



## Original Research

# The *PanCareFollowUp* Care Intervention: A European harmonised approach to person-centred guideline-based survivorship care after childhood, adolescent and young adult cancer



Rebecca J. van Kalsbeek<sup>a</sup>, Renée L. Mulder<sup>a</sup>, Riccardo Haupt<sup>b</sup>,  
 Monica Muraca<sup>b</sup>, Lars Hjorth<sup>c</sup>, Cecilia Follin<sup>d</sup>, Tomas Kepak<sup>e</sup>,  
 Katerina Kepakova<sup>e</sup>, Anne Uyttebroeck<sup>f</sup>, Marlies Mangelschots<sup>f</sup>,  
 Jeanette Falck Winther<sup>g,h</sup>, Jacqueline J. Loonen<sup>i</sup>, Gisela Michel<sup>j</sup>,  
 Edit Bardi<sup>k,l,m</sup>, Line Elmerdahl Frederiksen<sup>g</sup>, Jaap den Hartogh<sup>k,n</sup>,  
 Luzius Mader<sup>g,o</sup>, Katharina Roser<sup>j</sup>, Carina Schneider<sup>n</sup>,  
 Morven C. Brown<sup>p,q</sup>, Melanie Brunhofer<sup>n</sup>, Irene Göttgens<sup>r</sup>,  
 Rosella P.M.G. Hermens<sup>s</sup>, Anita Kienesberger<sup>n</sup>, Joke C. Korevaar<sup>t</sup>,  
 Roderick Skinner<sup>q,u,v</sup>, Helena J.H. van der Pal<sup>a,k,l,\*</sup>,  
 Leontine C.M. Kremer<sup>a,w,x,l</sup>

<sup>a</sup> Princess Máxima Centre for Paediatric Oncology, Utrecht, the Netherlands

<sup>b</sup> Epidemiology and Biostatistics Unit and DOPO Clinic, IRCCS Istituto Giannina Gaslini, Genoa, Italy

<sup>c</sup> Lund University, Skane University Hospital, Department of Clinical Sciences Lund, Paediatrics, Lund, Sweden

<sup>d</sup> Lund University, Skane University Hospital, Department of Clinical Sciences Lund, Oncology, Lund, Sweden

<sup>e</sup> International Clinical Research Centre (FNUSA-ICRC), St. Anne's University Hospital, Masaryk University, Brno, Czech Republic

<sup>f</sup> Department of Oncology, Paediatric Oncology, KU Leuven, Department of Paediatric Haematology and Oncology, University Hospitals Leuven, KU Leuven, Leuven, Belgium

<sup>g</sup> Childhood Cancer Research Group, Danish Cancer Society Research Centre, Copenhagen, Denmark

<sup>h</sup> Department of Clinical Medicine, Faculty of Health, Aarhus University Hospital, Aarhus University, Aarhus, Denmark

<sup>i</sup> Department of Haematology, Radboud Institute for Health Sciences, Radboud University Medical Centre, Nijmegen, the Netherlands

<sup>j</sup> Department of Health Sciences and Medicine, University of Lucerne, Lucerne, Switzerland

<sup>k</sup> PanCare, Bussum, the Netherlands

<sup>l</sup> St Anna Children's Hospital, Vienna, Austria

<sup>m</sup> Department of Pediatric and Adolescent Medicine, Kepler University Clinic, Linz, Austria

<sup>n</sup> Childhood Cancer International Europe, Vienna, Austria

<sup>o</sup> Institute of Social and Preventive Medicine, University of Bern, Bern, Switzerland

\* Corresponding author: Princess Máxima Centre for Paediatric Oncology, Heidelberglaan 25, 3584 CS Utrecht, the Netherlands.

E-mail address: [H.J.H.vanderPal@prinsesmaximacentrum.nl](mailto:H.J.H.vanderPal@prinsesmaximacentrum.nl) (H.J.H. van der Pal).

<sup>1</sup> These authors shared last authorship.

