

WP8 : Survivorship and Rehabilitation

Joint Action Meeting – presentation of WP8 chapter



CanCon
Cancer Control Joint Action

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REMINDER OF THE DELIVERABLES

Objective 1 - List of recommendations in the field of survivorship and rehabilitation

Objective 2 – Process of assessment of patients' symptoms and needs

Objective 3 - Survivorship Care Plan

WP8 PARTNERSHIP

Associated partners	Collaborating partners
<ul style="list-style-type: none">- National Cancer Institute (France)- Catalan Institute of Oncology (Spain)- Institute of Public Health (Slovenia)- National Cancer Research Centre GPII (Italy)- Trondheim University Hospital (Norway)- Cancer Society of Finland	<ul style="list-style-type: none">- EU Cancer Patient Coalition (ECPC)- Dutch Cancer Society- Institute of Public Health (Belgium)- Ministry for Energy and Health (Malta)- International psycho-oncology society- Association of EU Cancer Leagues- EU CanCer Organisation (ECCO)- European Organisation for Research and Treatment of Cancer (EORTC)- European Collaborative Group on Cancer Survivorship (ECGCS)

WP8 METHODOLOGY

DRAFTING PROCESS

Literature review:

WP8 partners coordinated the literature review (including analysis, summary and drafting of the recommendations).

Expert meeting:

8 EU experts have been invited to review /discuss/sharpen the recommendations formulated based on the existing knowledge.

Survey on Survivorship Care Plan:

to collect information on how the survivorship follow-up care is organised in EU countries.

Deliberative process:

5 meetings have been organized with all WP8 partners where the process and content of the chapter was discussed.

KEY TOPICS COVERED:

- clinical follow-up : management of the late effects, tertiary prevention and physical activity;
- supportive and palliative care;
- psychological support;
- social rehabilitation including employment issues;
- education of survivors;
- multi-disciplinary approach and coordination of cancer care providers;
- clinical research.

CROSS-CUTTING ISSUES

- childhood cancer survivors' care;
- inequalities in survivorship.

WP8 DEFINITIONS

SURVIVORSHIP

For the purpose of this chapter, the survivorship definition encompasses different categories of patients and situations following the diagnosis and acute treatment phases of cancer:

- Patients who are in remission or fully cured and would need to return to normal activity;
- Patients with recurrence after a prolonged period of remission who may receive new courses of treatment with a curative intent;
- Patients who live with incurable cancer as a “chronic disease” and receive life prolonging treatment;
- Patients with advanced incurable disease receiving symptom management and palliative care .

WP8 DEFINITIONS

REHABILITATION

In the absence of a definition for cancer rehabilitation we have adopted a multidimensional (physical and psychosocial) concept of rehabilitation. Cancer rehabilitation dimensions and measures include the following :

- Physical functioning and activity, and limitations (e.g. sleep disorder, pain and fatigue)
- Distress and psychological morbidity (e.g. anxiety and depression);
- Cognitive functioning and impairments (e.g. attention and memory losses);
- Sexual function and sexual difficulties (e.g. loss of libido, menopausal symptoms, erectile dysfunctions);
- Nutrition and weight management;
- Social isolation (return-to-work but also return-to-formal education, social participation in the community, social integration).

PRESENTATION OF THE FINAL DRAFT

PRESENTATION OF THE FINAL DRAFT

MAIN MESSAGES OF WP8 CHAPTER:

- N° 1: Cancer survivors' follow-up, late effect management and tertiary prevention needs to be anticipated, personalised and implemented into care pathways, with active participation of survivors and relatives.
- N° 2: The improvement of early detection of patient's needs and the access to rehabilitation, psychosocial and palliative care services is required.
- N° 3: An integrated and multi-professional care approach with a coordination of community care providers and services are needed to implement a Survivorship Care Plan (SCP) that enhances patient's self-management and quality of life (QoL).

PRESENTATION OF THE FINAL DRAFT

MAIN MESSAGES OF WP8 CHAPTER (bis)

- N° 4: For children, adolescents and young adults survivors (AYA), late health and psychosocial effects of cancer and its treatments need to be anticipated and addressed.
- N° 5: More research in the area of survivorship is needed to provide data on late effects, as well as the impact and cost-effectiveness of supportive care, rehabilitation, palliative and psychosocial care interventions.

