

**D36, D9.5 Guidelines and recommendations on models of healthcare to assure adequate follow-up of children surviving cancer, transition to adult medicine, and the use of the Survivorship Passport**

The JARC is coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan (Italy).

Work Package 9 is coordinated by SIOP Europe – the European Society for Paediatric Oncology.



**Co-funded by  
the Health Programme  
of the European Union**

*“This Deliverable is a part of the joint action “724161/JARC” which has received funding from the European Union’s Health Programme (2014-2020)”.*

*“The content of this Deliverable represents the views of the authors only and they are sole responsibility: it can not be considered to reflect the views of the European Commission and/or the Country, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may of the information it contains”.*

Table of Contents	
DELIVERABLE DESCRIPTION.....	3
Introduction .....	6
Material and methods .....	7
Results .....	8
General recommendations .....	8
Recommendations on surveillance of late side effects .....	9
Recommendations on delivery of long term follow up incl. transition of care .....	10
Recommendations on models of care incl. the Survivorship Passport.....	11
Recommendations on underlying topics: Education and awareness raising .....	12
Recommendations on underlying topics: Research.....	13
Discussion.....	14
Annex 1: EU Projects on childhood cancer survivorship.....	15
Annex 2: International guidelines on childhood cancer survivorship: a collaboration between IGHG and PanCare.....	16
Annex 3: Guideline development schedule .....	17
References .....	18

## DELIVERABLE DESCRIPTION

### Joint Action on Rare Cancers (JARC)

The Joint Action on Rare Cancers (JARC) is aimed to integrate and maximize efforts of the European Union (EU) Commission, EU Member States and all stakeholders to advance quality of care and research on rare cancers.

The public health challenges posed by rare cancers include the limited professional expertise in the community, the difficulties in clinical research, the need of a timely and appropriate diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate clinical, pathologic and biological assessment of the disease of the individual patient is key to survival and cure, as well as an expert clinical decision provided by a multidisciplinary team. To this end, proper referral of patients and effective clinical networking are crucial in rare cancers. This is the main reason why JARC decided to shape its efforts around the new European Reference Networks (ERNs) with the following objectives:

1. Improving epidemiological surveillance of rare cancers in the EU
2. Identifying standards of care for all families of rare cancers to ensure sharing of best practices and equality of care for rare cancers across Europe, particularly through clinical networking
3. Improving the implementation at local level and within ERNs of clinical practice guidelines on rare cancers
4. Promoting integration of translational research innovations into rare cancer care
5. Improving education on rare cancers for medical and non-medical experts to ameliorate management of rare cancers and to improve rare cancer patients' empowerment in the EU
6. Identifying core strategies to incorporate in National cancer plans and Rare disease plans to address the specific needs of rare cancers across EU MSs

The JARC is structured in 10 work packages (WPs). Three cross cutting WPs (WP1 coordination, WP2 dissemination, WP3 evaluation) and 7 specific WPs based on the JARC objectives: WP4 epidemiology, WP5 quality of care, WP6 clinical practice guidelines, WP7 innovation and access to innovation, WP8 medical education, WP9 childhood cancers and, WP10 rare cancers policy. Patients work across all work packages, driving the JARC efforts along the needs of the only end users of all what we can do, in care and research as well.

### Description of WP

Work Package 9 – Childhood cancers contains actions to define evidence-informed recommendations for:

- Ensuring access to standard and innovative therapies for children with cancer
- Addressing the research and clinical issues in young people with extremely rare cancers and in survivors of childhood cancers.

### The aim and the purpose of the specific deliverable

There are currently 300,000 - 500,000 long-term survivors of childhood cancer in Europe, and this number increases over time. At least two-thirds of this population experience adverse late-occurring side effects, with considerable impact on their daily lives and participation as EU citizens. Improving the quality of life of childhood cancer survivors is a goal of a major public health and socio-economic importance. The European childhood cancer community has been collaborating in a series of European Union (EU)-funded projects on survivorship since 2011. The aim of the present JARC deliverable is to consolidate policy recommendations based on these prior initiatives in three thematic areas: i) Surveillance of long-term side effects of disease and treatment in childhood cancer survivors, ii) Delivery of long-term follow up care, and iii) Models of care including the Survivorship Passport. Additional proposals address activities that underpin a successful implementation of these recommendations, namely, education and awareness raising and research on childhood cancer survivorship.