<sup>p</sup> Population Health Sciences Institute, Newcastle University, Sir James Spence Institute, Royal Victoria Infirmary, Newcastle Upon Tyne, United Kingdom

<sup>q</sup> Newcastle University Centre for Cancer, Wolfson Childhood Cancer Research Centre, Herschel Building, Newcastle Upon Tyne, United Kingdom

<sup>r</sup> Department of Primary and Community Care, Radboud University Medical Centre, Radboud Institute for Health Sciences, Nijmegen, the Netherlands

<sup>s</sup> Radboud University Medical Centre, Radboud Institute for Health Sciences, Scientific Institute for Quality of Healthcare (IQ Healthcare), Nijmegen, the Netherlands

<sup>t</sup> Netherlands Institute for Health Services Research (Nivel), Utrecht, the Netherlands

<sup>u</sup> Great North Children's Hospital, Royal Victoria Infirmary, Newcastle Upon Tyne, United Kingdom

<sup>v</sup> Translational and Clinical Research Institute, Wolfson Childhood Cancer Research Centre, Herschel Building, Newcastle Upon Tyne, United Kingdom

<sup>w</sup> Department of Paediatrics, Emma Children's Hospital, Amsterdam UMC, Amsterdam, the Netherlands

<sup>x</sup> Faculty of Medicine, Utrecht University and Utrecht Medical Centre, Utrecht, the Netherlands

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Long-term follow-up care;  
Person-centred care;  
Shared decision-making;  
Quality of life

**Abstract Background:** Long-term follow-up (LTFU) care, although endorsed, is not available for the majority of adult survivors of childhood, adolescence and young adult (CAYA) cancer. Barriers to implementation include lack of time, knowledge, personnel and funding. Sustainable solutions are urgently needed to address the needs of CAYA cancer survivors to improve the quality of life and reduce the burden of late effects on survivors, health care systems and society. The European Union–funded *PanCareFollowUp* project, initiated by the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer, was established to facilitate the implementation of person-centred survivorship care across Europe.

**Patients and methods:** The *PanCareFollowUp Care Intervention* was co-developed with survivors as part of the *PanCareFollowUp project*. It is a person-centred approach to survivorship care, supported by guidelines and with flexibility to adapt to local health care settings. The Care Intervention consists of three steps: (1) previsit completion of a Survivor Questionnaire (by the survivor) and Treatment Summary (by the health care provider [HCP]), (2) a clinic visit including shared decision-making, and (3) a follow-up call to finalise the individualised Survivorship Care Plan.

**Results:** We developed the key components of the *PanCareFollowUp Care Intervention*: a *PanCareFollowUp Survivor Questionnaire*, *Treatment Summary* template, *Survivorship Care Plan* template, and educational materials for HCPs and survivors. Wide implementation of the *PanCareFollowUp Care Intervention* will be supported with a freely distributed *Replication Manual* on completion of the *PanCareFollowUp project*.

**Conclusions:** The *PanCareFollowUp Care Intervention* will support the implementation of person-centred, guideline-based LTFU care in different health care settings across Europe to improve survivors' health and well-being.

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## 1. Introduction

The importance of long-term follow-up (LTFU) care to reduce survivor, family and societal burden is widely acknowledged [1–3]. At current, the European childhood, adolescent and young adult (CAYA) cancer survivor population is estimated at 500,000 individuals and is expected to increase by 12,000 each year [4]. After overcoming their initial disease, these survivors are challenged with an increased risk of developing medical

and psychosocial late effects [5–9]. In a recent study from the United States, the average CAYA cancer survivor is suffering from 17 chronic health conditions by the age of 50 years, which is almost twice as many as in the general population [10]. The type and severity of late effects are largely influenced by initial diagnosis and treatment. Survivors are consequently at higher risk of premature mortality compared with peers or siblings without a CAYA cancer diagnosis [11–13], and regular follow-up is recommended.

Although the model of care might vary, it is agreed that high-quality survivorship care should consist of prevention, early detection and management of late effects [14]. Evidence-based clinical practice guidelines, developed by the International Late Effects of Childhood Cancer Guideline Harmonization Group and within European Union–funded PanCare projects (PanCareSurFup, PanCareLIFE), are available to inform effective surveillance strategies for late adverse effects [15–24]. In addition, a survivorship care plan including a summary of cancer treatment and personalised recommendations for LTFU care is endorsed as an important tool to increase knowledge and empowerment of survivors, oncologists and primary care providers [1,14,25]. A survivorship care plan contains information about the survivor's individual risks and care requirements, based on harmonised recommendations, and can evolve with changing health and personal needs. Survivorship care plans delivered by a late effects clinic increase primary care physicians' and survivors' knowledge of late effects and contribute to earlier detection of health problems in primary care, thus potentially resulting in a lower health care burden [26]. Furthermore, LTFU care offers an opportunity to provide age-appropriate education about the late effects of a survivor's diagnosis and treatment as well as guidance in matters of health behaviour, health or life insurance, education and work [27,28].

