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Original Research

The European multistakeholder PanCareFollowUp project: novel, person-centred survivorship care to improve care quality, effectiveness, cost-effectiveness and accessibility for cancer survivors and caregivers

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Abbreviations: CastorEDC, Castor Electronic Data Capture; CPG, clinical practice guideline; ENCCA, European Network for Cancer Research in Children and Adolescents; ExPO-r-Net, European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment; HCP(s), healthcare provider(s); IGHG, International Late Effects of Childhood Cancer Guideline Harmonisation Group; JARC, Joint Action on Rare Cancers; PanCare, Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer; QoL, quality of life; SurPass, Survivorship Passport.

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Abstract Background: The majority of childhood cancer survivors are at risk of treatment-related adverse health outcomes. Survivorship care to mitigate these late effects is endorsed, but it is not available for many adult survivors of childhood cancer in Europe. The PanCareFollowUp project was initiated to improve their health and quality of life (QoL) by facilitating person-centred survivorship care.

Methods: The PanCareFollowUp consortium was established in 2018, consisting of 14 project partners from ten European countries, including survivor representatives. The consortium will develop two PanCareFollowUp Interventions, including a person-centred guideline-based model of care (Care Intervention) and eHealth lifestyle coaching (Lifestyle Intervention). Their development will be informed by several qualitative studies and systematic reviews on barriers and facilitators for implementation and needs and preferences of healthcare providers (HCPs) and survivors. Implementation of the PanCareFollowUp Care Intervention as usual care will be evaluated prospectively among 800 survivors from Belgium, Czech Republic, Italy and Sweden for survivor empowerment, detection of adverse health conditions, satisfaction among survivors and HCPs, cost-effectiveness and feasibility. The feasibility of the PanCareFollowUp Lifestyle Intervention will be evaluated in the Netherlands among 60 survivors.

Results: Replication manuals, allowing for replication of the PanCareFollowUp Care and Lifestyle Intervention, will be published and made freely available after the project. Moreover, results of the corresponding studies are expected within the next five years.

Conclusions: The PanCareFollowUp project is a novel European collaboration aiming to improve the health and QoL of all survivors across Europe by developing and prospectively evaluating the person-centred PanCareFollowUp Care and Lifestyle Interventions.

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1. Introduction

Each year, 35,000 European children, adolescents and young adults are diagnosed with cancer [1]. Fortunately, as treatments have improved, so have 5-year survival rates. In Western European countries, survival has surged from 40% to more than 80% since the 1970s, with similar trends but lower survival rates in Eastern European countries [2]. As a result, the current population of European childhood cancer survivors has increased to around 500,000 and expands each year [1]. Cancer therapeutic regimens, such as chemotherapy, radiotherapy and surgery, are crucial for achieving survival, but are likely to have adverse effects on physical and mental health as well as psychosocial well-being later in life such as risk of subsequent neoplasms, organ dysfunction, fatigue or educational and employment difficulties [3–7].

Person-centred and guideline-based survivorship care can mitigate the negative impact on quality of life (QoL) of survivors and their families [8]. Survivorship care has a strong focus on education, prevention or early detection of late effects and timely intervention when problems occur [9]. In addition to risk-based surveillance, a healthy lifestyle is a powerful tool to reduce survivors' elevated risk of chronic health conditions. Survivorship care may include person-centred lifestyle advice with consideration of their medical history, physical limitations, psychosocial functioning or other barriers and facilitators that survivors may experience in adapting to and maintaining a healthy lifestyle [10,11]. Considering limited healthcare resources, provision of follow-up care also needs to be sustainable and cost-effective [12]. Person-centred strategies that engage patients, allow shared decisions and support empowerment have been shown to produce more satisfaction, better health, higher QoL and lower costs [13]. Person-centred care facilitates shared decision-making between the survivor and healthcare provider (HCP) through three key elements: initiating, working and safeguarding the partner relationship [14–16]. It may support survivors as they transition from treatment to follow-up, from childhood to adolescence and from paediatric to adult healthcare settings. Thus, they may be able to navigate the complexity of various specialists being involved in adult healthcare and take responsibility for their own health [17].

