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the final step of successful cancer treatment**

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1 Executive Summary

Background: With over 500,000 childhood, adolescent, and young adult (CAYA) cancer survivors in Europe, there is a growing need for long-term follow-up (LTFU) care to monitor and treat late effects after treatment. 75% of survivors of CAYA cancer develop physical and/or mental health problems after cancer or cancer treatment that require follow-up care. Early detection, treatment and guidance can help to minimise the burden of these late effects and their negative impact on quality of life. Unfortunately, there are still huge differences within Europe in the availability and organisation of LTFU care causing many survivors to not receive adequate LTFU care or no LTFU care at all.

The EU-CAYAS-NET project aims to enhance the quality of life for CAYA cancer survivors. Specifically, Task 3.5 covers the priority areas of late effects and LTFU Care.

By providing resources and disseminating information through the Platform (www.beatcancer.eu), EU-CAYAS-NET aims to improve the well-being of young cancer survivors and support their potential, while also reducing the burden on healthcare systems and society as a whole.

Approach: A series of activities including workshops and surveys were conducted to gather information on the current status of LTFU care in Europe and on the needs and preferences of CAYA cancer survivors, as well as healthcare professionals. Additionally, resources such as e-learning modules or information on late effects were developed to be shared with the community.

Results and recommendations: Based on existing knowledge and information gathered within EU-CAYAS-NET, a series of recommendations for the implementation of optimal LTFU care was developed. These recommendations cover five main themes:

- Access to LTFU care,
- Organisation of LTFU care,
- Personalised LTFU care,
- Collaboration, representation and improvement, and
- Support systems for CAYA cancer survivors and caregivers.

Conclusion: The activities within Task 3.5 of the EU-CAYAS-NET project identified the needs, preferences, barriers and facilitators to organise and implement optimal LTFU care for all CAYA cancer survivors in Europe. The activities were, together with existing knowledge from other projects and initiatives, analysed and bundled into recommendations for LTFU care. These recommendations create a clear picture of all aspects needed to set up LTFU care that will optimally contribute to the quality of life of CAYA cancer survivors. Adoption of the recommendations will increase the empowerment of survivors and guide healthcare professionals by providing insight into what is needed to establish and deliver LTFU care.

2 Introduction & Background

As EU-CAYAS-NET aims to improve the quality of life of CAYA cancer survivors, targeted actions and initiatives were carried out, covering areas which are of demonstrated benefit to the quality of life of young cancer survivors. This deliverable falls under the theme of Quality of Life, one of three themes identified by young survivors throughout Europe as most important for equitable, lifelong care (along with Adolescent and Young Adult (AYA) care and Equity, Diversity and Inclusion (EDI)).

D3.4 'Recommendations for LTFU care to be seen as the final step of successful cancer treatment' is part of WP3 – Quality of Life, under the priority areas of Late Effects & Long-Term Follow-Up Care (Task 3.5), alongside other areas related to Quality of Life in WP3 (Education & Career Support, Transition and Mental Health & Psychosocial Care).

Background and aims

Over the past years, survival rates of CAYA cancer have increased drastically, leading to over 500,000 survivors of CAYA cancer currently living in Europe (Vassal et al., 2014) (Vassal et al., 2016). However, treatment is harsh and causes many side effects, even long after cancer treatment has ended. 75% of survivors of CAYA cancer develop health problems requiring follow-up care (Oeffinger et al., 2006) (Geenen et al., 2007). These late effects vary greatly and depend on the type of cancer and the cancer treatment received. Close surveillance of all survivors is the appropriate way to monitor survivors' general health and detect late effects early and, if possible, intervene in a timely manner (Kremer et al., 2012). Moreover, proper guidance can help to minimise the burden of these late effects and their negative impact on quality of life. Unfortunately, there are huge differences in the availability and organisation of LTFU care within Europe. This results in large groups of survivors not receiving adequate LTFU care and many of those not receiving any care at all (Essig et al., 2012) (Saloustris et al., 2017).

In recent years, LTFU care in Europe has been improved by national and international collaborations of healthcare professionals, researchers and survivors. As a result, various guidelines have been developed to address the surveillance and treatment of late effects and the organisation of LTFU care as a whole. This includes the guidelines developed by the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG, <https://www.ighg.org/>), as well as the PanCareFollowUp recommendations for surveillance of late effects (Kalsbeek et al., 2021) and the recommendations for organisation of LTFU care (Michel et al., 2019). However, up to today, LTFU care is not implemented in all European healthcare systems and even where there is LTFU care in place, it often does not follow the latest guidelines and the accessibility is not optimal for many survivors.