PRESENTATION OF THE FINAL DRAFT

I. INTRODUCTION AND BACKGROUND

- Presentation of the context, the purpose and key terms of the chapter.

II. METHODS

- Presentation of the drafting process of the recommendations (literature review, expert groups, survey)

PRESENTATION OF THE FINAL DRAFT

III. RESULTS AND RECOMMENDATION

- **1 - New challenges in medical follow-up: focus on late effects and tertiary prevention.**

Findings from the literature review

- *Management of late effects;*
- *Tertiary prevention*

6 recommendations

5 pieces of advice for implementation

PRESENTATION OF THE FINAL DRAFT

RECOMMENDATIONS

1. An early and personalised follow-up program should be systematically planned and delivered to each survivor:

- Adequately assessing the survivors' individual risk of multidimensional late effects of treatment and respective rehabilitation needs (e.g. physical, psychological, social, cognitive, sexual, nutrition, etc.)
- Creating opportunities for socially disadvantaged people to fully engage in follow-up programs.

2. Adequate and updated information on medium and long term effects of treatments should be available to survivors and their relatives, as well as to care providers involved in the follow-up, in particular primary care professionals, for a better prevention and care.

3. Identification and management of late effects of cancer treatment should be integrated in the professional training and continuous medical education of clinicians (including general practitioners).

4. In tertiary prevention, self-management should be emphasized, particularly on lifestyle recommendations and on the risks of long term effects :

- Smoking cessation;
- Weight control and healthy diet including limited alcohol consumption;
- Sufficient sustained physical activity;
- Avoidance of excessive exposure to UV-radiation.
- Stress management

PRESENTATION OF THE FINAL DRAFT

RECOMMENDATIONS

5. Physical activity should be integrated early in the care pathway for all cancer survivors. It should be an important component to consider at every phase of survivorship care for all survivors in order to maintain healthy life-style.

6. The evaluation of the physical and psychosocial rehabilitation needs should first be screened as follow:

- The baseline screening should be performed prior to the start of any cancer-specific treatment
- Both physical and psychosocial screening should be carried out simultaneously by using simple algorithms; for physical screening at least the following items should be screened: cardiac function, muscle strength and flexibility. For psychosocial screening, please refer to Topic 2 (p.14).
- After the first screening regular updates should be performed on individual basis.

2) PRESENTATION OF THE FINAL DRAFT

2 - Needs for a person-centred approach in psychosocial rehabilitation, supportive and palliative care.

Findings from the literature review

- *Psychological care;*
- *Social and employment issues;*
- *Supportive and palliative care;*
- *Inequalities in accessing psychosocial and palliative care*

5 pieces of advice for implementation

- *6 policy recommendations in psychological care;*
- *4 policy recommendations in social rehabilitation and back-to-work issues;*
- *3 policy recommendations in supportive and palliative care.*
- *Recommendations on the principles for the assessment of patient's symptoms and needs*

PRESENTATION OF THE FINAL DRAFT

2 - Recommendations

PSYCHOLOGICAL CARE

1. Periodic screening of psychological distress and psychosocial needs should be conducted during the entire cancer pathway by the health care professionals (*e.g.* oncologists, physicians, and nurses) and integrated in routine cancer care; this screening will be followed by adequate provision of psychosocial care.

2. For the diagnosis of psychological conditions a specific assessment should be carried out by a psychological care professional:

- Using validated and simple tools and according to clinical practice guidelines for the assessment and management of psychological distress and morbidity.
- Anticipating the specific needs of populations at high risk, including young populations (*e.g.* children, adolescents, young adults) and relatives.

3. A step-wise or tiered model of psychological care is recommended depending on the level of distress, psychological condition and morbidity of each patient. Interventions can range from:

- Information and psycho-education by primary oncology team to peer support
- E-health platforms for psychosocial support and self-management programmes
- Psychological interventions by psycho-oncology trained professionals, *e.g.* psychologists, social workers, psychiatrists
- Complementary spiritual support by chaplains and others
- Psychotropic treatments by trained physicians, *e.g.* psychiatrists, oncologists

PRESENTATION OF THE FINAL DRAFT

PSYCHOLOGICAL CARE (bis)

- 4. Psychosocial interventions in individual or group format should be delivered by appropriately trained professionals with specific expertise in psychosocial oncology.**
- 5. Increased investment in training in psycho-oncology and communication skills for primary oncology staff is highly recommended.**
- 6. Existing Clinical Practice Guidelines for psychosocial support of patients with cancer** could be highly valuable and recommended for the provision of evidence based psychosocial care.