Despite the fact that most survivors need lifelong survivorship care, as underlined more than 40 years ago, implementing follow-up care has proven challenging across Europe [29,30]. A survey in 2012 indicated that only 32% of European paediatric oncology institutions had established services for adult CAYA cancer survivors, with considerable differences between countries [31]. Nearly, all institutions without such programmes expressed a wish to implement survivorship care but were limited by various barriers, such as lack of time, personnel, knowledge and funding.

The *PanCareFollowUp* project ([www.pancarefollowup.eu](http://www.pancarefollowup.eu)) was initiated by the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare; [www.pancare.eu](http://www.pancare.eu)) to improve the quality and availability of person-centred LTFU care for CAYA cancer survivors across Europe [32,33]. It includes the development and prospective cohort study of the *PanCareFollowUp Care Intervention*, a person-centred, guideline-based approach to survivorship care, to support future implementation of LTFU care across Europe [34].

The aim of this paper is to describe the development of four essential elements of the *PanCareFollowUp Care Intervention*: the *Survivor Questionnaire*, the *Treatment Summary*, the *Survivorship Care Plan* and online information for survivors and health care providers (HCPs). The development of European *PanCareFollowUp Recommendations* to guide LTFU care, as well as the protocol and results of the *Care Study*, a prospective cohort

study to evaluate the outcomes and feasibility of the *Care Intervention* implementation in Belgium, the Czech Republic, Italy and Sweden, will be reported in separate publications [35,36].

## 2. Methods

The *PanCareFollowUp Care Intervention* was developed by late effects specialists, paediatric oncologists, implementation and guideline experts and survivor representatives from Childhood Cancer International, Europe (CCI Europe), representing a total of 14 stakeholders and ten European countries as part of the European Horizon 2020–funded *PanCareFollowUp* project. The *PanCareFollowUp* Consortium is described in detail previously [33]. *PanCareFollowUp Care Intervention* is intended for 5-year CAYA cancer survivors of 16 years or older. The model is based on previous experiences with person-centred survivorship care in Dutch LTFU care clinics [37]. Central elements of the person-centred approach include initiating, working and safeguarding the relationship between survivor and HCP and are incorporated in the structure of the *PanCareFollowUp Care Intervention* [38,39].

The *Care Intervention* consists of three steps, including a previsit preparation, clinic visit and follow-up call (Fig. 1).

1. *Before the clinic visit*: The *PanCareFollowUp Survivor Questionnaire* will be sent to the survivor 2–8 weeks before the clinic visit. The primary Web-based questionnaire is the first step of person-centred care: initiating the partner relationship. It provides an opportunity for the survivor to share information about their health, well-being, medication use, medical and family history, lifestyle, social situation, health care needs, and preferences for care with their HCP. Simultaneously, the HCP prepares a *PanCareFollowUp Treatment Summary*, comprising details on the survivor's cancer diagnosis and treatment history. In addition, the HCP prepares the standard *PanCareFollowUp Survivorship Care Plan* based on the risk factors identified in the *Treatment Summary*, information reported in the *Survivor Questionnaire* and relevant recommendations for LTFU care as described in the *PanCareFollowUp Recommendations*. Availability of this information before the late effects clinic visit can help establish an individual and tailored care pathway. Based on the local logistic and referral structure, this potentially enables advanced planning of surveillance tests for the day of the clinic visit, thus reducing the number of appointments required. The *Survivorship Care Plan* is co-developed with the survivor over the course of the *Care Intervention* (Fig. 2).
2. *At the clinic visit*: The HCP and the survivor engage in a two-way sharing of information that is important for working the partnership as the second step to person-centred care. Together, they discuss the potential health concerns of the survivor, the content of the *Survivor Questionnaire* and *Treatment Summary*, and the standard *Survivorship Care Plan*. In addition, the HCP delivers health information