The EU co-financed project EU-CAYAS-NET aims to improve this situation by identifying best practices, gaps and needs for LTFU care in Europe. Using various methods, the current status of LTFU care in Europe was researched, as well as the needs, preferences, barriers and facilitators for optimal LTFU care from the perspective of both survivors and healthcare professionals. The results of these activities, together with the knowledge from the previous projects and initiatives, have led to a series of recommendations for LTFU care, as described in this document.

In addition, to address informational needs, 45 existing PLAIN language summaries on late effects were refined and improved and made available to CAYA cancer survivors (<https://www.pancare.eu/plain-language-summaries/>) (van den Oever et al., 2024). These PanCare PLAIN language summaries support

survivors in their own health-management by providing them with understandable information about late effects and their needs for LTFU Care.

3 Approach

The recommendations for LTFU care were developed within Task 3.5 of EU-CAYAS-NET. PanCare together with CCI Europe, SIOP Europe, PMC, FSJD/HSJD and MUW initiated a series of activities to get a better understanding of the current status of LTFU care in Europe, the needs and preferences of survivors, healthcare professionals and caregivers for LTFU care, and the barriers and facilitators in implementing optimal LTFU care. Task 3.5 can be divided into sub-tasks each described individually below.

3.1 Task 3.5.1 Identify best practices and lack of LTFU care

Gathering information about the perspectives of both healthcare professionals and survivors is crucial for getting a deeper understanding in the type of LTFU care provided as well as obtaining meaningful insights into the needs and preferences for LTFU care.

Two surveys were set out to CAYA cancer survivors and healthcare professionals working in the field of LTFU care. The main aim of the surveys was to gain more insights into the current situation of LTFU care within Europe, as well as identifying potential barriers and gaps in implementing appropriate LTFU care. Participants were asked to give insight into the current organisation of LTFU care in their country. This included the organisation of care, the content of care and who is involved in the provision of care. Additionally, survivors were asked about the LTFU care they have received since the end of their treatment. Both groups were asked about their level of satisfaction with the current LTFU care and their vision of optimal LTFU care in their country.

For an overview of currently available LTFU care in Europe, PanCare has developed an interactive map of Europe, available on the PanCare website (<https://www.pancare.eu/european-map/>).

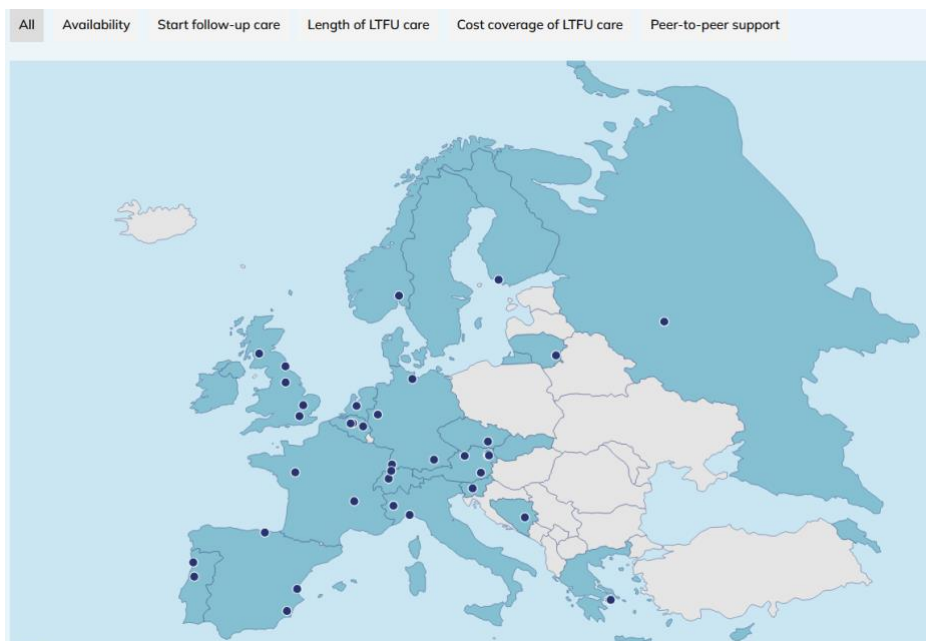


Figure 1. Map providing overview of LTFU care in Europe (<https://www.pancare.eu/european-map/>)