PRESENTATION OF THE FINAL DRAFT

SOCIAL REHABILITATION AND EMPLOYMENT ISSUES

7. Social and return-to-work issues should be integrated early into the cancer care pathway. The adaptation of the working conditions for any patient returning to his/her previous work should be assessed at early stages.

8. Public policies should be developed and implemented to support cancer patients from diagnosis to return to work including :

- Financial aspects such as access to loan, mortgages, life insurances;
- Implementation of a pan-European strategy to tackle the differences between workers with cancer in different countries and to prevent discrimination;
- Generate more evidence to better understand the living conditions of cancer survivors who return to work.

9. A person-centred approach should be implemented :

- To access a multidimensional physical and psychosocial rehabilitation plan focusing on the skills of cancer survivors;
- To safeguard cancer survivors' working lives, their employability, competencies and capacity to work, as well as their motivation to work; offer new skills to self-employed workers to help them achieve balance between health needs and work;
- Peers, patients' organizations and trade unions could also help the patients and survivors
- Patients' bill of rights including the right to work with special conditions (*e.g.*, reduced hours of work or adapted working conditions) should be negotiated.

10. A work-centred approach should be implemented with a better involvement of employers in the survivors' return-to-work process:

- To explore possibilities of changes in job functions for cancer survivors and encourage them to acquire new skills;
- To facilitate the implementation of flexible working hours and options (remote working, part-time work);
- To offer economic benefits to employers who agree to adapt the workplace to the needs of cancer survivors and self-employed workers respectively to help them adapt their workplace and business to address health needs.

PRESENTATION OF THE FINAL DRAFT

SUPPORTIVE AND PALLIATIVE CARE

11. Somatic and psychological symptoms as well as social challenges should be addressed in all phases of the cancer disease trajectory early, systematically and regularly, and treated according to the best scientific evidence available.

12. Formal education in palliative care should be a compulsory component of the professional curriculum for specialists in medical oncology, for GPs and community MDs. A basic training should be mandatory in medical and nursing school. Specialised palliative care skills and services should be accessible to patients with advanced incurable disease and part of multidisciplinary tumour boards.

13. Best achievable quality of life for the individual patient and the relatives should be part of a survivorship care plans for patients with late side effects due to cancer and antineoplastic treatments.

PRESENTATION OF THE FINAL DRAFT

3 - Multidisciplinary approach in survivorship care: coordination of providers and empowerment of survivors.

Findings from the literature review

- *Multidisciplinary approach and coordination of care providers;*
- *Empowerment/Education of survivors*

- *5 policy recommendations for multidisciplinary approach and coordination of care providers*

- *3 recommendations for empowerment / education of survivors.*
- *Recommendations on the principles of a Survivorship care plan (SCP)*

7 pieces of advice for implementation

PRESENTATION OF THE FINAL DRAFT

3 - RECOMMENDATIONS

MULTIDISCIPLINARY APPROACH AND COORDINATION OF CANCER CARE PROVIDERS

- 1. Psychosocial care, rehabilitation and palliative care should be integrated into the entire cancer pathway including the survivorship and rehabilitation period. Psychosocial, rehabilitation and palliative care specialists should be members of (or associated to) the medical team in hospitals and in community care.**
- 2. After the completion of the acute treatment phase, the follow-up period should begin with the elaboration of a survivorship care plan (SCP).**
- 3. The role of GPs and other primary care professionals should be actively supported to help them manage all the care plan challenges.** Their role should be clearly defined and tailored to the patient and the care plan needs. This role could evolve during the follow-up period.
- 4. Communication between primary healthcare providers and healthcare specialists needs to be improved.** Electronic patient records systems (EPRS) should be accessible to all healthcare providers treating the patients. Communication between patients and healthcare providers needs to be improved.
- 5. A key health care professional assuming a case management role should be assigned to each patient in accordance with medical and/or psychosocial specific requirements.** This health care professional could play a main role in reducing the vulnerability of patients, as for example with the management of adverse drug effects.

PRESENTATION OF THE FINAL DRAFT

EMPOWERMENT/EDUCATION OF SURVIVORS

7. Empowerment of patients and their relatives should be enhanced to increase their participation in self-management, rehabilitation and back to work programs. Online programs would facilitate this process.

