EJC Paediatric Oncology 3 (2024) 100165

Contents lists available at ScienceDirect

EJC Paediatric Oncology

journal homepage: www.journals.elsevier.com/ejc-paediatric-oncology

Original research

From long-term follow-up Recommendations for clinical practice to plain language summaries for childhood, adolescent, and young adult cancer survivors

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ARTICLE INFO

Keywords:
Patient information
paediatric oncology
long-term follow-up care
survivorship

ABSTRACT

Background: Having sufficient knowledge of cancer diagnosis, treatment and late effects in survivors of childhood, adolescent, and young adult (CAYA) cancer is important for effective self-management and optimising health outcomes. Therefore, in collaboration with different stakeholders, the PanCare PLAIN Information Group converted the PanCareFollowUp Recommendations for late effects surveillance into information summaries that are Person-centred, written in Lay language, Accessible, Internationally relevant, and Navigable (PLAIN).

Methods: The PanCare PLAIN Information Group, comprising 21 stakeholders from seven European countries, collaborated to provide concise information for survivors and their families. The aim was to deliver PLAIN summaries that are clear and accessible for the majority of survivors, while providing links to additional sources of information. The PLAIN summaries were drafted by the PanCare PLAIN Information Group and subjected to two internal and one external consultation round, the latter involving experts, CAYA cancer survivors and parents/caregivers.

Results: In total, 45 PLAIN summaries were developed, each corresponding to one of the PanCareFollowUp Recommendations for late effects surveillance. The summaries provide information about late effects, personal

Abbreviations: CAYA, Childhood, adolescent and young adult; CPG, Clinical practice guideline; EU-CAYAS-NET, European Network of Youth Cancer Survivors; HCP, Healthcare professional; LTFU, Long-term follow-up; PLAIN, Person-centred, written in lay language, accessible, internationally relevant and navigable; SCP, Survivorship care plan; SurPass, Survivorship Passport; PanCare, Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer; CCI-E, Childhood Cancer International Europe; IGHG, International Guideline Harmonization Group.

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https://doi.org/10.1016/j.ejcped.2024.100165

Available online 16 May 2024

health risks, important symptoms and signs, recommended surveillance strategies, possible referral and treatment options, and self-care.
Conclusions: The PLAIN summaries are meant to increase knowledge in survivors and their families, while they may also inform healthcare professionals. Along with their translations, the PLAIN summaries will be made freely available on the PanCare website, with a link provided on the European Network of Youth Cancer Survivors information platform. In addition, they will become and integral part of the Survivorship Passport.

1. Introduction

Due to their cancer journey, childhood, adolescent, and young adult (CAYA) cancer survivors are at increased risk for physical and psychosocial health effects later in life (late effects), including second primary neoplasms, organ dysfunction and lower socioeconomic status [1–5]. To optimise their health outcomes, it is crucial to have comprehensive, well-organised long-term follow-up (LTFU) care programs in place. Primarily, these programs should provide late effects surveillance, management and referral for expert assessment and treatment in accordance with (evidence-based) clinical practice guidelines (CPGs). Other important elements include psychological support, fertility counselling, and education on self-care and maintaining a healthy lifestyle [6,7]. Nevertheless, research has shown that LTFU care programs for CAYA cancer survivors are often lacking, in particular when survivors transition from paediatric to adult health care settings [8].

To aid implementation of LTFU care, the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare) (www.pancare.eu) established the Horizon 2020-funded PanCareFollowUp project (www.pancarefollowup.eu) [9]. Within this project, professionals and CAYA cancer survivors from ten European countries collaborated to develop a person-centred LTFU care model (the PanCareFollowUp Care Intervention). This care model includes a consultation with a late effects specialist, after which the survivor is provided with a treatment summary and individualised survivorship care plan (SCP) based on 40 recommendations for clinical practice (the PanCareFollowUp Recommendations) [10,11]. The objective of this care model is to offer the best possible care while empowering CAYA cancer survivors to take charge of their own health and encouraging the survivor and healthcare professional (HCP) to make decisions collectively. By means of a prospective cohort study, the PanCareFollowUp Care Intervention is currently being evaluated across four European countries [12].