3.2 Task 3.5.2 Webinar on LTFU care

Webinar - Long-term Survivorship Care



On 30 Jan 2024, the webinar ‘Long Term Survivorship Care’ (<https://www.pancare.eu/e-learning-modules/webinar-on-long-term-survivorship-care/>) was held to highlight the importance of LTFU care (Survivorship Care) and how it can improve the quality of life of CAYA cancer survivors. The webinar gave an in-depth overview of the sustainable solutions, tools, and approaches available to implement effective LTFU care. Together with other healthcare professionals and survivors, experiences and knowledge were shared about the content and necessary steps for organising LTFU care. Participants were given the opportunity to ask questions and share their ideas and priorities in LTFU care. Speakers were: Dr. Helena van der Pal (survivorship

care specialist from PanCare/PMC), Jeroen te Dorsthorst and Cherine Mathot (PanCare members and CAYA cancer survivors), Aneta Žáčková (CAYA cancer survivor and EU-CAYAS-NET Ambassador) and Dr. Tomáš Kepák (survivorship care specialist from EU-CAYAS-NET Associated Partner ICRC). The webinar was chaired by haematologist/oncologist Prof. Dr. Med. Katrin Scheinneman, who is also the chair of the PanCare Board.

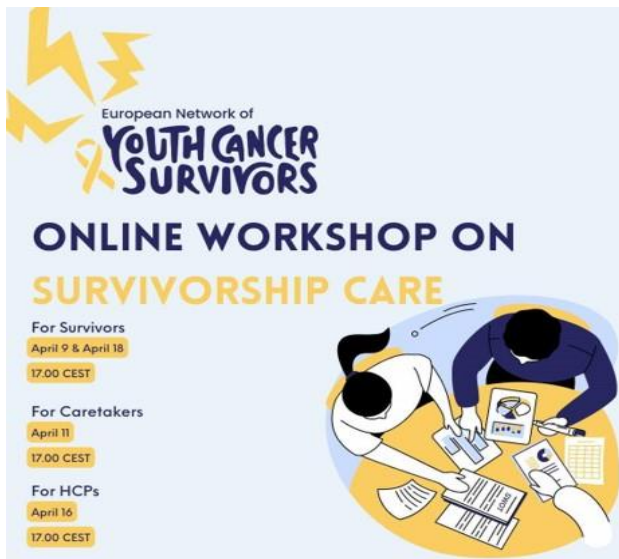
Webinar – Long-Term Survivorship Care: Navigating Intimacy and Fertility challenges

On 26 Mar 2024, the webinar ‘Long-term Survivorship Care: Navigating Fertility and Intimacy Challenges’ (<https://www.pancare.eu/e-learning-modules/webinar-long-term-survivorship-care-navigating-fertility-and-intimacy-challenges/>) was held, focusing on how LTFU care can be of help to CAYA cancer survivors when navigating fertility and intimacy challenges. Together with experts, panellists and attendees talked about how survivors can be supported when facing challenges related to fertility and intimacy, including topics like self-love, body image and (intimate) relationships. Participants were given the opportunity to ask questions and share their ideas and thoughts related to these topics. Speakers included: Dr.



Helena van der Pal (survivorship care specialist from PanCare/PMC), Simone Broer (gynaecologist), Irene Ijgosse (nurse practitioner and oncofertility specialist) and the couple Iris Wilmink and Lon van Keulen (CAYA cancer survivors). The webinar was hosted by haematologist/oncologist Prof. Dr. Med. Katrin Scheinneman, who is also the chair of the PanCare Board.

3.3 Task 3.5.3 Workshops to identify needs, preferences and barriers



A series of workshops titled ‘Getting Long-Term Survivorship Care on Track’ was conducted to identify best practices, preferences, barriers, and facilitators for optimal LTFU care. To get a broad perspective on this topic workshops were organised with survivors (n=2), health care professionals and caregivers of CAYA cancer survivors.

All workshops started with a short discussion to identify a sub-theme of optimal LTFU care and identify related needs, preferences, barriers and facilitators. After identifying the current status of LTFU care in the participants’ countries, participants worked collaboratively

to determine the ideal situation for LTFU care related to this sub-theme. The participants were asked to get this sub-theme ‘on track’ imagining a starting station where nothing is in place yet. Based on the discussions, the participants designed a train track leading to the end station which represented the ideal situation.

Moreover, in building the train track to the desired outcome, participants were asked to identify which elements are needed to build the train track itself and the potential barriers and facilitators which would slow down or speed up the process of reaching the train station, representing the ideal outcome. The topics covered during the workshops were:

- Appropriate LTFU care,
- Support for CAYA cancer survivors during LTFU care,
- Organisation of LTFU care from the healthcare professionals’ perspective, and
- Support for caregivers during LTFU care.

