

**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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**Highlights:**

- Survivorship care may improve survivors' health and quality of life
- Many adult childhood cancer survivors do not receive optimal survivorship care
- PanCareFollowUp facilitates the implementation of survivorship care across Europe
- Harmonised recommendations for long-term follow-up care will be developed
- Models for survivorship care and lifestyle coaching will be developed and evaluated

### **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) = Health care provider(s)

IGHG = International Late Effects of Childhood Cancer Guideline Harmonization 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 for treatment-related adverse health outcomes. Survivorship care to mitigate these late effects is endorsed, but 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 health care 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.

## ***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 wellbeing 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 health care 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 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 health care settings. Thus, they may be able to navigate the complexity of various specialists being involved in adult health care 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 that have left paediatric oncology services, with availability and 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). Further, 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](http://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](http://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 (JARC) and the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment (ExPO-r-Net). The PanCareFollowUp Consortium was established in 2018, consisting of 14 project partners from ten European countries. As a project partner, Childhood Cancer International Europe (CCI-E) 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 (Figure 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 health care 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.

## ***Methods***

### **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) (Figure 2); 2) Development and evaluation of the PanCareFollowUp Lifestyle Intervention using a

feasibility study (Lifestyle Study) (Figure 2); and 3) Sustainable replication, including free distribution of a Care and Lifestyle Replication Manual after the project.

### **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).

### **Work Package 1: Development of the person-centred PanCareFollowUp Care Intervention**

#### *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 health care 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 where no evidence-based recommendations exist yet, using a pragmatic methodology. Further, the PanCareFollowUp project will develop a “living guideline tool” that regularly searches for new literature and automatically informs specified guideline groups. Novel findings can thus be promptly discussed and guidelines updated in a timely manner, advancing CPG development and state-of-the art care provision (36).

#### *PanCareFollowUp Care Intervention*

The novel person-centred guideline-based PanCareFollowUp Care Intervention consists of three steps: 1) a pre-visit Survivor Questionnaire to identify the survivor’s health needs and preferences; 2) a clinic visit during which the survivor receives a personalised Treatment Summary summarising their childhood cancer treatment, engages in shared decisions about appropriate surveillance strategies, receives or is scheduled for additional tests, and receives 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 pre-implementation study will be conducted at the 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 post-project Replication Manual.

### **Work Package 2: Conduct of the Care study**

WP2 is responsible for the preparation and conduct of the Care study at the 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  $\geq 16$  years with 6 months 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 health care systems with various levels of pre-existing survivorship care implementation.

### **Work Package 3: 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 health care 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 (Castor EDC) system, managing data collection from survivors and HCPs, monitoring of data quality and the study recruitment process, and conducting study analyses.

#### **Work Package 4: 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 (Figure 2). The SurPass is an online tool that details a survivor's diagnosis, treatment history and personalised guideline-based care plan plain language (39). 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.

#### **Work Package 5: 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 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 that 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.

#### **Work Package 6: 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, health care policy makers, researchers, the general public and media. The activities include a project website ([www.pancarefollowup.eu](http://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.

### **Work Package 7: 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.

### **Work Package 8: 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.

### ***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 health care 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.

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 while the entire PanCareFollowUp project will reach over 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 health care resources. Lastly, 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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## Tables

Table 1. Overview of tasks and project partners involved in the eight Work Packages comprising the PanCareFollowUp project.

<p style="text-align: center;"><b>Work Package 1: Person-centred PanCareFollowUp Care Intervention</b></p> <p style="text-align: center;"><i>Work package lead: PMC</i></p> <p style="text-align: center;"><i>Other work package members: ULUND, IGG, ICRC, KU Leuven, UNILU, RUMC, UNEW, SIOP-E, CCI-E, PanCare</i></p>
<ul style="list-style-type: none"><li>• Develop the PanCareFollowUp Care Intervention, including PanCareFollowUp Recommendations, Survivor Questionnaire, Treatment Summary template, Survivorship Care Plan template and information materials for survivors and HCPs</li><li>• Perform pre-implementation study and develop tailored implementation strategies</li><li>• Deliver workshop on person-centred care</li><li>• Develop system to update current guidelines when new evidence is published</li><li>• Develop a Replication Manual for future implementation of the PanCareFollowUp Care Intervention after the end of the project</li></ul>
<p style="text-align: center;"><b>Work Package 2: Conduct of PanCareFollowUp Care prospective cohort study</b></p> <p style="text-align: center;"><i>Work package lead: ULUND</i></p> <p style="text-align: center;"><i>Other work package members: PMC, IGG, ICRC, KU Leuven, DCS, RUMC, NIVEL, CCI-E</i></p>
<ul style="list-style-type: none"><li>• Develop the PanCareFollowUp Care Study Protocol</li><li>• Develop and test the PanCareFollowUp Care Study Handbook and SOPs</li><li>• Prepare study sites, including establishment of local working groups and securing local ethics approval</li><li>• Conduct and manage PanCareFollowUp Care prospective cohort study, including data collection</li><li>• Perform pre-implementation study and develop tailored implementation strategies</li><li>• Deliver workshop on person-centred care</li></ul>
<p style="text-align: center;"><b>Work Package 3: Measures and analyses of PanCareFollowUp Care prospective cohort study</b></p> <p style="text-align: center;"><i>Work package lead: DCS</i></p> <p style="text-align: center;"><i>Other work package members: PMC, ULUND, IGG, ICRC, KU Leuven, UNILU, RUMC, UNEW, SIOP-E, NIVEL, CCI-E</i></p>
<ul style="list-style-type: none"><li>• Select outcome measures and data collection instruments and develop data dictionary</li><li>• Design and build database of PanCareFollowUp Care prospective cohort study</li><li>• Data management and statistical analysis of PanCareFollowUp Care prospective cohort study</li></ul>