An essential element in empowering survivors is providing them with the accurate knowledge needed for effective self-management [13]. In a questionnaire study involving 145 CAYA cancer survivors, a significant need for personalised information about (recognising) late effects was reported, as well as a desire for guidance on self-care practices [14]. Therefore, one of the aims within the PanCareFollowUp project was to convert the 40 PanCareFollowUp Recommendations into 45 plain language summaries, or brochures, that are **P**erson-centred, written in **L**ay language, **A**ccessible, **I**nternational and **N**avigable (PLAIN).

2. Methods

2.1. The PanCareFollowUp Recommendations

Several (multi)national paediatric oncology groups have developed evidence-based CPGs, yet differences are observed in their recommendations for late effects surveillance. To ensure all CAYA cancer survivors receive a similar, high standard of care, the International Guideline Harmonization Group (IGHG) was established. Their aim is to harmonise existing CPGs for LTFU care and formulate international recommendations, while making use of a transparent, evidence-based methodology [7]. CPGs developed by the IGHG are published in peer-reviewed journals and available at www.ighg.org.

Along with person-centred care, the IGHG's CPGs form the foundation of the PanCareFollowUp Care Intervention. Yet the development of international, harmonised recommendations is a time-consuming process and multiple topics still need to be addressed. To expedite implementation of the PanCareFollowUp Care Intervention, the PanCareFollowUp Recommendations Working Group formulated 25 additional recommendations that were consensus-based. The pragmatic methodology used to develop these recommendations, as well as the final set of PanCareFollowUp Recommendations, is presented elsewhere [11].

2.2. PanCare PLAIN Information Group

To convert the PanCareFollowUp Recommendations into PLAIN summaries, the PanCare PLAIN Information Group was established. This group included 21 stakeholders (including 11 HCPs, six professional patient advocates, three guideline experts, two science communication experts, and one PanCareFollowUp partner representative), representing seven European countries. In addition to many years of professional experience in this working field, the patient advocates had firsthand experience with cancer in childhood or adolescence, enabling them to deeply understand the needs of this community. Six out of 21 involved stakeholders were native English speakers.

2.3. PLAIN summary structure and content

In accordance with the PanCareFollowUp Recommendations' structure, the PLAIN summaries were structured into the following sections: (1) *The late effect* (2) Am I at risk of *this late effect*? (3) What are the symptoms and signs of *this late effect*? (4) I have a higher risk of *this late effect*. What tests should I have and when? (5) What happens if I have *this late effect*? (6) What else can I do? and (7) Where can I find more information? The information provided in Sections 2 and 4 aligns with the corresponding PanCareFollowUp recommendation.

Section 1 serves as an introduction, to briefly explain the late effect and associated organs, body parts, or bodily processes. Section 2, "*Am I at risk?*", lists the higher risk groups for that particular late effect, based on the diagnosis and treatment history. In addition, this section highlights the occurrence of health problems in the general population, explaining that all individuals have a baseline risk and that not all health problems are the late effects of cancer or its treatment. The third section lists the symptoms and signs the survivor should be aware of and underlines the importance of reporting new symptoms and signs to a HCP. Section 4 describes the surveillance tests that should be performed and at what frequency. This section is omitted in PLAIN summaries corresponding to those recommendations where no surveillance test was recommended but only guidance by "awareness only" (see Table 1). The fifth section describes what might happen after diagnosis with the specific late effect. This mainly includes referral to a medical specialist, and in some cases treatment options are mentioned. Section 6 includes information on self-care, psychological support (if appropriate) and things CAYA cancer survivors can do independently to lower their risk of late effects, such as positive lifestyle changes. In addition, survivors are encouraged to contact their HCP in case of any worries or doubts. Finally, the last section contains links to additional sources of information or support groups, or other PLAIN summaries that are closely associated.