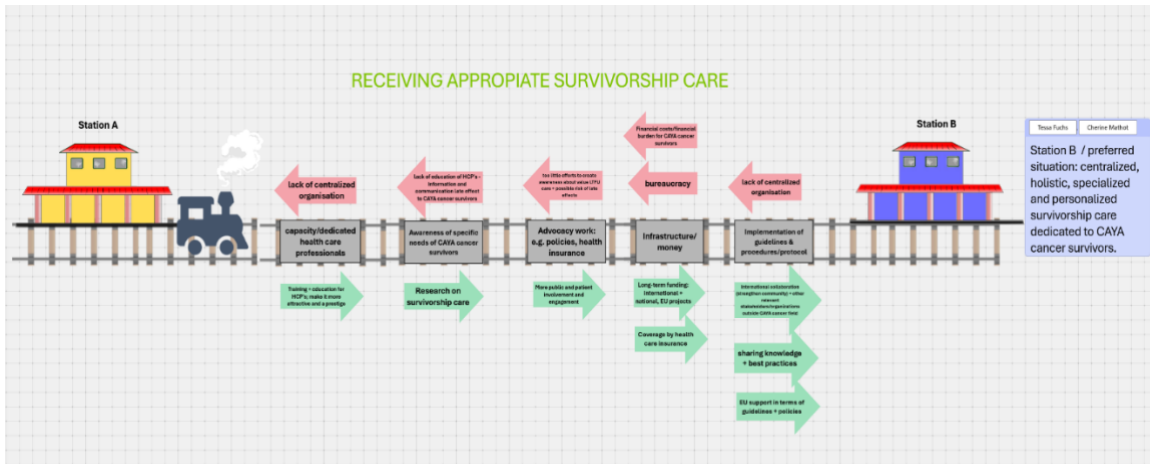


Figure 2. Example of train track developed during the workshops together with the participants

3.4 Task 3.5.4 Develop key recommendations for LTFU care implementation & roadmap

Based on the outcomes of all tasks described above and existing knowledge, PanCare developed a set of recommendations for the implementation of LTFU care and a roadmap providing a clear overview of the results of the recommendations.

The recommendations are presented in the results section below.

3.5 Task 3.5.5 Focus Group Discussion on communication and full disclosure



Another workshop focused on the communication of late effects from CAYA cancer treatment was held to discuss: i) whether and how this communication and education are currently being done, and ii) what the participants' experiences with this process based on the current communication process. Based on this, discussions were held on how such communication and education should ideally be conducted, from the perspective of survivors themselves, and what aspects should be taken into consideration.

The key points from these discussions will be used to formulate recommendations for healthcare professionals to follow in the future, which will be incorporated in D3.5 'Position Paper on Mental

Health & Psychosocial Care, Transition and Long- Term Follow-Up Needs during CAYA Cancer Survivorship - Standard, not luxury'. These recommendations will aim to ensure that the communication about late effects is as honest as possible, while also being empathetic and supportive. This way, those affected can be provided with all the necessary information to help them manage their own health and well-being as effectively as possible.

3.6 Task 3.5.6 Patient advocate/survivor-driven communication recommendations for HCPs

Based on the results of Task 3.5.5, an initial draft of recommendations regarding the communication of late effects from cancer treatment during childhood, adolescence, and young adulthood has been developed, which will be incorporated in D3.5 'Position Paper on Mental Health & Psychosocial Care, Transition and Long- Term Follow-Up Needs during CAYA Cancer Survivorship - Standard, not luxury'.

3.7 Task 3.5.8 Peer Visits

To identify, understand and report on existing LTFU care practices, a series of Peer Visits was organised. During the visits, CAYA cancer survivors, parents and healthcare professionals from 15 EU countries visited three cancer centres in Europe. These centres were selected based upon their leading position in providing LTFU care for CAYA cancer survivors. The institutions visited included the Princess Máxima Center for Pediatric Oncology in Utrecht (Netherlands), Sant Joan de Déu Paediatric Cancer Center Barcelona (Spain), and the Medical University of Vienna (Austria). During these visits, all peer visitors completed a peer observation form reporting on the status of LTFU care in the visited centre. The main topics address were:

- Organisation of LTFU care,
- Who is involved in LTFU care,
- Training and education of LTFU care providers,
- LTFU care content,
- Personalised care and shared decision making, and
- Information provided to survivors.

These Peer Visits gave valuable insight about both the situation on LTFU care in the visited centres but also about the perceived observations on this of the peer visitors (Figure 3).