Implementation of survivorship care, however, has proven challenging across the globe [18]. Only 38% of European hospitals offer a survivorship care programme for survivors who have left paediatric oncology services, with availability and the level of person-centred care varying considerably [19]. Although HCPs generally agree on the importance of person-centred survivorship care, multiple barriers exist that prevent proper implementation, including lack of personnel, time required by HCPs and funding [19]. Furthermore, the absence of optimal survivorship care for most survivors might also be explained by the fact that it is complex. Although different care models have been

suggested over the years, improvement in long-term follow-up care is still urgently needed [20].

To meet this request, the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare) established the Horizon 2020–funded PanCareFollowUp project (www.pancarefollowup.eu) to improve current care and get more insight into the feasibility and effectiveness of delivering optimal person-centred survivorship care. The multidisciplinary PanCare network (www.pancare.eu) unites professionals, childhood cancer survivors and their families with the aim of reducing the frequency, severity and impact of late adverse effects by establishing high-quality and sustainable survivorship care for all survivors in Europe [21]. PanCare has initiated and/or contributed to multiple European-funded projects to improve survivors' health and QoL, such as PanCareSurFup [22], PanCareLIFE [23], the European Network for Cancer Research in Children and Adolescents (ENCCA), the Joint Action on Rare Cancers and the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment. The PanCareFollowUp Consortium was established in 2018, consisting of 14 project partners from ten European countries. As a project partner, Childhood Cancer International Europe ensures that survivors contribute to all stages of the project, from development and assessment to implementation.

The PanCareFollowUp project includes the development and evaluation of two person-centred interventions: the PanCareFollowUp Care and Lifestyle Interventions (Fig. 1).

The Care Intervention consists of a person-centred, guideline-based care model that can be tailored to the survivor's needs and preferences within the local healthcare context. The Lifestyle Intervention innovatively builds upon current survivorship care through an eHealth intervention with personalised lifestyle coaching. Experiences of Dutch survivorship that have already implemented person-centred care successfully [24,25] will be used to govern the development of both interventions.

2. Methods

2.1. Aims and objectives of the PanCareFollowUp project

The overall aim of the PanCareFollowUp project is to empower childhood cancer survivors across Europe and improve their health and QoL by facilitating a high standard of person-centred survivorship care. This research has three main objectives: (1) development and evaluation of the person-centred PanCareFollowUp Care Intervention using a prospective cohort study (Care study) (Fig. 2), (2) development and evaluation of the PanCareFollowUp Lifestyle Intervention using a feasibility study (Lifestyle Study) (Fig. 2), and (3) sustainable replication, including free distribution of a Care and Lifestyle replication manual after the project.

Fig. 1. Overview of the PanCareFollowUp project, including the PanCareFollowUp Care and Lifestyle Interventions and the corresponding Care and Lifestyle studies. HCP = healthcare provider, SurPass = Survivorship Passport.

2.2. Organisational structure of the PanCareFollowUp project

The project consists of eight work packages (WPs): WP1–4 to develop and conduct the Care study, WP5 to develop and conduct the Lifestyle study and WP6–8 to cover dissemination, management and ethics, respectively (Table 1).

2.3. WP1: Development of the person-centred PanCareFollowUp Care Intervention

2.3.1. Clinical practice guidelines

To ensure consistent high-quality care in daily practice, evidence-based clinical practice guidelines (CPGs) that inform on effective preventative measures and surveillance methods are essential [9]. CPGs describe the risk-based surveillance that is recommended and discussed with the survivor in a shared decision-making process. Recognition of the advantages of international collaboration in CPG development led to the initiation of the

International Late Effects of Childhood Cancer Guideline Harmonisation Group (IGHG) by several guideline groups in 2010 [25–28]. So far, eight widely accepted IGHG guidelines have been published in peer-reviewed journals, several with major contributions from PanCareSurFup, with further ones in development [29–36]. PanCareSurFup has published recommendations for models of long-term follow-up care, and a guideline for transition from paediatric to adult healthcare settings is close to completion [17,37].