8. Education and self-management programs should be developed and evaluated. Better access to these programs should be available for underserved and deprived populations (low income/low education). Assessment of patients' needs should be systematically part of the development of an education program. The evaluation of these programs should assess the impact on the personal, organisational and health care policy levels, including cost-effectiveness and impact on health care quality.

9. Training of health care professionals should include communication skills next to medical education regarding information/communication/knowledge of survivorship and rehabilitation needs and management of late effects.

Survivorship Care Plan (SCP)

- A SCP should be delivered to all patients following a multidimensional needs' assessment and this SCP should be tailored and updated regularly according to the patient's health conditions.

After the completion of the acute treatment phase, the patient should be given a survivorship care plan (SCP) that would contain:

- baseline information on the personal and medical profile of the patient (ID, age, summary of the treatment received), with additional data on possible late and long-term effects and medical history;
 - a minimum set of tailored supportive care services consisting of pain management and psychological support for patients and their relatives against anxiety and depression. Healthy lifestyle issues (including *e.g.* tobacco cessation, physical activities, nutrition and weight management, beauty care) as well as sexuality and fertility support should also be considered;
 - social support and professional rehabilitation services.
- The survivorship care plan (SCP) should be elaborated and implemented by the MDT composed of:
 - an oncologist in collaboration with other professionals plan the follow-up process;
 - a general practitioner (GP) who deals with the impact of cancer and its treatment of the general health;
 - a (specialist) nurse or a support worker who is in charge of coordinating follow-up care amongst all services providers involved;
 - a community care centre which deliver information, educational activities about survivorship care.
- From a technical point of view, in order to meet its communication and care coordination objectives, the SCP should be:
 - accessible to all health care professionals having therapeutic relationships with the patient;
 - updated regularly;
 - using a format that optimize the understanding and the communication of information between patients and health care providers (and amongst health care providers).

PRESENTATION OF THE FINAL DRAFT

4 - Childhood, adolescent and young adults issues in cancer survivorship care.

Findings from the literature review

4 policy recommendations

2 pieces of advice for implementation

PRESENTATION OF THE FINAL DRAFT

4 - Recommendations

- 1. Transition of care from pediatric oncology to adult medicine**, including a survivorship passport for each patient, should be organised to guarantee adequate long-term follow-up and setting up appropriate intervention.
- 2. It is necessary aim for a more efficient survivorship care planning and coordination** to respond to the challenges of the prevalence of chronic conditions, health status deteriorations, treatment and complex prevention. Determining the most effective models of care for childhood cancer survivors is the main step forward.
- 3. Rehabilitation and supportive care should be specifically offered to children and AYA cancer survivors** in particular adapted physical activity. A routine yearly psychosocial assessment with attention to social, psychological, and behavioral issues, educational and/or vocational progress should be provided to this population.
- 4. End of life care and palliative care for children and adolescents should be improved across Europe.**