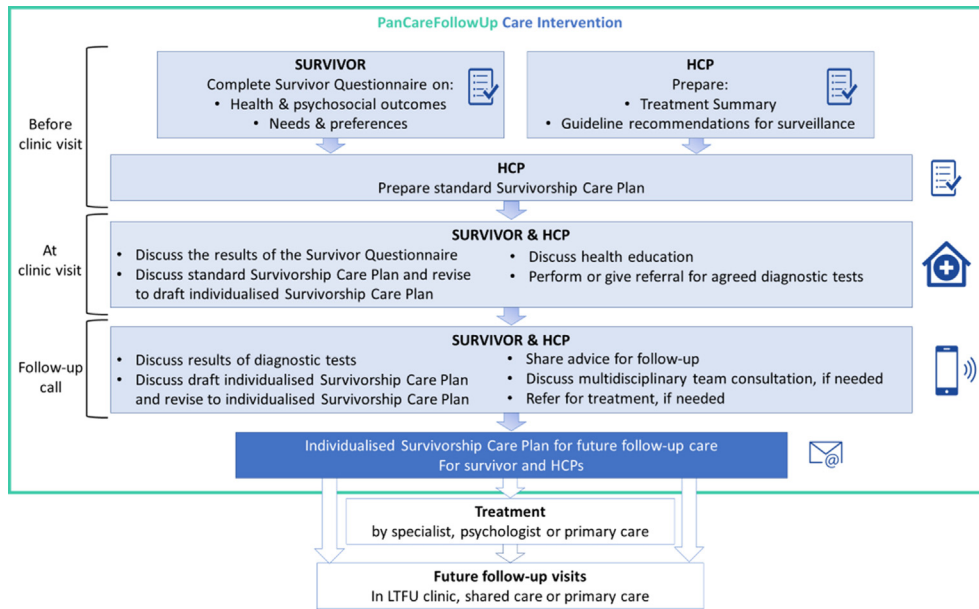


Fig. 1. The PanCareFollowUp Care Intervention steps: previsit preparation, clinic visit, and follow-up call.

relevant to the survivor, raises awareness about certain health issues the survivor is possibly faced with and discusses the importance of a healthy lifestyle. Subsequently, the physical examinations and diagnostic tests are performed as per plan. If necessary, further appointments for more advanced tests or referrals can be scheduled for a later time. Based on this clinic visit, the HCP and the survivor develop a draft individualised Survivorship Care Plan. The structure and background of this person-centred visit will be described in more detail in a separate publication.

3. *Follow-up call:* After consultation with the multidisciplinary team, the HCP contacts the survivor to discuss the results of the diagnostic tests performed at, or in relation to, the clinic visit. Where needed, referrals for management of identified health problems are arranged, taking into account the *PanCareFollowUp Recommendations* and the preferences of the survivor. Furthermore, the survivor and the HCP will decide on a preferred model for future follow-up with regard to potential health conditions, the health care system and survivor’s preferences. Shared decision-making about these issues contributes to the modified individualised *Survivorship Care Plan*. The survivor will

receive the individualised *Survivorship Care Plan* by post and/or secured e-mail and can use it to communicate about their care preferences with other HCPs.

For this *PanCareFollowUp Care Intervention*, the Consortium developed a *Survivor Questionnaire*, a *Treatment Summary* and a *Survivorship Care Plan*, as well as online education materials, based on clinical examples and previous experience in setting up survivor questionnaires, treatment summaries and care plans within Europe and the United States. In addition, *PanCareFollowUp Recommendations* to guide LTFU care were developed in a wider European collaboration using a pragmatic methodology and are described in a separate paper.

### 2.1. Development of the PanCareFollowUp Survivor Questionnaire

Development of the *Survivor Questionnaire* started with the establishment of a core group (including H.P., L.K.,



Fig. 2. Development timeline of the individualised Survivorship Care Plan. PCFU, PanCareFollowUp.