**Work Package 4: Survivorship Passport**

*Work package lead: SIOP-E*

*Other work package members: PMC, IGG, CCI-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*

*Other work package members: PMC, ICRC, UNEW, CCI-E*

- 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*

*Other work package members: PMC, ULUND, IGG, ICRC, KU Leuven, DCS, UNILU, RUMC, UNEW, SIOP-E, NIVEL, CCI-E, PT*

- 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**

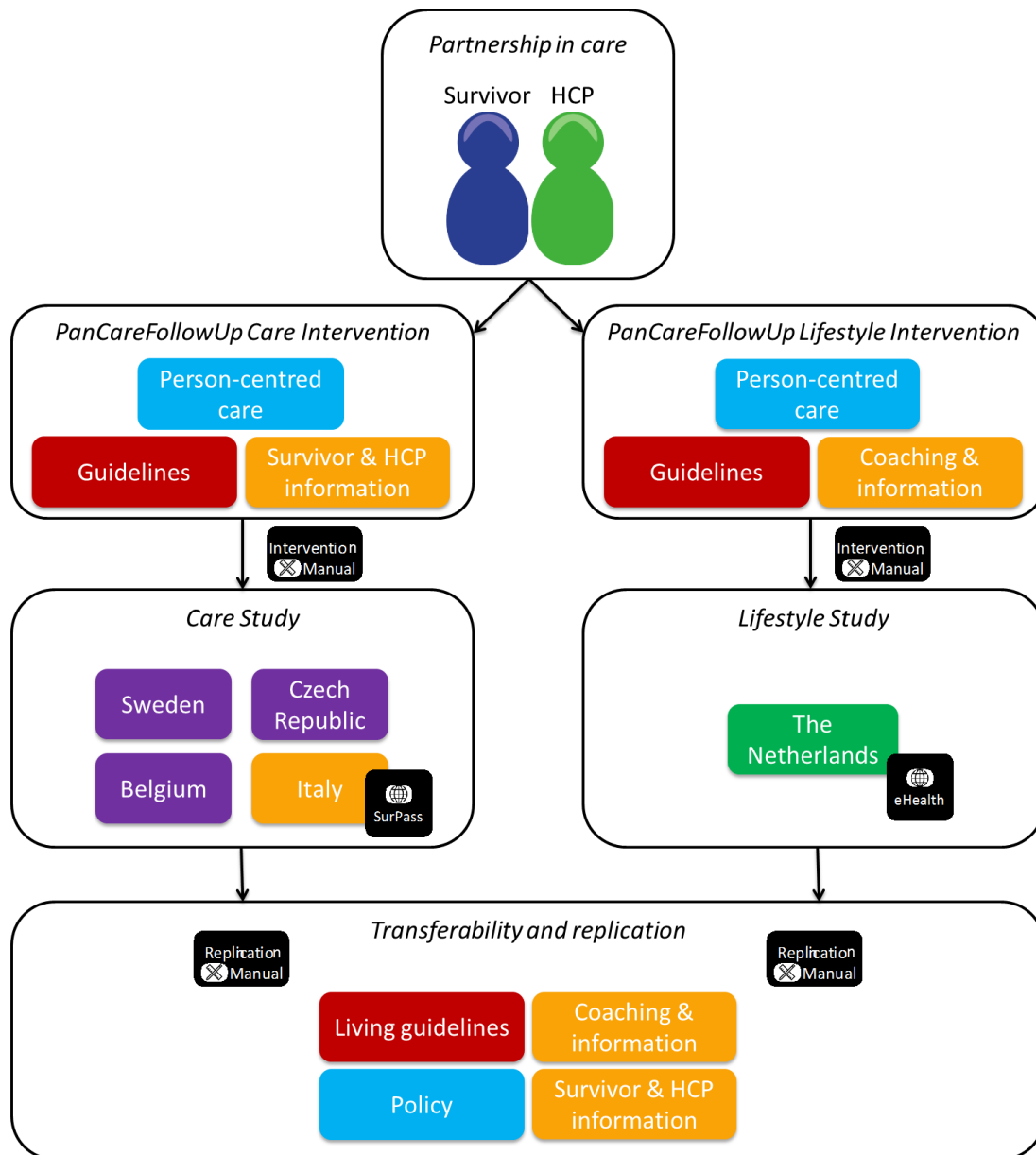
*Work package lead: ICRC and PMC*

- Ensure compliance with ethical requirements

Abbreviations used in the table: CCI-E = Childhood Cancer International Europe, the Netherlands; KU Leuven = University Leuven, Belgium; DCS = Danish Cancer Society, Denmark; HCP = health care provider; ICRC = International Clinical Research Centre at St. Anne's University Hospital, Czech Republic; IGG = Giannini Gaslini Children's Hospital, Italy; NIVEL = Netherlands Institute