### The target group of the specific deliverable

Two sets of recommendations are put forward in each thematic area – recommendations addressed to Member States and those addressed to EU actors. The distinction is made considering the primary role of Member States in organising health care delivery at the national level, while recognising the contribution of EU level coordination in the field of rare diseases such as all childhood cancer and their related survivorship issues.

More generally, the recommendations are relevant for all stakeholders involved in decision-making on healthcare organisation and delivery across Europe.

### Summary of the main conclusions of the deliverable

#### - Recommendations to Member States

- Include a clearly designated section on paediatric cancers in National Cancer Control Plans (NCCPs) or equivalent programmes and integrate specific provisions for childhood cancer survivorship (CCS) therein, addressing the followings aspects:
  - o Surveillance of long-term side effects in childhood cancer survivors based on internationally recognised guidelines, such as those produced by PanCare and the International Guideline Harmonisation Group (IGHG);
  - o Delivery of long-term follow up care to childhood cancer survivors, including transition to adult care and a holistic psychosocial dimension, based on internationally recognised guidelines;
  - o Models of follow up care including a survivorship care plan based on a treatment summary and internationally recognised guidelines (e.g. PanCare/IGHG guidelines) and tools such as the Survivorship Passport.
- Foster contextualised implementation of international evidence-based guidelines on surveillance and care delivery to the childhood cancer survivor population;
- Foster contextualised implementation of a survivorship care plan based on a treatment summary and internationally recognised guidelines for each child and adolescent treated for cancer, for instance through the Survivorship Passport tool;

- Promote the integration of childhood cancer survivorship topics into medical education, including the dissemination of relevant guidelines on surveillance and care delivery;
- Consider the collection of data on long-term outcomes in national cancer or other relevant registries, according to local context, with appropriate consent procedures to foster research on long-term health status of childhood cancer survivors;
- Participate in international dialogue, cooperation and exchange of good practice models regarding childhood cancer survivorship care;
- Systematically involve healthcare professionals, academia, and parent, patient and survivor representatives in the planning, implementation and evaluation of initiatives on childhood cancer survivorship care.

- Recommendations to the European Union

- Foster systematic inclusion of issues pertaining to childhood cancer and childhood cancer survivorship in EU health, research and other relevant programmes, projects, and policy initiatives;
- Support collaborative efforts to develop further international evidence-based guidelines on surveillance and care delivery to childhood cancer survivors;
- Support opportunities for awareness-raising, peer exchange and learning on childhood cancer survivorship issues and resources at the European level;
- Support sustainability of networks and platforms that can foster successful implementation of childhood cancer survivorship care plans that combine a treatment summary and relevant surveillance guidelines (e.g. through the Survivorship Passport tool);
- Systematically involve healthcare associations, learned societies, and parent, patient and survivor organisations in the planning, implementation and evaluation of relevant actions.

## Introduction

Overall, survival rates in paediatric cancer have improved substantially over recent decades. With an 80% overall survival rate at five years, there are currently 300,000 - 500,000 long-term survivors of childhood cancer in Europe, and this number will increase over time. (Hjorth L, 2015)

Research has shown that most childhood cancer survivors (CCSs) are at substantially increased risk of adverse health outcomes and premature mortality (Bagnasco F, 2019) compared with the general population (Hjorth L, 2015). An estimated two-thirds of CCSs experience late-occurring side effects due to their disease and treatments, with 25% having a serious or life-threatening late complication (Oeffinger KC, 2006), (Geenen MM, 2007).

The CanCon European Guide on Quality Improvement in Comprehensive Cancer Control, 2017, identified childhood cancer survivorship as an important area for policy action:

“The implementation of a long-term follow-up policy for childhood, adolescent and young adult cancer survivors would improve their QALY [Quality-adjusted life years], which will have a positive economic impact of reduction of direct (medical care, treatments) and indirect (sick leaves, incapacity of work) costs linked to long-term morbidities in this population.” (Albrecht T, 2017)

Since 2008, the PanCare network of multidisciplinary health professionals, survivors of paediatric cancer and their families has been working to formulate evidence-based solutions for CCSs in Europe (Hjorth L, 2015) (Kremer LC, 2013). A series of projects were supported by EU programmes on research and public health, making important advances possible (Annex 1).

The outcomes and future orientations resulting from this work are embedded in the multi-stakeholder endorsed SIOPE European Strategic Plan (Vassal G, 2016), to which PanCare contributed.

The JARC represents the opportunity to integrate this shared vision, deliverables, and expertise on childhood cancer survivorship into a series of focused recommendations to policy makers at the national and the European levels.