Table 1
Overview of PanCareFollowUp Recommendations and their corresponding PanCareFollowUp PLAIN summaries.

PanCareFollowUp Recommendation for surveillance of	PanCareFollowUp PLAIN summary
Awareness only	
Higher risk groups (consensus-based)	Late effects of childhood cancer and cancer treatment
Alopecia (consensus-based)	Hair loss (alopecia)
Cerebrovascular problems (consensus-based)	Stroke
Dental and oral problems (consensus-based)	Dental and oral problems
Gastro-intestinal problems (consensus-based)	Gastro-intestinal problems
Peripheral neuropathy (consensus-based)	Peripheral neuropathy
Awareness, history and/or physical examination without surveillance test	
Craniofacial growth problems (consensus-based)	Craniofacial (skull and face) growth problems
Eye problems (consensus-based)	Eye problems
Fatigue (cancer-related) (evidence-based IGHG guideline)	Cancer-related fatigue
Health promotion (consensus-based)	A healthy lifestyle: taking care of your body
Mental health problems (evidence-based IGHG guideline)	A healthy lifestyle: taking care of your mental health
Lower urinary tract problems (consensus-based)	Lower urinary tract problems
Neurocognitive problems (consensus-based)	Neurocognitive problems
Obstetric problems (evidence-based IGHG guideline)	Problems during pregnancy
Pain (chronic) (consensus-based)	Chronic pain
Psychosocial problems (evidence-based IGHG guideline)	Psychosocial problems
Spine scoliosis and kyphosis (consensus-based)	Spine scoliosis and kyphos
Subsequent neoplasms (consensus-based)	Subsequent (also called second) cancer: general Subsequent cancer: blood cancer Subsequent cancer: bladder cancer Subsequent cancer: bone cancer Subsequent cancer: lung cancer Subsequent cancer: oral cancer
Melanoma and non-melanoma skin cancer (consensus-based)	Subsequent cancer: skin cancer
Awareness, history and/or physical examination with surveillance test	
Breast cancer (evidence-based IGHG guideline)	Subsequent cancer: breast cancer
CNS neoplasms (evidence-based IGHG guideline)	Subsequent cancer: brain or spinal cord cancer
Subsequent colorectal cancer (consensus-based)	Subsequent cancer: colorectal cancer
Thyroid cancer (evidence-based IGHG guideline)	Subsequent cancer: thyroid cancer
Bone problems (consensus-based, including evidence-based IGHG guideline for bone mineral density)	Bone problems
Cardiac problems (consensus-based, including evidence-based IGHG guideline for cardiomyopathy)	Heart problems
Coronary artery disease (asymptomatic) (evidence-based IGHG guideline)	Coronary artery disease
Dyslipidaemia (consensus-based)	Dyslipidaemia
Hypertension (consensus-based)	High blood pressure
Impaired glucose metabolism and diabetes mellitus (consensus-based)	Impaired glucose metabolism and diabetes
Overweight and obesity (consensus-based)	Overweight and obesity
Ear problems (evidence-based IGHG guideline)	Hearing problems
Fertility problems and sexual dysfunction (male) (evidence-based IGHG guideline)	Fertility problems, testosterone deficiency and sexual dysfunction in men
Premature ovarian insufficiency (female) (evidence-based IGHG guideline)	Premature ovarian insufficiency (POI)
Precocious puberty (central) (evidence-based IGHG guideline)	Unusually early puberty (central precocious puberty - CPP)
HP axis problems (evidence-based IGHG guideline)	Hypothalamic-pituitary (HP) axis problems
Liver problems (evidence-based IGHG guideline)	Liver problems
Pulmonary problems (consensus-based)	Lung problems
Renal problems (consensus-based)	Kidney (renal) problems
Thyroid function problems (consensus-based)	Thyroid function problems
Spleen problems (consensus-based)	Spleen problems

Abbreviations: IGHG, International Guideline Harmonization Group; CNS, central nervous system.