WP1 will contribute to the completion of ongoing evidence-based IGHG efforts by developing recommendations for several topics wherein no evidence-based recommendations exist yet, using a pragmatic methodology. Furthermore, the PanCareFollowUp project will develop a ‘living guideline tool’ that regularly searches for the new literature and automatically informs specified guideline groups. Novel findings can thus be promptly discussed and guidelines can be updated in a timely manner, advancing CPG development and state-of-the-art care provision [36].

Fig. 2. Study cohorts in the PanCareFollowUp Care and Lifestyle studies. CCS = childhood cancer survivors, NL = the Netherlands.

2.3.2. PanCareFollowUp Care Intervention

The novel person-centred guideline-based PanCareFollowUp Care Intervention consists of three steps: (1) a previsit Survivor Questionnaire to identify the survivor's health needs and preferences; (2) a clinic visit during which survivors receive a personalised Treatment Summary summarising their childhood cancer treatment, engage in shared decisions about appropriate surveillance strategies, receive or are scheduled for additional tests and receive a draft Survivorship Care Plan; and (3) a follow-up call to discuss diagnostic test results and refine the Survivorship Care Plan based on the test results.

WP1 will develop the PanCareFollowUp Care Intervention, including the PanCareFollowUp Recommendations, Survivor Questionnaire, Treatment Summary and Survivorship Care Plan template as well as online education materials for survivors and HCPs. A preimplementation study will be conducted at four study sites to qualitatively identify barriers and facilitators for implementing person-centred survivorship care from both survivors' and HCPs' perspectives. WP1 will also train participating HCPs in person-centred care. The resulting implementation strategies and intervention materials will be evaluated throughout the project and summarised in a postproject replication manual.

2.4. WP2: Conduct of the Care study

WP2 is responsible for the preparation and conduct of the Care study at four sites in Belgium, Czech Republic, Italy and Sweden. The PanCareFollowUp Care Intervention will be implemented as usual care and evaluated in a prospective cohort study among 800 survivors aged ≥ 16 years with 6-month follow-up. WP2 will facilitate identification and recruitment of participants and local data collection. The benefits of the Care Intervention for

survivors, as well as experiences of HCPs, and costs for the system will be examined through questionnaires and clinical data. The four study sites have been selected to represent different healthcare systems with various levels of pre-existing survivorship care implementation.

2.5. WP3: Measures and analyses of the Care study

WP3 will select appropriate outcome measures and develop the study questionnaires for the Care study. The main outcome is survivor empowerment, which contributes to self-management and becomes increasingly important when transitioning from paediatric to adult healthcare settings [38]. Other patient-reported outcomes include health-related QoL, mental health, resilience, shared decision-making and satisfaction. In addition, prevalent adverse health conditions and detection of new clinical conditions as well as cost-effectiveness and feasibility of the PanCareFollowUp Care Intervention will be evaluated.

WP3 also constitutes the PanCareFollowUp data coordination centre. This centre will be responsible for building and maintaining the database in the cloud-based Castor Electronic Data Capture system, managing data collection from survivors and HCPs, monitoring of data quality and the study recruitment process and conducting study analyses.

2.6. WP4: Survivorship Passport

WP4 will update the existing Survivorship Passport (SurPass) developed within the ENCCA and PanCareSurFup projects with the PanCareFollowUp Recommendations and will evaluate the feasibility of providing web-based delivery of the PanCareFollowUp Care Intervention at the Italian study site (Fig. 2). The SurPass is an online tool that details a survivor's diagnosis,

Table 1

Overview of tasks and work package leads involved in the eight work packages comprising the PanCareFollowUp project.

Work package 1: Person-centred PanCareFollowUp Care Intervention

Work package lead: PMC

- Develop the PanCareFollowUp Care Intervention, including PanCareFollowUp Recommendations, Survivor Questionnaire, Treatment Summary template, Survivorship Care Plan template and information materials for survivors and HCPs
- Perform preimplementation study and develop tailored implementation strategies
- Deliver workshop on person-centred care
- Develop the system to update current guidelines when new evidence is published
- Develop a replication manual for future implementation of the PanCareFollowUp Care Intervention after the end of the project