**The purpose of this deliverable is to put forward targeted policy recommendations to decision-makers at the national and EU levels to sustain the well-being and socio-economic participation of childhood cancer survivors as a growing group of European citizens.**

## Material and methods

The work was performed by PanCare as Task Leader in close collaboration with SIOP Europe as WP9 Leader, CCI Europe as Collaborating Partner representing parents, patients, and survivors, and other JARC WP9 partners who had expressed an interest in the childhood cancer survivorship (CCS) topic.

The scope of the recommendations and respective roles and contributions were discussed and delineated at a face-to-face meeting on 3 May 2017 in Lund, Sweden.

The drafting of recommendations was led by a core expert group composed of representatives of PanCare, SIOP Europe, and CCI Europe. A literature search was performed to identify other EU Joint Action recommendations relevant to childhood cancer survivorship and to revisit the methodologies and conclusions of previous EU projects on this topic. Inputs from JARC partners were sought and obtained at the face-to-face meeting and subsequently by email.

An intermediary document was produced by PanCare and SIOP Europe to summarise the main results of prior EU projects on CCS, entitled: 'Background information: Prior projects in key work areas of CCS'. This overview was sent to WP9 partners on 25 Sept. 2017.

A specific structure of the recommendations was agreed upon. Thus, general recommendations were introduced first and specific aspects elaborated further under three (3) main headings:

1. Surveillance of late side effects,
2. Delivery of long term follow up,
3. Models of follow up care based on evidence-informed guidelines and survivorship care plans, with reference to the Survivorship Passport tool.

Two (2) sets of recommendations were formulated under each heading – those addressed to Member States and those addressed to European Union (EU) actors. The distinction was made considering the primary role of Member States in organising health care delivery at the national level, while recognising the contribution of EU-level coordination in the field of rare diseases such as all childhood cancer and their related survivorship issues.

Recommendations that would underpin the successful implementation of CCS policies – education, awareness-raising, and research – were presented in the final part.

## Results

### General recommendations

#### - Preamble

The EPAAC Joint Action produced a European Guide for Quality National Cancer Control Programmes (Albreht T, 2015), which highlights the importance of addressing paediatric cancers specifically in National Cancer Control Plans (NCCPs):

“An important overall consideration is the differentiation and provision of specialised services for and support to paediatric cancer patients and their families” (Travado L, 2015).

The EPAAC European Guide also identifies common survivorship issues and differentiates those that affect children and adult survivors of childhood cancers in particular (Van den Bulcke M, 2015).

The CanCon European Guide as well highlights survivorship as an important part of NCCPs and related initiatives:

“Health care system and patients benefit from the inclusion of survivorship and rehabilitation issues in national cancer control plans and policies” (Albreht T, 2017).

#### - Recommendations to Member States

- Include a clearly designated section on paediatric cancers in National Cancer Control Plans (NCCPs) or equivalent instruments guiding cancer or general health efforts at the national level and integrate a specific sub-section on provisions for childhood cancer survivors therein;
- Ensure that the NCCP (or equivalent) sub-section on childhood cancer survivorship covers the following aspects:
  - Surveillance of long-term side effects in childhood cancer survivors based on internationally recognised guidelines, such as those produced by PanCare and IGHG;
  - Delivery of long-term follow up care to childhood cancer survivors, including transition to adult care and a holistic psychosocial dimension, based on internationally recognised guidelines;
  - Models of follow up care including a survivorship care plan based on a treatment summary, internationally recognised guidelines (e.g. PanCare/IGHG guidelines) and tools such as the Survivorship Passport.
- Systematically involve healthcare professionals, academia, and parent, patient and survivor representatives in the planning, implementation and evaluation of specific initiatives stemming from NCCP or other policy provisions on CCS.

## - Recommendations to the EU

- Foster systematic inclusion of issues pertaining to childhood cancer and childhood cancer survivorship in EU programmes and initiatives in fields of research, public health, and other relevant areas such as socio-economic participation and education;
- Systematically involve healthcare associations, learned societies, and parent, patient and survivor groups in the planning, implementation and evaluation of actions on CCS.

## Recommendations on surveillance of late side effects

### - Preamble

Guidelines concerning the surveillance of late side effects during long-term follow up of childhood cancer survivors are increasingly called for to optimise the quality of life and participation of this growing population (Mulder RL H. M., 2013).