R.M. and R.K.) and identification of questionnaires that are currently used in LTFU care or research through the *PanCareFollowUp* network. A total of nine questionnaires were provided by *PanCareFollowUp* project partners or their network, including a holistic tool for survivorship care from Lund University, a care transition questionnaire from the Charité University Hospital Berlin, a Dutch care plan for paediatric palliative care, and study questionnaires of the British Childhood Cancer Survivor Study, Dutch Childhood Cancer Survivor Study, Swiss Childhood Cancer Survivor Study, Childhood Cancer Survivor Study from the United States, St. Jude LIFE study, and a Dutch breast cancer study. Additional questions were identified by reviewing the available Patient-Reported Outcomes Measurement Information System (PROMIS) tools and the Patient-Reported Outcome version of the Common Terminology Criteria for Adverse Events [40,41] and by including the Emotion Thermometer [42].

The core group established the following eight domains upfront to be relevant for the *Survivor Questionnaire* based on previous research [43] and clinical expertise: (1) self-reported physical symptoms; (2) self-reported psychosocial symptoms; (3) medication use; (4) medical history including hospital admissions; (5) family history; (6) social situation, education and employment; (7) health behaviour including lifestyle; and (8) needs and preferences. Questionnaires were included for further review if they contained questions related to any of these domains.

All extracted questions were grouped by domain and discussed at regular face-to-face core group meetings. A preselection was made in collaboration with survivor representatives and distributed to the entire *PanCareFollowUp* Consortium for review. The questionnaire was subsequently reviewed by survivor representatives of CCI Europe external to the project. Suggestions were provided to refine the psychosocial and lifestyle sections. This included the development of a novel psychosocial tool specifically for CAYA cancer survivors addressing challenges they may face in daily life. Finally, the *Survivor Questionnaire* was translated to Czech, Dutch, Italian and Swedish by native speakers from the Consortium for the purposes of the *PanCareFollowUp Care Study*. During the translation process, a few additional minor alterations were made to improve the ease of use and understandability of the *Survivor Questionnaire*. The final version of this questionnaire was approved by the Consortium through a digital check.

## 2.2. Development of the *PanCareFollowUp* treatment summary template

A core group (H.P., L.K., M.M., R.H., R.M. and R.K.) was assembled in the preparation phase. Treatment summaries currently used in survivorship care were requested from all *PanCareFollowUp* project partners

and reviewed. A total of six treatment summary templates were collected, which are currently used in Linz (Austria), Utrecht (the Netherlands), Leuven (Belgium), Lund (Sweden), Newcastle upon Tyne (the United Kingdom) and in six centres of the Italian Association of Paediatric Haematology and Oncology (AIEOP; Italy). Two of the examples consisted of databases with predefined variables and answer options, including the Web-based Survivorship Passport used in Italy (SurPass – [www.survivorshippassport.org](http://www.survivorshippassport.org)) [44], and the Dutch treatment summary, whereas the other documents required manual completion with open text fields.

The SurPass was developed as part of previous European Union projects (e.g. European Network for Cancer Research in Children and Adolescents and PanCareSurFup). Its comprehensive variable list was used as a starting point and compared with the other treatment summaries to develop a draft *Treatment Summary* template. In addition, the Consortium agreed on a three-tiered radiotherapy classification to systematically document radiation exposure. The *Treatment Summary* template was disseminated to a broader group within the *PanCareFollowUp* project, including researchers, clinicians and survivor representatives. Following clarification of variables and final modifications, it was accepted by the entire *PanCareFollowUp* Consortium.

## 2.3. Development of the *PanCareFollowUp* Survivorship Care Plan

A core group (H.P., L.K., R.K. and R.M.) was established and requested care plans among *PanCareFollowUp* project partners. A total of six care plan templates were collected, which are currently used in Linz, six AIEOP centres, Utrecht, Lund, Newcastle upon Tyne and Memphis (the United States). Using the SurPass as a starting point, the core group developed a draft including elements from all provided care plans. Plain language recommendations for use in the *Survivorship Care Plan* were developed for each of the diagnostic tests included in the *PanCareFollowUp Recommendations*. The statements were reviewed by CCI Europe survivor representatives for language and content. After review and endorsement by the entire *PanCareFollowUp* Consortium, these English recommendations were translated to Czech, Dutch, Italian and Swedish by native speakers from the Consortium and included in a user manual for use in the *PanCareFollowUp Care Study*.