To facilitate development and ensure consistency across all PLAIN summaries, a PLAIN summary template was created. This template was structured according to Sections 1–7 outlined above and comprised standard sentences and frequently used wording, which could be modified to fit each topic. New insights obtained during the writing process led to frequent updates of the template. Therefore, after completion of the 45 drafts, the final PLAIN template was used to harmonise all the PLAIN summaries. The final version of the PLAIN template is provided in the supplementary information.

2.4. Considerations of the PanCare PLAIN Information Group

Prior to drafting of the PLAIN summaries, important considerations were deliberated. First, there is evidence that CAYA cancer survivors' knowledge of their cancer diagnosis, subsequent treatment and (risk of) late effects varies [15,16]. As many survivors have low levels of knowledge and awareness, we decided to develop information summaries that are comprehensible for as many survivors as possible, limiting the content to information that is essential for proper understanding and self-management. For those survivors needing more detailed information, additional sources are provided at the end of the PLAIN summaries. In addition to this, since the risk of late effects is strongly dependent on the survivors' cancer diagnosis and treatment, survivors are directed to seek information in their treatment summary. Those who did not receive a treatment summary are encouraged to contact their treating hospital/oncologist.

Although comprehensive LTFU care delivered by a multidisciplinary team of HCPs is essential in optimising health outcomes in CAYA cancer survivors, it is important to consider that many paediatric oncology centers in Europe still lack adequate LTFU programs. Hence, we found it crucial to direct the information conveyed in the PLAIN summaries not only at survivors who visit late effects clinics, but also those who seek late effects monitoring and management from their primary care physician.

Finally, a consensus decision was made on the PLAIN summaries' target audience. In some cases, for instance when the survivor is still very young, the PLAIN summaries are more likely to be accessed by the survivor's parent(s) or caregiver(s). Nevertheless, attempting to address both audiences in each PLAIN summary (i.e., "am I or is my child at risk of …") could compromise readability. In addition, directly addressing survivors in the summaries and acknowledging their capacity for autonomy, may encourage empowerment and support the transition from parent-managed care to self-managed care. We therefore opted to primarily address the survivor in the majority of the PLAIN summaries, while addressing both parties in the summaries that discuss late effects that are more likely to manifest during childhood, such as growth disorders.

2.5. Development process

From February 2019 until December 2023, the PanCare PLAIN

Information Group collaborated to develop PLAIN summaries for each of the PanCareFollowUp Recommendations. During a two-day face-to-face meeting in 2019, members of the PanCare PLAIN Information Group met to decide on the structure and content, and discuss important considerations. Subsequently, a video conference was scheduled each month.

Using the PLAIN summary template, each PLAIN summary was drafted (in English) by a science communication expert, with inputs from one assigned HCP and patient advocate. The first drafts were then circulated among all members of the PanCare PLAIN Information Group and CAYA cancer survivors affiliated with Childhood Cancer International Europe (CCI-E). Their feedback was discussed during the monthly video conferences, and the assigned HCPs made the necessary revisions. Subsequently, the revised versions were circulated again, to be endorsed by all members during the subsequent video conference.

When all 45 PLAIN summaries were agreed by the PanCare PLAIN Information Group, medical specialists, as well as a larger panel of CAYA cancer survivors, parents and caregivers were invited for an external consultation round. Finally, the PLAIN summaries were harmonised and translated into Italian for integration in the Survivorship Passport (SurPass), a digital SCP which is currently implemented across more than 50 Italian paediatric cancer institutions (www.pancaresurpass.eu). To facilitate a streamlined translation process across other European languages, a comprehensive translation manual will be created.