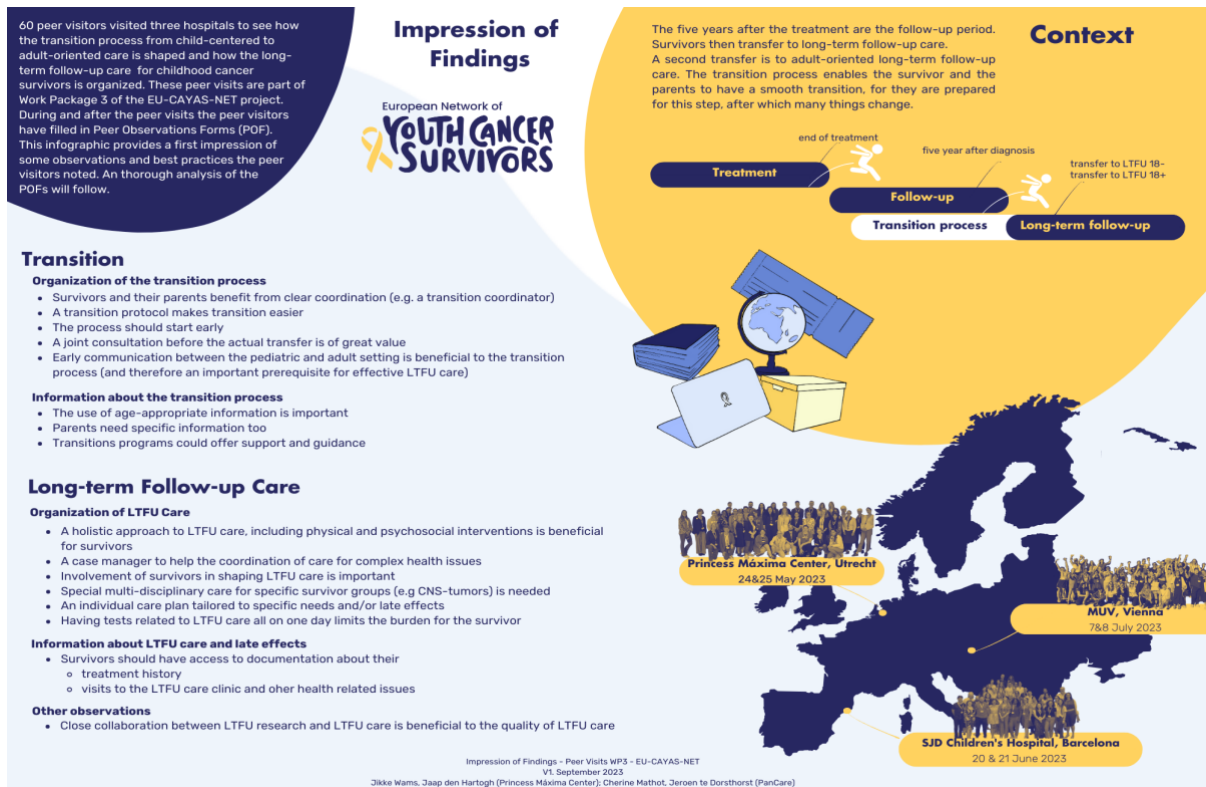


Figure 3. Summary of findings from LTFU care Peer Visits

3.8 Task 3.5.10 Accelerate animation & graphics' process for PLAIN language brochures

PLAIN language brochures provide information about late effects and recommendations for LTFU care in lay language for CAYA cancer survivors and non-specialist healthcare providers, as well as family and friends of survivors. The PLAIN brochures aim to support survivors in their own health-management by providing them with understandable information about late effects and their needs for LTFU care. The PLAIN summaries are based on the 40 PanCare recommendations for surveillance of late effects (<https://www.pancare.eu/pancare-follow-up-recommendations-for-surveillance-of-late-effects/>).

These recommendations are themselves based on the IGHG guidelines (International Group for Guideline Harmonisation for Late Effects of Childhood Cancer) (<https://www.ighg.org/>) and on the consensus of different national guidelines.

45 existing PanCare PLAIN language brochures were refined and supplemented with info boxes and figures. They are available on the PanCare website (<https://www.pancare.eu/plain-language-summaries/>). Within the scope of the EU-CAYAS-NET project, the PanCare PLAIN information group developed 49 info boxes that provide additional information about medical terms and phrases, such as 'stem cell transplantation' or 'phantom pain'. This additional information makes the PLAIN language brochures more accessible to readers with different educational backgrounds.

Furthermore, a total of 29 figures were created to make the information presented in the PLAIN summaries more comprehensible and more visually appealing.