A pan-European survey undertaken by the EU FP7 PanCareSurFup project (2011-2017) found a lack of harmonised use of such guidelines in Europe (Brown MC, 2014). High variability within and between countries in addressing long-term follow up was detected (Essig S, 2012).

PanCare in cooperation with the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG) adopted a standardised approach and began the development of evidence-based guidelines addressing the surveillance of side effects associated with childhood cancer and its treatment (Kremer LC, 2013). A number of such guidelines have been produced and the process is ongoing (Annex 2, 3).

### - Recommendations to Member States

- Integrate the need for international evidence-based surveillance guidelines for childhood cancer survivors into NCCPs or equivalent instruments guiding healthcare efforts at the national level;
- Include the already available PanCare/IGHG standardised surveillance guidelines into medical education programmes and foster their further dissemination;
- Foster contextualised implementation of international evidence-based surveillance guidelines for childhood cancer survivors;
- Put in place systems to periodically evaluate the implementation of surveillance guidelines for childhood cancer survivors;
- Participate in international dialogue and cooperation on the development of further standardised surveillance guidelines for childhood cancer survivors and the updating of existing guidelines as relevant.

### - Recommendations to the EU

- Support collaborative initiatives to further develop standardised surveillance guidelines that cover all possible late-occurring side effects in childhood cancer survivors;
- Foster dissemination of the available surveillance guidelines for childhood cancer survivors, for instance through online best practice repositories and international conferences and workshops.

### Recommendations on delivery of long term follow up incl. transition of care

#### - Preamble

According to published research, adult childhood cancer survivors are not consistently engaged in long-term follow up care. Healthcare settings may lack formal transition programmes from child- to adult-oriented healthcare. There may also be lack of reference professional figures towards whom such transition can be targeted. Failure of transition may have important medical consequences and hinder effective long-term surveillance. (Mulder RL e. a., 2016)

The CanCon Joint Action conclusions echo these issues by stating: “Transition of care from paediatric oncology to adult medicine should be organized to guarantee adequate long-term follow-up and setting up of appropriate interventions” (Albrecht T, 2017).

#### - Recommendations to Member States

- Integrate the need for evidence-based care delivery guidelines for childhood cancer survivors into NCCPs or equivalent instruments guiding healthcare efforts at the national level;
- Recognise systematic health care transition as a standard of care for childhood cancer survivors in NCCPs or equivalent instruments of national health policy;
- Engage in international dialogue and exchange of good practice models on organising care delivery for childhood cancer survivors;
- Undertake contextualised national level implementation of long-term care delivery guidelines and/or best practice models, such as through pilot studies where needed to assess feasibility in the local context.

#### - Recommendations to the EU

- Support collaborative initiatives to define common approaches to formulating care delivery guidelines for childhood cancer survivors;
- Foster dissemination of the available evidence-based care delivery guidelines for childhood cancer survivors, for instance through online best practice repositories and international conferences and workshops.

## Recommendations on models of care incl. the Survivorship Passport

### - Preamble

A treatment summary and survivorship care plan based on evidence - informed surveillance guidelines should be made available at the end of treatment and include at least a treatment summary and recommendations for follow up. Ideally, its implementation should be part of the standards of care for former childhood cancer patients and thus subject to applicable reimbursement practices. Successful implementation will furthermore be facilitated by harmonisation of health data sets as well as clear rules and mechanisms governing information input and transfer.

A tool for implementation of a survivorship care plan – Survivorship Passport – was developed in the EU FP7 ENCCA project (2011-2015). This tool is designed as an automatically generated and translatable electronic document that summarises the clinical history of the child or adolescent, including diagnosis, treatment, toxicities, and complications (Haupt R, 2018). It provides a template of the information that is recommended for inclusion in any treatment summary and enables automatic linkage with appropriate PanCare/IGHG surveillance guidelines (these are automatically suggested based on the individual treatment and risk factor data). It can also provide a link with clinical trial, hospital and other databases. Importantly, the tool enables survivors to have access to and manage their own information and informs them of the surveillance and prevention guidelines that are appropriate to their case.

A treatment summary and survivorship care plan that can be combined with a tool such as the Survivorship Passport are intended to facilitate screening programmes for timely detection and treatment of side effects, by providing the relevant information in an easily understandable way. It is designed to help both healthcare professionals and survivors monitor and potentially prevent the possible occurrence of secondary complications after sustained cancer treatments.