3. Results

3.1. Overview of the PanCareFollowUp PLAIN summaries

In total, 40 PanCareFollowUp Recommendations have been converted into 45 PLAIN summaries. Each PLAIN summary corresponds to one surveillance recommendation, with the exception of the consensus-based PanCareFollowUp Recommendation for subsequent neoplasms. This recommendation has been translated into six separate PLAIN summaries; one discussing subsequent cancer in general and five dedicated to discussing different types of malignancies (acute myeloid leukemia or myelodysplasia (blood cancer), bladder cancer, bone cancer, lung cancer, and oral cancer). An overview of the PLAIN summaries and their corresponding recommendation is provided in Table 1.

The PLAIN summaries are made freely available on the PanCare website (www.pancare.eu/plain-language-summaries/) (Fig. 1), as will their translations. For wider dissemination, a link to this page will also be incorporated into an information platform for youth cancer survivors, created within the European Network of Youth Cancer Survivors (EU-CAYAS-NET) project (www.beatcancer.eu). In addition, the PLAIN summaries will be integrated in the SurPass, of which implementation is currently being expanded to six European countries (www.pancaresurpass.eu). This will ensure that CAYA cancer survivors can access accurate information needed for effective self-management, regardless of where they are in Europe.

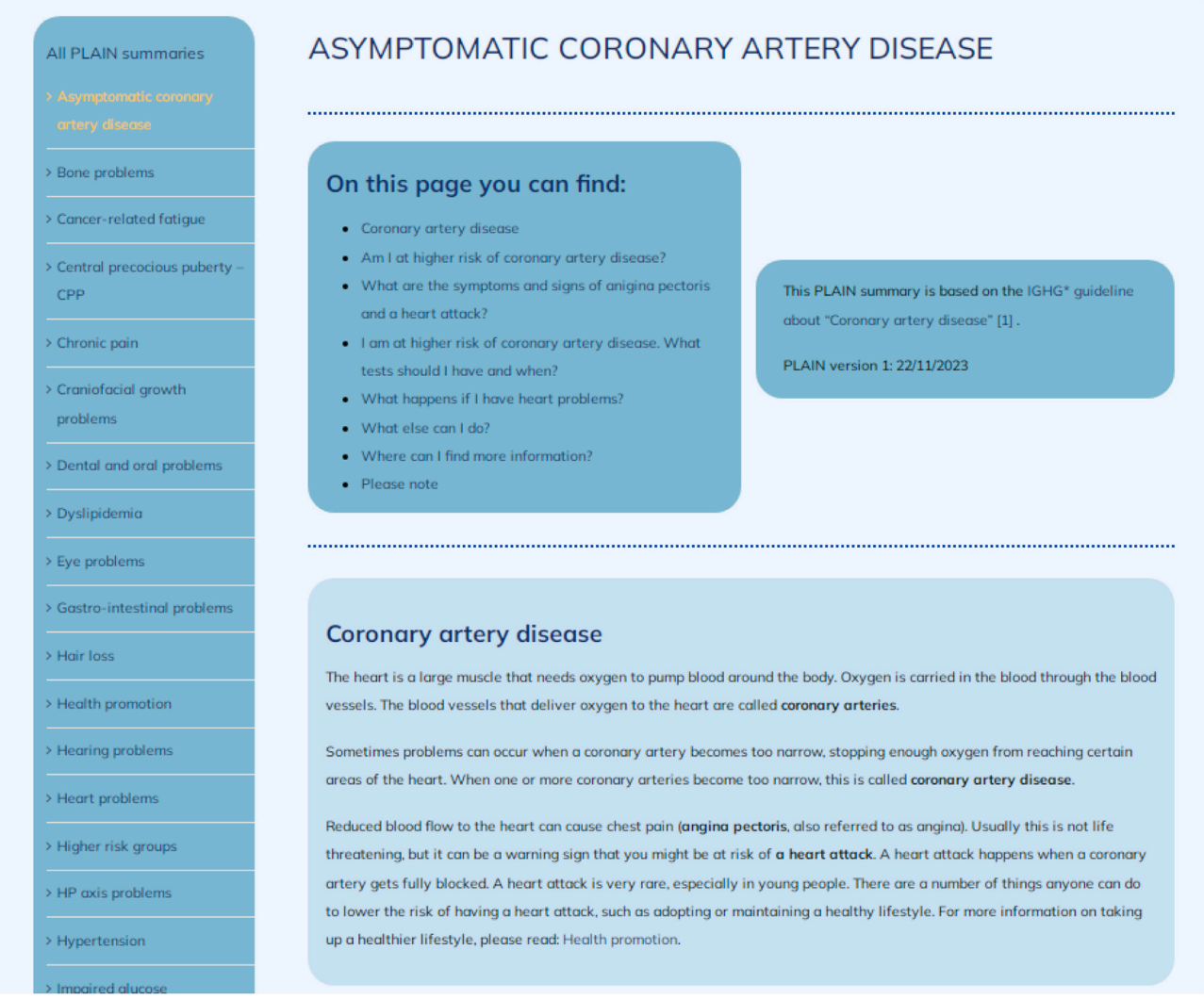

Fig. 1. Example of part of a PanCareFollowUp PLAIN summary, posted on the PanCare website.

4. Discussion

To provide survivors of CAYA cancer with the knowledge and resources they need to practice self-care effectively, the 40 PanCareFollowUp Recommendations were converted into 45 PLAIN information summaries. These summaries are unique in their collaborative development with survivors and adherence to clinical practice recommendations. While recommendations for care usually target HCPs, we created a platform where this information is accessible and comprehensible for survivors. It is hoped that this freely accessible information will empower survivors to take a more active role in their care, consulting their HCP and participating in shared decision making. In addition, we expect the PLAIN summaries will increase awareness and understanding in HCPs, especially general practitioners and non-cancer specialists, and support adherence to clinical practice recommendations.