for Health Services Research, the Netherlands; 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; UNEW = Newcastle University, United Kingdom; UNILU = University of Luzern, Switzerland.

**Artwork**

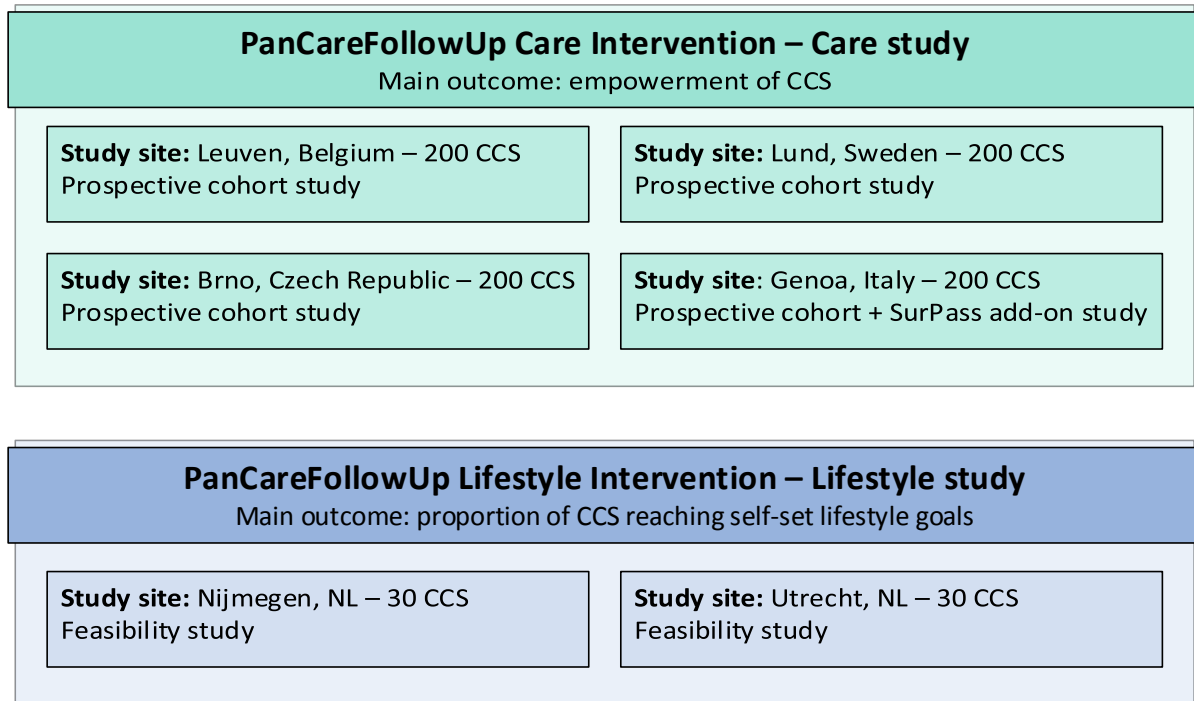
Figure 1. Overview of the PanCareFollowUp project, including the PanCareFollowUp Care and Lifestyle Interventions and the corresponding Care and Lifestyle Studies.



Abbreviations used in this figure: HCP = health care provider, SurPass = Survivorship Passport.

Additional information: 1-column fitting image, colour needed online only (not in print).

Figure 2. Study cohorts in the PanCareFollowUp Care and Lifestyle studies.



Abbreviations used in the figure: CCS = childhood cancer survivors, NL = the Netherlands.

Additional information: 2-column fitting image, colour needed online only (not in print).

### **Appendix A: PanCareFollowUp Consortium**

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