### - Recommendations to Member States

- Encourage the principle of self-management with support for survivors of childhood cancer by creating survivorship care plans;
- Recognise survivorship care plans as a standard of care for childhood cancer survivors in NCCPs or equivalent instruments of national health policy;
- Foster the implementation of a survivorship care plan for each child and adolescent treated for cancer including by exploring digital tools such as the Survivorship Passport;
- Foster a secure interactive web platform to put a digital tool for a survivorship care plan, such as the Survivorship Passport, into practice;
- Foresee resource allocation to enable consistent data entry at the end of treatment as the cornerstone for a cost-effective automated follow up model throughout the survivor's life.

### - Recommendations to the EU

- Foster sustainability of eHealth networks and platforms as the setting where tools such as the Survivorship Passport can produce substantial benefits, including in relation to the European Reference Networks;
- Support initiatives on interoperability, harmonisation and security of interactive eHealth platforms to foster cross-border implementation of digital survivorship care plans that include treatment summaries (such as through the Survivorship Passport tool);
- Provide opportunities for peer exchange and learning regarding the implementation of survivorship care plans and relevant tools between Member States.

### Recommendations on underlying topics: Education and awareness raising

#### - Preamble

Childhood cancer survivors are a distinct group with specific needs. Successful realisation of the above recommendations rests on the premise that healthcare providers, end users, and their representative groups are appropriately informed and involved in relevant initiatives.

#### - Recommendations to Member States

- Engage with healthcare professionals, survivor advocacy groups, and academia at local and international levels regarding CCS issues;
- Support initiatives to educate and empower survivors to take the responsibility for their own follow-up care, such as by ensuring consistent requirement that survivors and their families are informed in an age-appropriate manner and throughout their follow up regarding possible risks, necessary screening pathways, and available tools to facilitate surveillance and transition to adult care;
- Integrate appropriate educational modules and material into training and continuous education of specialised and primary health care providers and foster ongoing interaction and collaboration between paediatric haemato-oncologists and other medical professions;
- Foster the development of national or regional knowledge hubs of expertise on late effects to support professionals working with childhood cancer survivors;
- Support survivor representation groups, which can act as a liaison between individual survivors and local/regional knowledge centres on late effects.

#### - Recommendations to the EU

- Support initiatives of awareness-raising and education on the needs of childhood cancer survivors as a growing population in Europe;
- Support the continuity of the work done in the ExPO-r-Net project (EU Health Programme, 2013-2017) on a virtual platform on late effects within the European Reference Network for Paediatric Oncology (ERN PaedCan).

## Recommendations on underlying topics: Research

### - Preamble

Research into long-term health-related sequelae after childhood cancer is an emerging area of work. Generally, less is known regarding effects beyond the fourth decade of a childhood cancer survivor's life (Bhakta N, 2017). There is furthermore scope to validate novel approaches to healthcare delivery and follow up. The application of genetic testing on predisposition and susceptibility to specific late effects is another emerging research area in the CCS field. In view of the rarity of individual types of childhood cancers, the EU has a particularly important role in supporting relevant collaborative research initiatives.

### - Recommendations to Member States

- Foster integration of late effect outcomes into national cancer or other relevant registries, according to local context, to maintain a repository of the health status of CCSs, with appropriate consent procedures.

### - Recommendations to the EU

- Allocate funding to research on late-occurring side effects and quality of survival after childhood cancer, including psychosocial aspects and the impact of possible interventions;
- Integrate considerations on long-term toxicity into policy and regulatory dialogue on innovative therapies for childhood cancers;
- Support research into the needs of and optimising the delivery of care to childhood cancer survivors;
- Support initiatives on health data standardisation and system interoperability to facilitate cross-border health research;
- Support relevant platforms, mechanisms and functionality in the context of the European Reference Network model.

Additional recommendations on access to innovation are applicable specifically to widening countries, which can be defined as those with a less pronounced focus on research and innovation in the paediatric cancer field:

- Promote a vision where all patients are discussed in a tumour board at diagnosis as a first step to provide access to best standard therapy and clinical trials, when relevant, including referral pathways when needed;

## Discussion

Childhood cancer survivors are a distinct and growing sub-group of the European population with specific long-term follow up care needs. The recommendations to address these needs to Member States and EU actors can be subdivided into three core thematic areas: surveillance of late side effects, delivery of long-term follow up, and models of care including the Survivorship Passport. In addition, two underlying topics can be identified: education and awareness-raising, and research. The above recommendations can be used by decision-makers to put in place programmes and interventions that empower survivors and improve their health, quality of life, and socio-economic participation.