Person-centred care is a fundamental concept that should form the basis of LTFU care. Likewise, tailoring information to meet the unique needs and circumstances of CAYA cancer survivors is essential in delivering the best possible care, especially since this population confronts such a broad range of health risks. Providing too much information about potential health issues that may be encountered in the (near) future can easily lead to survivors feeling overwhelmed [17]. As such, it is important to restrict the information to topics that are applicable to the survivor's circumstances. However, screening 45 PLAIN summaries to find the ones that apply to a specific survivor's situation can be a time-consuming task. To accelerate this process, a navigation tool is incorporated into the PanCare website, where survivors can select the treatments they received and are automatically directed to the PLAIN summaries relevant for them. Similarly, the built-in algorithmic function of the SurPass will be used to automatically select PLAIN summaries based on the survivor's treatment summary.

To guarantee international relevance, we aim to translate the PLAIN summaries in all European languages. During this translation process, it is important to consider that cultural differences can influence preferences in wording or tone. For example, where some cultures value directness, others may favor a more nuanced delivery of information. While it is challenging to accommodate all cultural preferences, we recognise the importance of providing translations that are culturally sensitive and relevant. Therefore, in the translation manual, we will instruct translators of the PLAIN summaries to exercise some discretion and take liberties with the English text provided, to ensure that the translations are appropriate for their respective cultures without compromising the recommendations. That said, the PLAIN summaries are a freely accessible resource so it will not be possible to monitor all translations. As a consequence, PanCare will only assume responsibility for the original English content available on the PanCare website.