The PanCare PLAIN information group is a multidisciplinary group consisting of health-care professionals, professional CAYA cancer survivor representatives, guideline experts, science communication experts and partner representatives. To ensure optimal usability and clarity of the

developed info boxes and figures, they were reviewed by survivors and caregivers and improved based on their feedback.

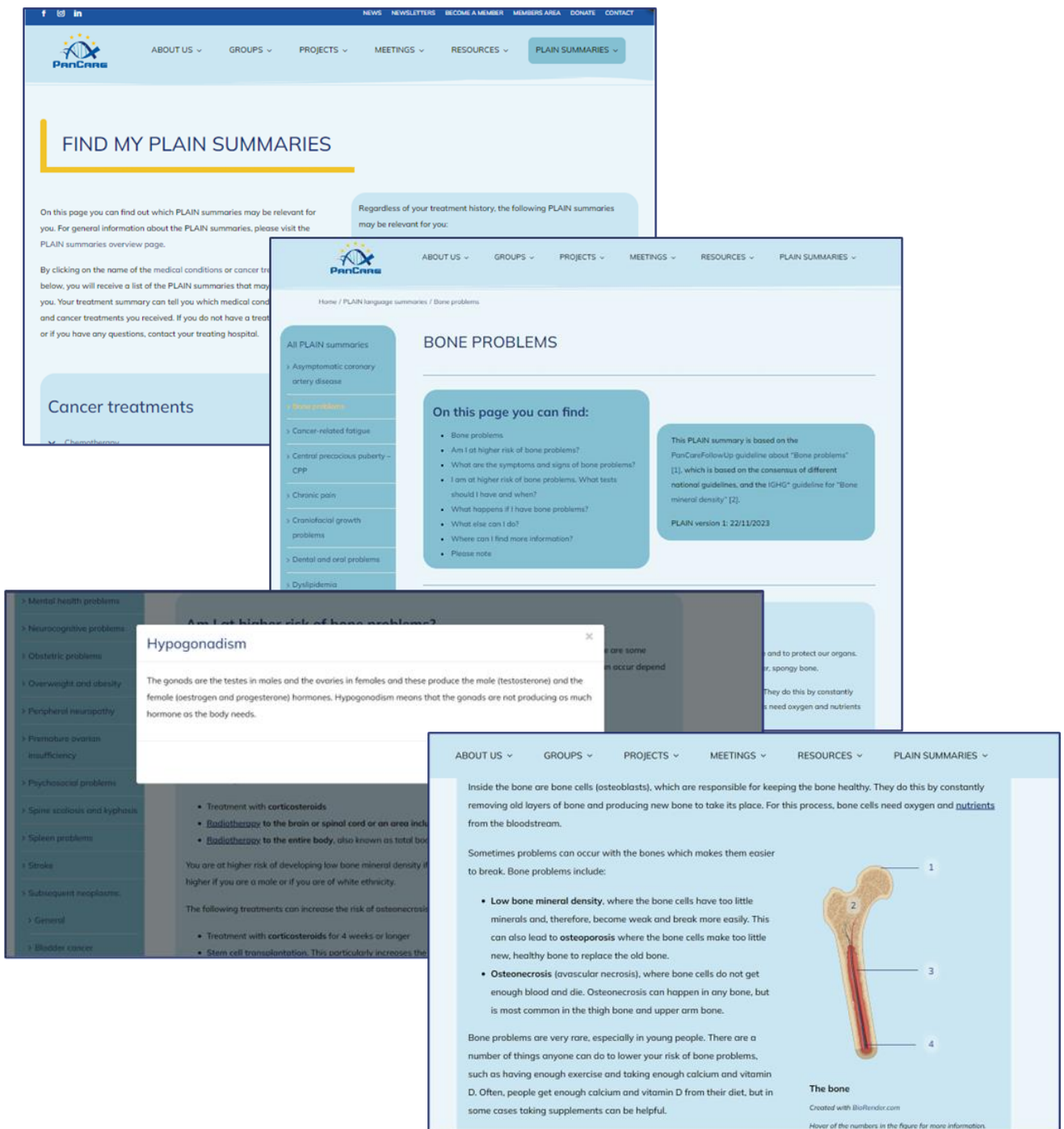


Figure 4. Examples of PLAIN materials on the PanCare website (<https://www.pancare.eu/plain-language-summaries/>)

4 Results

Based on the outcomes of the activities described above, previous knowledge from the IGHG, previous PanCare projects (PanCareSurFup, PanCareLIFE, PanCareFollowUp and PanCareSurPass) and models of care recommendations, recommendations for the implementation of optimal LTFU care for CAYA

cancer survivors in Europe were developed. The recommendations are divided into several main themes to create a clear picture of all aspects needed to set-up and deliver LTFU care that will contribute to the improvement of quality of life of survivors.