Work package 2: Conduct of PanCareFollowUp Care prospective cohort study

Work package lead: ULUND

- Develop the PanCareFollowUp Care Study Protocol
- Develop and test the PanCareFollowUp Care Study Handbook and SOPs
- Prepare study sites, including establishment of local working groups and securing local ethics approval
- Conduct and manage PanCareFollowUp Care prospective cohort study, including data collection
- Perform the preimplementation study and develop tailored implementation strategies
- Deliver workshop on person-centred care

Work package 3: Measures and analyses of PanCareFollowUp Care prospective cohort study

Work package lead: DCS

- Select outcome measures and data collection instruments and develop data dictionary
- Design and build database of the PanCareFollowUp Care prospective cohort study
- Data management and statistical analysis of the PanCareFollowUp Care prospective cohort study

Work package 4: Survivorship Passport

Work package lead: SIOP-E

- Feasibility study of SurPass web-based delivery of PanCareFollowUp Care Intervention, including exploration of a SurPass mobile app
- Develop plain-language brochures for survivors for all PanCareFollowUp Recommendations

Work package 5: PanCareFollowUp eHealth Lifestyle Intervention

Work package lead: RUMC and PMC

- Perform two systematic reviews on (1) effectiveness and effective components of eHealth lifestyle interventions and (2) barriers and facilitators for survivors in adapting to and maintaining a lifestyle with regular physical activity and/or a healthy dietary intake
- Qualitative interviews and focus group discussions with survivors and HCPs on barriers and facilitators in adopting a healthy lifestyle and delivering lifestyle advice to survivors
- Develop the PanCareFollowUp eHealth Lifestyle Intervention and evaluate with a feasibility study
- Develop a replication manual for future implementation of the PanCareFollowUp eHealth Lifestyle Intervention after the end of the project

Work package 6: Communication and dissemination

Work package lead: PanCare

- Develop and execute tailored communication and dissemination strategies
- Support future replication and legacy

Work package 7: Management

Project coordinator: PMC Project administrator: PT

- Coordination and scientific leadership
- Project management support

Work package 8: Ethics requirements

Work package lead: ICRC

- Ensure compliance with ethical requirements
-

DCS = Danish Cancer Society, Denmark; HCP = healthcare provider; ICRC = International Clinical Research Centre of St. Anne's University Hospital, Czech Republic; PMC = Princess Máxima Centre for Paediatric Oncology, the Netherlands; RUMC = Radboud University Medical Centre, the Netherlands; SIOP-E = European Society for Paediatric Oncology, Belgium; SOP = standard operating procedure; SurPass = Survivorship Passport; ULUND = Lund University, Lund, Sweden.

treatment history and personalised guideline-based care plan in plain language [39]. The platform is hosted in the Cineca data centre in Casalecchio di Reno, Italy, which is compliant with the highest security standards and data quality procedures, as per ISO 270001 and 9001 certifications. Personal data are encrypted, and privacy is enforced with role-based user security (survivor, health professional, data manager), authentication, identification and authorisation mechanisms to share and store data. WP4 will also collaborate with the

PanCare PLAIN group that aims to write plain language summaries of the surveillance guidelines, which will be available online and as recommendation brochures for each recommendation generated in WP1.

2.7. WP5: Development and feasibility study of the PanCareFollowUp eHealth Lifestyle intervention

WP5 will focus on the development and pilot testing of the person-centred PanCareFollowUp eHealth Lifestyle

Intervention, which aims to improve survivors' dietary intake and physical activity. It will consist of individual coaching sessions with an eHealth lifestyle coach delivered via secured video conferencing software. Two approaches (motivational interviewing and person-centred care) will be used to help survivors set their personal goals. The REVIVER study will be used as a background for developing the Lifestyle Intervention [40]. Further evidence-based strategies to inform the Lifestyle Intervention include two systematic reviews regarding (1) effectiveness and effective components of eHealth lifestyle interventions and (2) barriers and facilitators for survivors in adapting to and maintaining a healthy lifestyle with regular physical activity and/or a healthy dietary intake. In addition, qualitative interviews and focus group discussions with survivors and HCPs, together with the reviews, give a more comprehensive view on barriers and facilitators to adopt and support a healthy lifestyle.