Besides translating the PLAIN summaries, several additional tasks need to be performed. Within the EU-CAYAS-NET project, the majority of PLAIN summaries will be enriched with informative illustrations to make them even more understandable and visually appealing. Also, a more comprehensive evaluation by CAYA cancer survivors will be necessary. While the PLAIN summaries were co-developed with CAYA cancer survivors, we acknowledge that survivors who actively engage with such organisations may possess a higher educational background, which could result in a slight underestimation of the summaries' level of difficulty. In addition, further research will be required to understand survivors' response to receiving information summaries, and additional strategies may be needed to mitigate potential feelings of being overwhelmed. Moreover, as clinical practice recommendations rely on state-of-the-art knowledge, the summaries will require frequent updates. A systematic approach to keeping the PLAIN summaries and their translations up-to-date will be needed, in particular when their corresponding recommendations are revised. Finally, similar to the harmonisation of clinical practice guidelines, the PLAIN summaries and existing patient information, such as the information developed by the Children's Oncology Group, could be harmonised in a future endeavour to improve informational resources worldwide [7].

In summary, the PanCare PLAIN Information Group converted the PanCareFollowUp Recommendations into 45 PLAIN information summaries. Although primarily targeted at CAYA cancer survivors, these summaries may also increase knowledge in survivors' parents/caregivers, other family members, and friends. In addition, they may inform in HCPs and support compliance with clinical practice recommendations, thereby improving the overall quality of European survivorship care. The English versions of the PLAIN summaries will be made available online and may be used in clinical practice. Over the upcoming years and as part of ongoing and future European projects, the PLAIN summaries will be translated into other European languages, evaluated and improved, and systematically updated.

Funding

This work was supported by the European Union's Horizon 2020 research and innovation programme (grant number 824982). The funding source was not involved in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit this article for publication.

CRediT authorship contribution statement

S.R.v.d.O. contributed to drafting the PLAIN summaries, writing the article, visualisation, and project administration. T.F. contributed to harmonisation of the PLAIN summaries, writing the article, visualisation, and project administration. H.J.H.v.d.P. contributed to harmonisation of the PLAIN summaries, writing the article, visualisation, project administration, and funding acquisition. L.C.M.K, R.S., and R.L.M. contributed to PLAIN summary alignment with the PanCareFollowUp Recommendations, writing the article, visualisation, and funding acquisition. R.H. and G.L. contributed to writing the article and visualisation. All authors contributed to development of the PLAIN summaries, conceptualisation, methodology, and reviewing and editing the article.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

The authors gratefully acknowledge all CAYA cancer survivors, parents/caregivers and experts for their contributions and inputs during the (external) consultation rounds. In addition, we thank all members of the PanCareFollowUp Consortium for their contribution to the PanCareFollowUp project.

The PanCareFollowUp Consortium, established in 2018, is a unique and multidisciplinary collaboration between 14 project partners from ten European countries, including patient experts (https://pancarefollowup.eu). The aim of the consortium is to improve the quality of life for survivors of childhood, adolescent and young adult (CAYA) cancer by bringing evidence-based, person-centred care to clinical practice. The PanCareFollowUp Consortium has developed (and currently evaluates) two interventions: 1) a person-centred and guideline-based model of survivorship care (Care Intervention) and 2) an eHealth lifestyle coaching model (Lifestyle intervention). After the project, Replication Manuals that contain the instructions and tools required for implementation of the PanCareFollowUp interventions will be freely distributed.

Disclaimer

The material presented and views expressed here are the responsibility of the authors only. The EU Commission takes no responsibility for any use made of the information set out.

While the PanCare PLAIN information group strives to provide accurate and complete information that is up-to-date as of the date of publication, CAYA cancer survivors can check with their general practitioner or follow-up care specialist if the summaries we provide reflect the most up-to-date information available and whether it is relevant for them. We discourage survivors to rely solely on this information. It is best to also seek the advice of a qualified medical practitioner if they have questions regarding a specific medical condition, disease, diagnosis or symptom. No warranty or representation, expressed or implied, is made concerning the accuracy, reliability, completeness, relevance, or timeliness of the PLAIN summaries. PanCare has produced the English version and PanCare is not responsible for the translated versions of the summaries.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ejcped.2024.100165.

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