## 2.4. Development of online information for survivors and HCPs

The core group (H.P., L.K., R.K. and R.M.) collaborated with survivor representatives to develop online information specifically for survivors and HCPs, using



Date of Survivorship Care Plan issue: 01/ 06/ 2021

## General information

*This section was last updated on 01/ 06/ 2021*

Name	John Doe
Date of birth	01/ 01/ 1971
Last long-term follow-up visit	01/ 06/ 2021
Contact information of late effects clinic	Late Effects Clinic 0123-456789

## Treatment summary

### Cancer diagnosis

*This section was last updated on 01/ 06/ 2021*

Date of diagnosis	01/ 01/ 1973
Diagnosis	Acute lymphoblastic leukemia
Primary treatment centre	Children's Hospital

### Front line treatment

*This section was last updated on 01/06/ 2021*

The treatment has been given via	ALL-II	
Group/arm/randomization	Unknown	
Summary of major treatments	Chemotherapy	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	Stem cell transplantation	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
	Radiotherapy	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	Major surgery	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Progression during front line treatment	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>	
Relapse during front line treatment	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>	
Date of first elective end of treatment	31/ 12/ 1974	

Fig. 3. Example of a PanCareFollowUp Survivorship Care Plan.

### Standard recommendations for long-term follow-up care

Because of the treatment you have had, we have listed the tests recommended for you. This advice is based on international experience with people who have received the same treatment as you.

Because you had or have been treated with ...	... you may have a risk of ...	... therefore, it is recommended that you have ...
Immunosuppressives as part of your cancer treatment	High blood pressure	A blood pressure measurement at least every 2 years and at every long-term follow-up visit
Mercaptopurine and methotrexate	Liver problems	Blood tests of the liver once
Methotrexate, corticosteroids as part of your cancer treatment, and radiotherapy to your brain	Low bone mineral density	A DXA scan once
Radiotherapy to your brain	Brain cancer	Discussed the advantages and disadvantages of regular MRIs with your doctor
Radiotherapy to your brain	Overweight	A height and weight measurement at least every 2 years
Radiotherapy to your brain	Hormonal problems	Blood tests every year

### Individualised decisions for long-term follow-up care

This is an overview of the decisions regarding your long-term follow-up care that you have made together with your health care provider.

Individualised decision for long-term follow-up care:	Comments:	Planned for:
<b>Based on the standard recommendations for long-term follow-up care</b>		
- DXA scan 1x at entry LTFU		Already performed
- Blood pressure at least 1x/2 years and at every LTFU visit		2022
- ALT, AST, gGT, ALP 1x at entry LTFU		Already performed
- Discuss potential harms and benefits of MRI surveillance	Discussed with survivor, decided against MRI surveillance	Already discussed
- Height, weight, BMI at least 1x/2 years		2022
- FT4, TSH, morning cortisol, IGF-1 1x/year - Morning testosterone (or free testosterone if overweight) and LH 1x/year		2022
<b>Based on clinical indication</b>		
- Dermatological examination	History of basal cell carcinoma	2022

Fig. 3. Continued

current best practices such as the COG Health Links ([www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)) and Dutch Childhood Oncology Group website ([www.skion.nl/voor-patienten-en-ouders/late-effecten](http://www.skion.nl/voor-patienten-en-ouders/late-effecten)) as an example. The information describes the challenges of childhood cancer survivorship and the importance of LTFU care and provides an overview of the *PanCareFollowUp Care Intervention*.

### 3. Results

#### 3.1. *PanCareFollowUp Survivor Questionnaire*

The *Survivor Questionnaire* contains 74 (male version) or 77 (female version) standard questions, with additional follow-up questions depending on specific answers ([Appendix A and B](#)). Thereby, it is comprehensive, where needed, yet adjusted to the survivor's individual situation where possible. The average time of completion was 45 min, as assessed in the feedback round among seven CAYA cancer survivor representatives and one parent representative. Participants in the feedback round indicated that although time intensive, the questionnaire was well-balanced between physical and mental well-being, lifestyle and survivor-specific issues, encouraging them to complete it before a potential clinic visit. During the *Care Study*, an online version of the *Survivor Questionnaire* is provided through Castor EDC ([www.castoredc.com](http://www.castoredc.com)), a cloud-based Electronic Data Capture platform, with paper versions available on request.

