none"> 2. On what aspects of quality of life after treatment do you think research should invest more? 3. Can you share any good practice/experiences that you found particularly helpful
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