Member States have the primary role in the planning, organisation and advancement of optimal healthcare to their populations. Considering the diversity of national contexts across Europe, one can expect that the implementation efforts will be specific to each setting. The recommendations can thus provide an overarching framework for drawing up national approaches to childhood cancer survivorship.

One could highlight the importance of education on CSS-specific topics of all stakeholders involved in health care planning and delivery. In particular, the empowerment of childhood cancer survivors through the provision of appropriately formulated information about their disease, treatment, possible side-effects, and available resources is key.

Putting in place surveillance of late side-effects and organised care can help predict the numbers of individuals and populations for whom specific services may be needed. The recommendations thus also have an important potential to be used by health service planners for resource management.

Through EU Joint Actions and projects, Member States and other stakeholders cooperate to identify common approaches to shared health research and policy issues. The EU dimension is particularly relevant for childhood cancer considering the rarity of individual paediatric cancer types and their associated late effects, the increasing mobility of survivors in adult life, and the opportunities offered by the ERN model. Most recently, a new EU-funded project PanCareFollowUp (Horizon 2020, 2019-2024, Coordinator: Prof L Kremer (Utrecht, The Netherlands)) has been launched to further develop and validate care models for childhood cancer survivors.

Paediatric cancer professionals, academia, and survivors as well as their associations play an important role in shaping the policies and care models for childhood cancer survivors. Thus, representatives of PanCare have been instrumental in the development of CCS surveillance and delivery of care guidelines. PanCare, SIOP Europe and CCI-Europe, are active in a series of collaborative projects on childhood cancer survivorship, engage with the broader academic community and decision makers, and raise awareness of the latest scientific evidence and needs of the concerned population. In January 2019, the three organisations met to discuss an implementation plan for the Survivorship Passport tool as part of the JARC proposals.

In light of the above, one can identify the following components of a successful implementation model for the present recommendations on CCS: policies and actions on childhood cancer survivorship in the suggested thematic areas at the national level, EU-level coordination and support of relevant cross-border projects and platforms, and the informed participation of key stakeholders, particularly survivors themselves, across the policy cycle.

## Annex 1: EU Projects on childhood cancer survivorship

- ENCCA: European Network for Cancer Research in Children and Adolescents (EU FP7, 2011-2015)  
<https://www.siope.eu/encca/>
- PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies (EU FP7, 2011-2017)  
<http://www.pancaresurfup.eu/>
- ExPO-r-Net: European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment (EU Health Programme, 2013-2017)  
<http://www.expornet.eu/>
- PanCareLIFE: PanCare Studies in Fertility and Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood (EU FP7, 2013-2018)  
<http://www.pancarelife.eu/>
- PanCareFollowUp: Novel, patient-centred survivorship care to improve care quality, effectiveness, cost-effectiveness and accessibility for survivors and caregivers (H2020: 2019-2024)  
<http://pancarefollowup.eu/>

## Annex 2: International guidelines on childhood cancer survivorship: a collaboration between IGHG and PanCare

Chairs International Guideline Harmonisation Group (IGHG): Prof L Kremer (The Netherlands) Prof M Hudson (US)

Chairs PanCare Guideline Group: Prof R Skinner (UK) Prof L Kremer (The Netherlands)

- Recommendations for ototoxicity surveillance for childhood, adolescent, and young adult cancer survivors: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group in collaboration with the PanCare Consortium *Lancet Oncol* 2019, Volume 20, Issue 1, pe29-e41 ([https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(18\)30858-1/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(18)30858-1/fulltext))
- Balancing the Benefits and Harms of Thyroid Cancer Surveillance in Survivors of Childhood, Adolescent and Young Adult cancer: Recommendations from the International Late Effects of Childhood Cancer Guideline Harmonization Group in Collaboration with the PanCareSurFup Consortium. Clement SC, et al. *Cancer Treat Rev* 2018 Feb;63:28-39 ([https://www.cancertreatmentreviews.com/article/S0305-7372\(17\)30197-4/fulltext](https://www.cancertreatmentreviews.com/article/S0305-7372(17)30197-4/fulltext))
- Recommendations for gonadotoxicity surveillance in male childhood, adolescent, and young adult cancer survivors: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group in collaboration with the PanCareSurFup Consortium. Skinner, Roderick et al. *Lancet Oncol* 2017, Volume 18 , Issue 2 , e75 - e90 ([http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(17\)30026-8/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(17)30026-8/fulltext))
- Recommendations for Premature Ovarian Insufficiency Surveillance for Female Survivors of Childhood, Adolescent, and Young Adult Cancer: A Report From the International Late Effects of Childhood Cancer. Guideline Harmonization Group in Collaboration With the PanCareSurFup Consortium. Van Dorp W et al. *J Clin Oncol* 2016 34:28, 3440-3450 (<http://ascopubs.org/doi/full/10.1200/jco.2015.64.3288>)
- Recommendations for cardiomyopathy surveillance for survivors of childhood cancer: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group Armenian S H et al. *Lancet Oncol* 2015, Volume 16 , Issue 3 , e123 - e136 ([http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(14\)70409-7/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(14)70409-7/fulltext))
- Recommendations for breast cancer surveillance for female survivors of childhood, adolescent, and young adult cancer given chest radiation: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group Mulder R L et al. *Lancet Oncol* 2013, Volume 14 , Issue 13 , e621 - e629 ([http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70303-6/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70303-6/fulltext))