Access to LTFU Care

All survivors of CAYA cancer should have access to lifelong LTFU care to:

- Early detect late effects,
- Adequately manage late effects or the consequences of cancer treatment in general, and
- Provide guidance in life, coping with the physical, psychological and societal consequences of cancer treatment.

The threshold for visiting the LTFU clinic should be as low as possible for survivors to ensure that they are not lost to follow-up.

Access to LTFU care clinics should be easy and without barriers for all CAYA cancer survivors.

LTFU care should be free of charge for the survivor, e.g. covered by health insurance.

Organisation of care

- A dedicated LTFU care clinic is the preferred setting for receiving care:
 - This centre should be closely connected to the centre where cancer treatment took place.
 - The centre should provide links to other healthcare providers to consult if necessary.
- Dedicated infrastructure should be built around the organisation of LTFU care, to:
 - Ensure adequate admission and referral of survivors and monitor the needs for LTFU care
 - Oversee the general needs of every survivor via digital tools, treatment histories and survivorship care plans.
- LTFU care should be guideline based to create a standard of care:
 - The PanCare and IGHG guidelines give guidance to the monitoring and management of late-effects.
 - Guidelines draw on the latest research and expert consensus offering clear recommendations on when and how to monitor CAYA cancer survivors.
- Long-term follow-up care should be multi-disciplinary:
 - Joint multidisciplinary consultations and a one-stop visit help to minimise the burden on both the survivor and the healthcare providers.
- Long-term follow-up care should have a holistic approach covering all aspects of life:
 - This support should include all aspects of quality of life, e.g. mental health and psychosocial care, lifestyle advice and support in career and education.
- CAYA cancer survivors and caregivers should be proactively informed about late effects and the available long-term follow-up care.

- The PanCare PLAIN language summaries information brochures may help to inform survivors and non-specialist healthcare professionals about late effects after cancer treatment and the needs for long-term follow-up care.

Personalised care

- Long-term follow-up care should be a partnership between the healthcare professional and the survivor:
 - Having a strengthened relationship between healthcare professionals and survivors enlarges mutual trust, openness and compliance.
- Survivors should be involved in their own long-term follow-up care:
 - Survivors should be empowered to communicate their needs to the specialist healthcare provider.
- The involved health care professionals should provide own long-term follow-up care according to the treatment history and an individual care plan based on guidelines for own long-term follow-up care. This includes the:
 - Provision of a Treatment Summary,¹ and
 - Implementation of a Survivorship Care Plan,² with
 - Optional use of the Survivorship Passport (SurPass).³
- Personalised long-term follow-up care should focus on the individual needs and preferences in all areas of life of the survivors:
 - In communication to the survivor and/or caregivers, this should also be reflected, being open about late effects and the need for ongoing health management helps survivor to adapt to the new reality of life.
- Transition from paediatric to adult care and from follow-up to long-term follow-up care should be facilitated and the survivors and their caregivers should receive guidance into the new care system.

Collaboration, representation and improvement

- Collaboration between all stakeholders (e.g. healthcare professionals, CAYA cancer survivors and caregivers, patient organisations, networks and researchers) is essential to organise and implement optimal long-term follow-up care:
 - Long-term follow-up care clinics should foster (inter)national collaboration to exchange knowledge and further development.
- Advocating the need for long-term follow-up care and creating general awareness are important to create a foundation for implementing long-term follow-up care.
 - To promote the importance of personalised long-term follow-up care.
- Healthcare professionals should be thoroughly trained to provide long-term follow-up care:
 - Long-term follow-up Care should be acknowledged as a specialisation.

¹ <https://www.pancare.eu/pancarefollowup-care-intervention-replication-manual/treatment-summary-template/>

² <https://www.pancare.eu/pancarefollowup-care-intervention-replication-manual/survivorship-care-plan-template/>

³ <https://www.pancaresurpass.eu/>

- Healthcare professionals involved in long-term follow-up care should be empowered to stay up-to-date with the latest guidelines and knowledge.
- Healthcare professionals should have the opportunity to be actively engaged in international networks for knowledge exchange.

Support system for CAYA cancer survivors and caregivers

- Peer-to-peer supports for both caregiver and survivors are essential to help navigate life after cancer:
 - Peer-to-peer support should be professionalised with resources, training and capacities (workshops - caregivers).
 - Peer-to-peer support creates a sense of belonging, decreases loneliness, increases mental wellbeing and helps with coping with the experience of cancer and late effects.