PRESENTATION OF THE FINAL DRAFT

5 - Perspectives in survivorship and rehabilitation cancer research

Findings from the literature review

- Focus on the gaps identified

5 policy recommendations

Advice for implementation : None

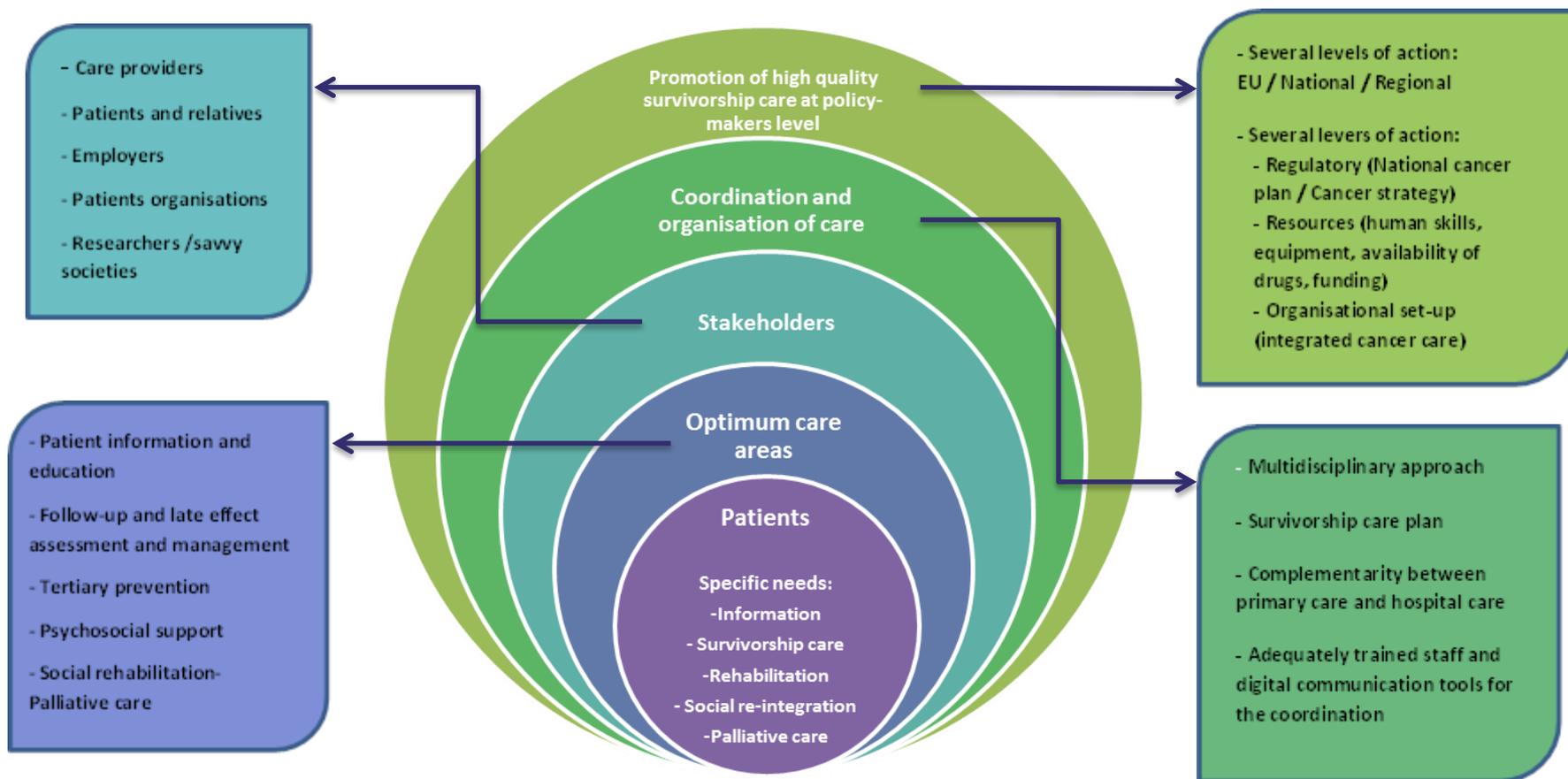
PRESENTATION OF THE FINAL DRAFT

5 - Recommendations

- 1. An information and data collection system focused on late adverse effects (physical, psychological, cognitive, social, sexual), coupled to the surveillance of patients and involving primary care professionals should be set up. More patients reported outcome measures (PROMS) and their routine use are needed.**
- 2. The use of cancer registries in collecting data on survivors should produce stronger epidemiological data, including lifestyle, QoL or socio-economic information to better identify the causes of inequalities in survivorship.** Moreover registries should be expanded to additional factors that influence the quality of life (*e.g.* rehabilitation and employment issues). Patient reported outcomes could be a way to collect appropriate information as well.
- 3. Clinical research should evaluate the feasibility, the efficacy and the cost-effectiveness (including the economical dimension) of non-drug related interventions such as self-management and e-health programs.**
- 4. Future research is needed to establish a multi-dimensional rehabilitation model focused on the quality of life and coordination of complex care** to better address the management of late effects across the whole survivorship trajectory. More research would also be required to maximise the long-term follow-up and care of childhood cancer survivors and to identify the genetic risks associated to late effects and second cancers.
- 5. More solid methodological RCTs and cohort studies are needed in order to reduce the intensity of cancer treatments while maintaining their efficacy and thus reducing the probability of late effects, especially in childhood cancer survivors.**

OVERVIEW ON THE CONTENT OF THE CHAPTER

IV. CONCLUSION/SUMMARY OF RECOMMENDATIONS



WP8 CHAPTER - FACTS

- 36 recommendations;
- 2 case studies;
- 1 framework for the assessment of patients' symptoms and needs;
- 1 survivorship care plan framework

Thank You