The feasibility of the PanCareFollowUp Lifestyle Intervention will be evaluated in a prospective study including 60 survivors affiliated with two survivorship clinics in the Netherlands, where person-centred survivorship care is already implemented [24]. The main outcome is the proportion of survivors who reach their personal goals for lifestyle change set with their eHealth lifestyle coach. Using an effect and process evaluation, a replication manual will be developed at the end of the project to disseminate the PanCareFollowUp Lifestyle Intervention across other survivorship care clinics.

2.8. WP6: Communication and dissemination

A key objective of the PanCareFollowUp project is to communicate the importance of survivorship care, including support to adopt a healthy lifestyle, to relevant stakeholders. The audiences include survivors and parents, HCPs, advocacy groups, healthcare policymakers, researchers, the general public and media. The activities include a project website (www.pancarefollowup.eu), social media and email updates, scientific publications of the project's protocols and results, evidence-based policy recommendations, conference presentations, seminars and workshops. After the end of the project, the materials will be hosted online through PanCare.

2.9. WP7: Management

The leadership of the PanCareFollowUp project is divided among the project management team, the project board and WP leaders. Overall responsibility is assigned to the project management team, which includes the project coordinator and project administrator. They are responsible for coordination and scientific leadership and for project management support, respectively. The project board governing the PanCareFollowUp project consists of one representative of each

project partner and is chaired by the project coordinator. Main tasks include managing progress and risks.

2.10. WP8: Ethics requirements

The role of WP8 is to oversee that PanCareFollowUp is conducted in compliance with relevant ethical requirements in clinical research, personal data protection and study participants' privacy. Under the oversight of WP8, participants will be informed of their rights: each centre collecting data will seek approval via relevant ethics committees, and the study participants' signed informed consents will be secured. An external, independent ethics advisor will provide advice on ethical issues raised during the project.

3. Results and discussion

Access to survivorship care is necessary across Europe and constitutes the main aim of the PanCareFollowUp project. A sustainable and cost-effective strategy is required, considering the limited healthcare resources available. This may be realised through CPG-based care, with a focus on prevention, early detection and timely management of late effects, and a person-centred approach, with high involvement of survivors to manage their needs. The PanCareFollowUp consortium will develop and evaluate the person-centred PanCareFollowUp Care and Lifestyle Interventions including replication manuals to empower survivors to achieve better health and QoL. These replication manuals are especially important to inform and support institutions with incomplete or without follow-up care to mitigate barriers and identify facilitators for implementation of person-centred survivorship care within their healthcare system and, as such, to improve its availability across Europe.

Several positive impacts are anticipated. The first is a reduced burden on survivors and their caregivers through education, awareness and shared decisions about adequate health management. Empowered survivors will be better equipped to take charge of their own care, with a care plan developed together with their HCP. Second, the PanCareFollowUp project will generate surveillance recommendations for topics currently lacking CPGs, initiate development of a living guideline tool and provide policy recommendations for survivorship care, which will be distributed across Europe. Third, the Care study will elucidate the benefits and cost-effectiveness of a person-centred survivorship care model, whereas the Lifestyle study will show the feasibility of eHealth to improve lifestyle. Fourth, it is important to consider that although the entire PanCareFollowUp project will reach more than 800 survivors, there are currently up to 500,000 European childhood cancer survivors in need of survivorship care [1]. Therefore, we will distribute the replication manuals of the PanCareFollowUp Care and Lifestyle Interventions after the

project to everyone interested in survivorship care for inspiration, comparison with their own practice and free use and adjustment to local circumstances and healthcare resources. Finally, as the survivor population continues to grow, the PanCareFollowUp project should contribute to reducing the associated economic and societal burdens by preventing or managing chronic health conditions through education, awareness, lifestyle changes and personalised surveillance.

To conclude, the PanCareFollowUp project is a highly collaborative endeavour involving 14 project partners from ten European countries. Several strategies (CPGs, targeted communication and dissemination of replication manuals) will be used to ensure sustainability of the project, to advance the accessibility and quality of survivorship care and promote the widest possible impact on QoL of European survivors.

Disclaimer

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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.

Appendix A. PanCareFollowUp Consortium

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