A visual summary of the recommendations for LTFU care as the final step of successful cancer treatment is available on the Platform, in 8 EU languages. This visual summary offers an accessible overview of the roadmap and key recommendation for LTFU care for young people living beyond cancer.

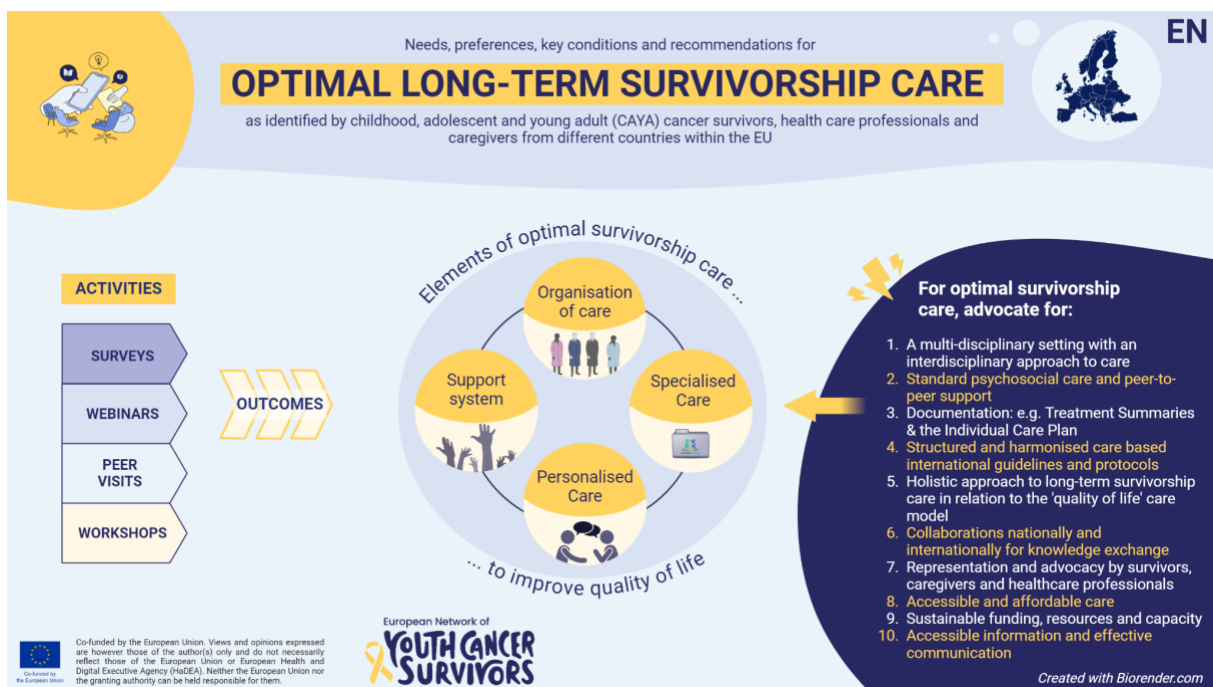


Figure 5. Visual summary of LTFU Care recommendations

Translations are available in eight EU languages, accessible through the links provided below:

- English: <https://www.pancare.eu/wp-content/uploads/2024/10/1-English-EN-final.png>
- German: <https://www.pancare.eu/wp-content/uploads/2024/10/2-German-DE-final.png>
- Spanish: <https://www.pancare.eu/wp-content/uploads/2024/10/4-Spanish-ES-final.png>
- Dutch: <https://www.pancare.eu/wp-content/uploads/2024/10/5-Dutch-NL.png>
- Lithuanian: <https://www.pancare.eu/wp-content/uploads/2024/10/7-Lithuanian-LT.png>

- HR: <https://www.pancare.eu/wp-content/uploads/2024/10/8-Croatian-HR-final.png>
- Italian: <https://www.pancare.eu/wp-content/uploads/2024/11/Roadmap-Italian-IT-final.png>
- French: <https://www.pancare.eu/wp-content/uploads/2024/11/Roadmap-French-FR-final.png>

5 Impact & Conclusion

This deliverable report gives an overview of the activities executed within Task 3.5 to develop an insight into the needs, preferences, barriers and facilitators to organise and implement optimal LTFU care for all CAYA cancer survivors in Europe. The activities have, together with existing knowledge from other projects and initiatives, been analysed and used to generate recommendations for LTFU care. This document connects with the overall project as it gives an overview of how LTFU care contributes to quality of life and survivorship in general. Adoption of the recommendations will help empower survivors and guide healthcare professionals by providing more insight into what is needed to establish LTFU care.

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