



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

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Background

- Long-term follow-up care, although endorsed, is not available for the majority of European adult survivors of childhood, adolescent and young adult cancer
- Sustainable solutions are urgently needed to address the needs of survivors
- The European Union-funded PanCareFollowUp project was established to facilitate the implementation of person-centred survivorship care across Europe

Methods

- The PanCareFollowUp Care Intervention has been co-developed with survivors
- It is a person-centred approach to survivorship care, supported by the PanCareFollowUp Recommendations (see separate poster) and with flexibility to adapt to local healthcare settings
- The PanCareFollowUp Care Intervention consists of three steps (see below)

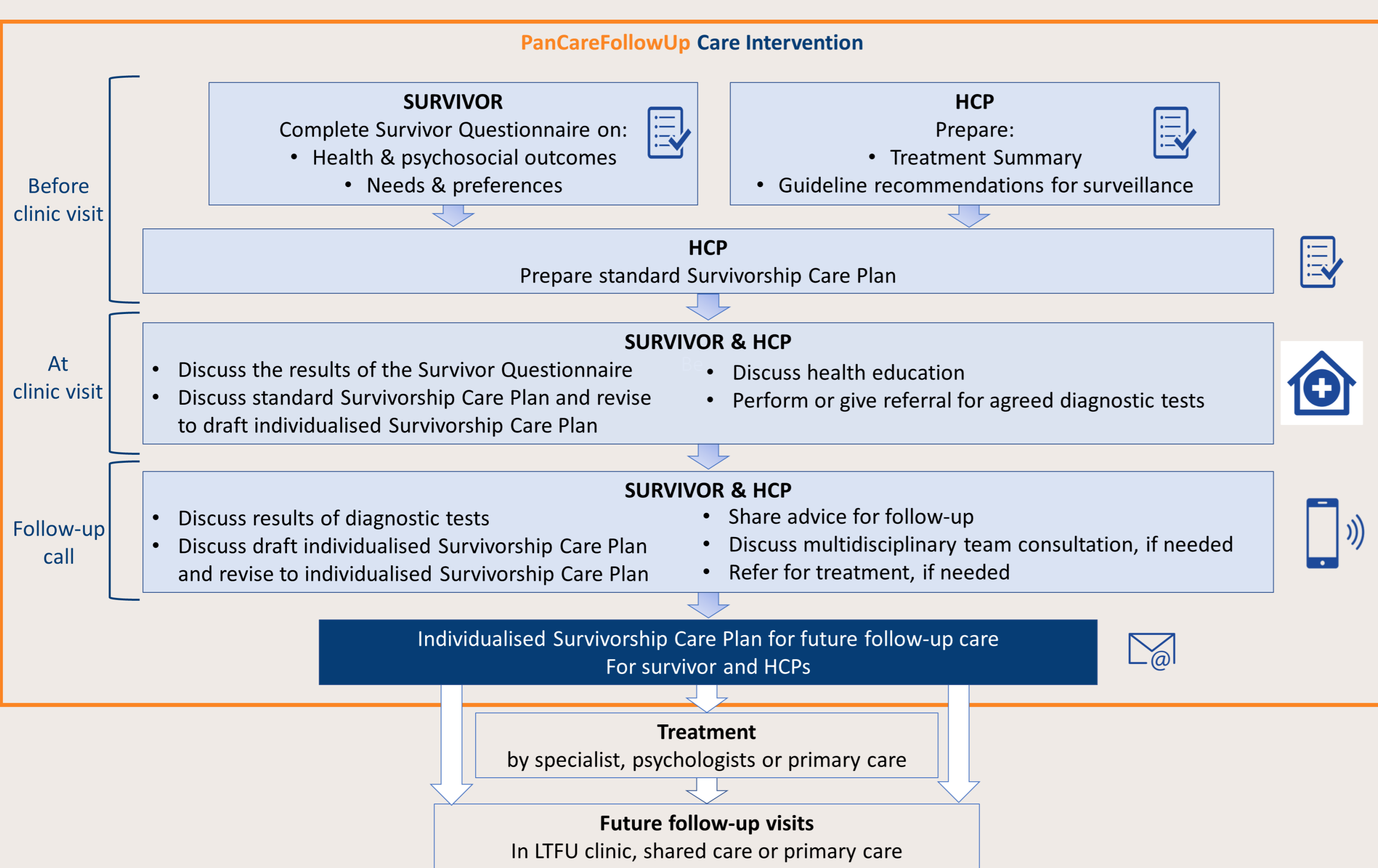


Figure. The PanCareFollowUp Care Intervention, including 1) pre-visit completion of a Survivor Questionnaire (by the survivor) and Treatment Summary (by the HCP), 2) a clinic visit including shared-decision making and 3) a follow-up call to finalise the Survivorship Care Plan. HCP = healthcare provider.

Results

- The key components of the PanCareFollowUp Care Intervention were developed:
 - PanCareFollowUp Survivor Questionnaire
 - PanCareFollowUp Treatment Summary template
 - PanCareFollowUp Survivorship Care Plan template
 - educational materials for healthcare providers and survivors
- The implementation of the PanCareFollowUp Care Intervention will be evaluated a prospective cohort study including 800 survivors.
- The main endpoints of this study are survivor empowerment, costs and satisfaction with person-centred care
- After the study, a Replication Manual will be developed, which will be freely available to support wide implementation

Treatment summary		
Cancer diagnosis		
Date of diagnosis	01/ 01/ 1973	This section was last updated on 01/ 06/ 2021
Diagnosis	Acute lymphoblastic leukemia	
Primary treatment centre	Children's Hospital	

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

Front line treatment		
This section was last updated on 01/06/ 2021		
The treatment has been given via	ALL-II	
Group/arm/randomization	Unknown	
Summary of major treatments	Chemotherapy	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	Stem cell transplantation	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
	Radiotherapy	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	Major surgery	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Progression during front line treatment	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>	
Relapse during front line treatment	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>	
Date of first elective end of treatment	31/ 12/ 1974	

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

Figures. Part of an example Survivorship Care Plan, detailing childhood cancer diagnosis and treatment (upper panels), standard recommendations based on the survivor's risk factors (lower left panel), and the individualized decisions for long-term follow-up care, based on shared-decision making during the clinic visit and follow-up call (lower right panel).

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Conclusions

- The PanCareFollowUp Care Intervention will support the implementation of person-centred, guideline-based long-term follow-up care after childhood cancer
- It is adaptable to different health care settings across Europe
- Through implementation, access to long-term follow-up care is facilitated, with the ultimate aim to improve survivors' health and wellbeing