#### 3.2. *PanCareFollowUp treatment summary*

The *Treatment Summary* contains sections on general information, cancer diagnosis, front line treatment, progression or relapse during front line treatment or after the first elective end of treatment, health problems during cancer treatment, family history, relevant medical history and current medication use. It specifically includes standardised cumulative treatment data with start and end dates, chemotherapy drug names and doses, other drug names and doses, radiotherapy fields and doses, details on stem cell transplantation and surgeries ([Appendix C](#)).

The treatment data cover treatments for the initial cancer, all relapses and subsequent neoplasms (either malignant or benign) and complications, if any. As such, it is a living document that can be updated by HCPs over the course of survivorship care, for example, in case of a relapse or subsequent neoplasm after the elective end of therapies. During the *Care Study*, the *Treatment Summary* is completed digitally within Castor EDC ([www.castoredc.com](http://www.castoredc.com)) or the SurPass platform.

#### 3.3. *PanCareFollowUp Survivorship Care Plan*

The *Survivorship Care Plan* ([Fig. 3](#)) includes the following sections: (1) general information (including name, birth date and LTFU care clinic details), (2) *PanCareFollowUp Treatment Summary*, (3) history and health problems (including relevant medical and family history, current health problems and current medication based on the *Survivor Questionnaire*), (4) standard recommendations for LTFU care (tailored to diagnosis and treatment according to the *PanCareFollowUp Recommendations*) and (5) individualised decisions for LTFU care (based on the clinic visit, diagnostic test results and follow-up call; [Appendix C](#)).

The corresponding user manual contains clear instructions to complete all sections of the *Survivorship Care Plan*, as well as an overview of the plain language statements. These have been sorted and colour coded by treatment exposure, such as chemotherapy, radiation therapy or surgery, to facilitate a user-friendly layout and smooth development process of each *Survivorship Care Plan*. The *Survivorship Care Plan* can be shared with the survivor on paper or digitally through the SurPass platform.

#### 3.4. *Online information for survivors and HCPs*

The online information is openly available through the project website ([www.pancarefollowup.eu](http://www.pancarefollowup.eu)) and will be sustained by PanCare ([www.pancare.eu](http://www.pancare.eu)) after the project ends. Furthermore, plain language brochures in question-and-answer style will be developed throughout the project, explaining each of the late effects addressed in the *PanCareFollowUp Recommendations*. This information can be consulted and printed through the Web sites.

### 4. Discussion

The *PanCareFollowUp Care Intervention* is the first European harmonised and person-centred approach to survivorship care. Furthermore, it focuses on sustainable implementation across the diverse landscape of European health care systems. Co-developed with survivors and representing a collaborative effort between ten European countries, it intends to address the needs of both survivors and HCPs.

Adequate knowledge of their cancer history, subsequent treatment exposure and potential risks of late effects are needed to enhance survivors' health and self-management skills. Accessible and reliable information is important to increase awareness about late effects and LTFU care among survivors and HCPs and is essential for shared decision-making. Moreover, it empowers survivors to seek medical or psychosocial help, if

needed, or to take responsibility for preventive lifestyle measures and attending LTFU care. An individualised survivorship care plan including a summary of treatment history and personal recommendations for surveillance and prevention is provided to support this process [1,14]. Given the heterogeneity of existing health care systems across Europe, it is important that interventions for survivorship care are flexible in how the care is delivered, while respecting common, core requirements such as a summary of treatment and personal recommendations for surveillance [45,46]. Endorsed models to provide LTFU care are surveillance in a survivorship clinic or shared care between the survivorship clinic and local hospital or primary care. An alternative is self-management supported by HCPs within a shared care or primary care model, with swift referral to survivorship expert centres if needed [14]. The choice of a preferred model and frequency of care will depend on the survivor's risk for late effects and pre-existing health conditions, the health care system and the survivor's preferences.

The *PanCareFollowUp Care Intervention* provides a state of the art-structure for survivorship care, which facilitates education about survivor-important issues as well as shared decision-making about surveillance strategies. Furthermore, it empowers the survivor by providing comprehensive yet understandable information about their health and potential risks and encouraging survivors to (co-)manage their LTFU care. HCPs are supported by the comprehensive previsit *Survivor Questionnaire*, *Treatment Summary* and *Survivorship Care Plan*, so the LTFU care visit can be tailored to the survivor's needs with optimum advance planning and preparation.