## Annex 3: Guideline development schedule

Before	2013	2014	2015	2016	2017	2018	2019
Cardiomyopathy SMN breast cancer							
	Models of care /transition/health promotion						
		Female gonadal toxicity					
		Male gonadal toxicity					
			CNS secondary neoplasms				
			Thyroid cancer				
			Mental health				
				Cardiac vasculopathy			
				Metabolic syndrome			
					Pituitary dysfunction		
					Hearing disabilities		
					Pulmonary dysfunction		
						Bone toxicity	
						Renal toxicity	
						Thyroid dysfunction	
						Neurocognitive toxicity	
					Liver		
						Secondary GIT, Craniofacial/Dental, Gastrointestinal, Lower Urinary Tract, Skin/alopecia, Spine/scoliosis, Spleen/Immunological, Visual	
IHG & PCSF collaboration	EBM method						
PCSF / PCFU / PanCare alone		Pragmatic method based on structured review of existing educational and guideline publications					

## References

- Albreht T, Borrás Andrés JM, Dalmas M, et al. Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States. In: Albreht T, Kiasuwa R, Van den Bulcke M, eds. *European Guide on Quality Improvement in Comprehensive Cancer Control*. Ljubljana: National Institute of Public Health 2017, 188.  
[https://cancercontrol.eu/archived/uploads/images/Guide/pdf/CanCon\\_Guide\\_FINAL\\_Web.pdf](https://cancercontrol.eu/archived/uploads/images/Guide/pdf/CanCon_Guide_FINAL_Web.pdf) (April 2019, last accessed)
- Albreht, T, Martin-Moreno JM, Jelenc M, Gorgojo L, Harris M, eds. *European Guide for Quality National Cancer Control*. Ljubljana: National Institute of Public Health 2015, 113.  
[https://cancercontrol.eu/archived/uploads/images/European\\_Guide\\_for\\_Quality\\_National\\_Cancer\\_Control\\_Programmes\\_web.pdf](https://cancercontrol.eu/archived/uploads/images/European_Guide_for_Quality_National_Cancer_Control_Programmes_web.pdf) (April 2019, last accessed)
- Bagnasco F, Byrne J, et al. Late mortality and causes of death among 5-year survivors of childhood cancer diagnosed in the period 1960-1999 and registered in the Italian Off-Therapy Registry. *Eur J Cancer* 2019; 110: 86 - 97. doi: 10.1016/j.ejca.2018.12.021  
[https://www.ejca.com/article/S0959-8049\(18\)31576-4/abstract](https://www.ejca.com/article/S0959-8049(18)31576-4/abstract) (April 2019, last accessed)
- Bhakta N, Liu Q, Ness KK, et al. The cumulative burden of surviving childhood cancer: an initial report from the St Jude Lifetime Cohort Study (SJLIFE). *Lancet* 2017; 390(10112): 2569–2582. doi:10.1016/S0140-6736(17)31610-0  
[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)31610-0/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31610-0/fulltext) (April 2019, date last accessed)
- Brown MC, Levitt GA, Frey E, et al. The views of European clinicians on guidelines for long-term follow-up of childhood cancer survivors. *Pediatr Blood Cancer* 2015; 62:322–328. doi:10.1002/pbc.25310  
<https://onlinelibrary.wiley.com/doi/pdf/10.1002/pbc.25310> (April 2019, last accessed)
- Essig S, Skinner R, von der Weid NX, Kuehni CE, Michel G. Follow-Up Programs for Childhood Cancer Survivors in Europe: A Questionnaire Survey. *PLoS ONE* 2012; 7(12): e53201. doi:10.1371/journal.pone.0053201  
<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0053201> (April 2019, last accessed)
- Geenen MM, Cardous-Ubbink MC, Kremer LCM, et al. Medical assessment of adverse health outcomes in long-term survivors of childhood cancer. *JAMA* 2007; 297(24): 2705–2015. doi:10.1001/jama.297.24.2705.  
<https://jamanetwork.com/journals/jama/fullarticle/207669> (April 2019, date last accessed)
- Haupt R, Menoni S, Gerlind B, et al. The ‘Survivorship Passport’ for childhood cancer survivors. *Eur J Cancer* 2018; 102: 69-81. doi:10.1016/j.ejca.2018.07.006  
[https://www.ejca.com/article/S0959-8049\(18\)30965-1/fulltext](https://www.ejca.com/article/S0959-8049(18)30965-1/fulltext) (March 2019, date last accessed)