Using the wide variety of available materials as a starting point, components of the *PanCareFollowUp Care Intervention* build on clinical experience and preference. Efficient organisation of tasks and review cycles was achieved by establishing core groups and including the entire *PanCareFollowUp Consortium* in regular consultation rounds. To strengthen the evidence base for comprehensive survivorship care, a prospective cohort study (*Care Study*) evaluating the feasibility, effectiveness (in terms of physical, psychological and social outcomes) and cost-effectiveness of the *PanCareFollowUp Care Intervention* will be conducted across four study sites: University Hospitals of Leuven (Belgium), St. Anne's University Hospital, Brno (Czech Republic), Giannina Gaslini Children's Hospital, Genoa (Italy), and Skåne University Hospital, Lund (Sweden). The main outcome is empowerment of the survivor, as self-management and taking responsibility for their own health are fundamental to the appropriate recognition and management of late effects and thereby the

survivor's quality of life. A detailed description of survivor recruitment, study coordination and conduct, selected outcomes, data collection and data analysis will be published elsewhere. Testing the *PanCareFollowUp Care Intervention* under realistic circumstances in four clinics representing different health care systems is important to identify strategies for tailoring to specific challenges and assure optimum replication potential across Europe. Therefore, a preimplementation study was conducted at each of the study sites, identifying barriers and facilitators to implementation of LTFU care among survivors, HCPs and health policymakers. This has resulted in site-specific implementation strategies. Lessons learned during the prospective cohort study will contribute to an update of these implementation strategies at the end of the project.

After the *Care Study* is finalised, open access to all relevant information and tools to implement the *PanCareFollowUp Care Intervention* will be provided through a freely available *Replication Manual* on the PanCare website. Expectations are that the results of the *Care Study* will help to motivate survivors and HCPs to organise the LTFU care in an efficient way with sustainable financial support.

In conclusion, the *PanCareFollowUp Care Intervention* supports the implementation of person-centred LTFU care in different health care models across Europe. The impact of this intervention will be explored by a prospective cohort study in four European countries and will yield a *Replication Manual* for sustainable replication at other institutions after the project. Ultimately, the implementation of such novel survivorship care is expected to have a robust impact on the well-being of CAYA cancer survivors, reduction of the societal burden and to demonstrate the (cost-)effectiveness of survivorship care.

#### Authors' contributions

R.J.v.K. contributed to conceptualisation, methodology, investigation, writing, reviewing and editing the article, visualisation and project administration. R.L.M., H.J.H.v.d.P. and L.C.M.K. contributed to conceptualisation, methodology, investigation, writing, reviewing and editing the article, visualisation, project administration and funding acquisition. R.H., M.M., L.H., C.F., T.K., K.K., A.U., J.F.W., J.J.L., G.M., J.d.H., C.S., M.C.B., R.P.M.G.H., A.K., J.C.K. and R.S. conceptualisation, methodology, investigation, reviewing and editing the article and funding acquisition. E.B., L.E.F., L.M., K.R., M.B. and I.G. contributed to conceptualisation, methodology, investigation and reviewing and editing the article. All authors contributed to the preparation of the article,

and no persons other than the authors listed have contributed significantly to its preparation. The article was written by the authors. All authors approved the final version.

### The PanCareFollowUp Consortium

The PanCareFollowUp Consortium, established in 2018, is a unique and multidisciplinary collaboration between 14 project partners from ten European countries (<https://pancarefollowup.eu/>). The aim of the Consortium is to improve the quality of life for survivors of childhood, young adult and adolescent (CAYA) cancer by bringing evidence-based, person-centred care to clinical practice. The PanCareFollowUp Consortium has developed two interventions, including a person-centred and guideline-based model of survivorship care (Care Intervention) and eHealth lifestyle coaching (Lifestyle intervention). After the project, Replication Manuals that contain the instructions and tools required for implementation of the PanCareFollowUp interventions will be freely distributed. (The European multistakeholder PanCareFollowUp project: Novel, person-centred survivorship care to improve care quality, effectiveness, cost-effectiveness and accessibility for cancer survivors and caregivers. Van Kalsbeek *et al.*, Eur J Cancer. 2021 Jun 18; 153:74–85, June 2021).

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### Disclaimer

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

### Conflict of interest statement

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.

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### Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.ejca.2021.10.035>.

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