Hjorth L, Haupt R, Skinner R. Survivorship after childhood cancer: PanCare: A European Network to promote optimal long-term care. *Eur J Cancer* 2015; 51(10): 1203-1211. doi: 10.1016/j.ejca.2015.04.002.  
[https://www.ejcancer.com/article/S0959-8049\(15\)00306-8/fulltext](https://www.ejcancer.com/article/S0959-8049(15)00306-8/fulltext) (April 2019, last accessed)

Kremer LC, Mulder RL, Oeffinger KC, et al. A worldwide collaboration to harmonize guidelines for the long-term follow-up of childhood and young adult cancer survivors: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group. *Pediatr Blood Cancer* 2013; 60(4): 543-549. doi: 10.1002/pbc.24445.  
<https://onlinelibrary.wiley.com/doi/full/10.1002/pbc.24445> (April 2019, last accessed)

Mulder RL, van der Pal HJH, Levitt GA. Transition guidelines: An important step in the future care for childhood cancer survivors. A comprehensive definition as groundwork. *Eur J Cancer* 2016; 54: 64-68. doi: 10.1016/j.ejca.2015.10.007.  
[https://www.ejcancer.com/article/S0959-8049\(15\)00921-1/fulltext](https://www.ejcancer.com/article/S0959-8049(15)00921-1/fulltext) (April 2019, last accessed)

Mulder RL, Hudson MM, Skinner R, Kremer LC. Health problems in survivors of childhood cancer: the need for international collaboration in long-term follow-up care. *Future Oncol* 2013; 9(11), 1667-1670. doi: 10.2217/fon.13.107.  
<https://www.futuremedicine.com/doi/10.2217/fon.13.107> (April 2019, last accessed)

Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med* 2006; 355: 1572-1582. doi:10.1056/NEJMsa060185  
<https://www.nejm.org/doi/full/10.1056/NEJMsa060185> (March 2019, date last accessed)

Travado L, Dalmas M. Psychosocial Oncology Care. In: Albrecht, T, Martin-Moreno JM, Jelenc M, Gorgojo L, Harris M, eds. European Guide for Quality National Cancer Control. Ljubljana: National Institute of Public Health 2015, 113.  
[https://cancercontrol.eu/archived/uploads/images/European\\_Guide\\_for\\_Quality\\_National\\_Cancer\\_Control\\_Programmes\\_web.pdf](https://cancercontrol.eu/archived/uploads/images/European_Guide_for_Quality_National_Cancer_Control_Programmes_web.pdf) (April 2019, last accessed)

Van den Bulcke M, Kiasuwa R. Survivorship & Rehabilitation. In: Albrecht, T, Martin-Moreno JM, Jelenc M, Gorgojo L, Harris M, eds. European Guide for Quality National Cancer Control. Ljubljana: National Institute of Public Health 2015, 113.  
[https://cancercontrol.eu/archived/uploads/images/European\\_Guide\\_for\\_Quality\\_National\\_Cancer\\_Control\\_Programmes\\_web.pdf](https://cancercontrol.eu/archived/uploads/images/European_Guide_for_Quality_National_Cancer_Control_Programmes_web.pdf) (April 2019, last accessed)

Vassal G, Schrappe M, Ladenstein R, et al. The SIOPE strategic plan: A European cancer plan for children and adolescents. *Journal of Cancer Policy* 2016; 8: 17-32. doi:10.1016/j.jcpo.2016.03.007.  
<https://www.sciencedirect.com/science/article/pii/S2213538316300017?via%3Dihub> (March 2019, date last accessed)