



# Joint Action on Networks of Expertise

## Deliverable 7.1

### NoE dedicated to Survivorship

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## LIST OF ABBREVIATIONS

Abbreviation	Definition
CCC	Comprehensive Cancer Center
CPG	Clinical Practice Guidelines
ECO	European Cancer Organisation
ESMO	European Society for Medical Oncology
EU	European Union
GP	General Practitioner
MS	Member State
MDT	Multidisciplinary Team
NoE	Network of Expertise
SAB	Scientific Advisory Board
SC	Steering Committee



## RECIPIENTS OF THIS DOCUMENT

This document is addressed to the whole JANE consortium. It is an official deliverable for the project and shall be delivered to the European Commission and appointed experts.

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## Executive summary

The number of patients surviving after cancer treatment is steadily growing and is associated with an increasing number of unmet physical and psychosocial needs. Accordingly, there is an increasingly clear need to set up a single Network of Expertise (NoE) dedicated to survivorship to define existing problems and integrate the different existing solutions across Europe. The NoE on Survivorship represents a concerted effort to improve the quality of life of patients across the European Union (EU). Leveraging the combined strengths of Member States (MS), other expert networks, EU initiatives, patient communities, and key organizations involved in cancer care and research, such network will promote a coherent, integrated strategy addressing the four key aspects of life. The network's activities will include improvements in certain aspects of health and physical, psychological, social, and economic issues affecting people after the end of primary cancer treatment. The strategies presented here will guide the implementation of the NoE on Survivorship in the next phase of the JANE Joint Action (JANE-2), ensuring a coordinated effort to improve the quality of life after cancer across Europe.

## Introduction

The basic aim of the Survivorship NoE is to establish sustainable, high-profile, well-coordinated support for patients cured from cancer. The network's mission is to integrate evidence-based approaches to cancer survivorship into routine after-treatment care and follow up and ensure equitable access across the EU. There are many unmet needs in this area, therefore the identification of all relevant issues and possible solutions is required to increase the survival of cancer patients. The mission of this Network is to cover all survivorship aspects, such as personalized cancer follow up; prevention and early detection of second cancers; prevention, early detection, and treatment of late sequelae and side effects related to primary cancer treatments; rehabilitation and management of psychological, social, and financial issues related to cancer.

Developing a survivorship care plan seems a valuable solution to address all the issues. The discipline of cancer survivorship needs to expand dynamically, in the era of modern therapies with increasing numbers of cured patients. Expectations and the number of unmet needs in this area are growing rapidly, and more complex, multi-professional health care for cancer survivors is becoming increasingly important. The network's activities are designed to unify clinical practice guidelines or initiatives to integrate existing ones on survivorship-specific issues (including the cross-border use of the Cancer

Patient Smart Card), educational programs for health professionals and patient advocates, including patient empowerment strategies, pathway optimization, and testing across the EU.

The survivorship care plan should consist of two main parts:

- a summary of the cancer diagnosis and treatment;
- after-treatment care and follow up, including psychosocial, cognitive, sexual, nutritional, and spiritual support. Good examples are the Treatment Summary and Survivorship Care Plan by the American Society of Clinical Oncology, the ESMO Patient Guide Survivorship, the “Life after Cancer” guidelines, and the pediatric European Survivorship Passport/PanCareFollowUp Care Intervention.

Cancer rehabilitation is one of the most important milestones in cancer survivorship care. The patient-centered approach is, therefore, highly important in planning (any type of) care provision.

The European Cancer Plan foresees social benefits, creating a virtual European Cancer Patient Digital Center for monitoring the survivor’s health condition. Additional protection to avoid discrimination in access to financial and insurance services should be provided to “cured” cancer patients.

## Methodology used to design the NoE

To create a team of experts in each field of survivorship, members of organizations dedicated to survivorship representing different EU countries, clinicians directly taking care of patients after cancer, and representatives of patient groups were invited to collaborate. Brainstorming sessions to gather the opinions of leaders, professional stakeholders, educators, patient advocates and expert patients, multi-professional researchers, and top clinicians resulted in the shaping of an NoE covering different aspects of survivorship. The members of the consortium took part in the specific tasks, which are listed below. A detailed review of existing literature and initiatives was performed for all aspects of Survivorship. Preparatory meetings included brainstorming on how the network is supposed to function and the next steps to be implemented.

Members of the developing NoE agreed to follow the guidelines and approach proposed by ESMO. Therefore, the definition of Survivorship and the direction of the network is based on the assumptions adopted and accepted by ESMO.



Activities (what, how, where) and division of work		
Task Name		Justification
7.1	Leading expert scoping	Assessment of potential members from EU countries. Creation of a list of collaborators .
7.2	Leading Expert Selection	Identification of the leading experts on 4 different aspects of survivorship (connected with cancers, adverse events, psychological distress, and social aspects)
7.3	Definition of the scope of the NoE on Survivorship	Use of the definition of survivorship provided by ESMO as a baseline
7.4	Identification of the endorsement criteria for the NoE survivorship sites	Identification of endorsement criteria regarding health providers (1st set) and other sites/entities (2nd set).
7.5	Scoping of sites and or services	Questionnaire on the organization of health care relating to survivorship in EU countries and to identify potential partners to collaboration purposes (CCC, networks, and societies)
7.6	Site and relevant stakeholder selection	Contact with bigger organizations for closer collaboration, including ESMO, SIOPE, OECI, PanCare, ECO, etc.
7.7	Planning the deliverables of the NoE on Survivorship	The list of deliverables (sites and services that the NoE will provide). Comprehensive and coordinated management and care for cancer survivors. Implementation of the plan requires coordination and organization across health systems.
7.8	NoE governance development	Governance of the NoE will be developed with JANE2

To get an overview of survivorship care organization in the EU countries, and to define the scope of sites and services, members of WP7 were asked to complete a short questionnaire (Task 7.5). The survey included 3 questions :

1. Does your institution routinely use a formal survivorship care plan for all patients in long-term remission or after radical cancer therapy?

- YES
- NO

2. What kind of survivorship care plan is used at your institution:

- Treatment Summary and Survivorship Care Plan by the American Society of Clinical Oncology,
- ESMO Patient Guide Survivorship,
- “Life after Cancer” guidelines,
- Pediatric European Survivorship Passport/ PanCareFollowUp Care Intervention
- other – give details
- institutional format

3. Please provide proposals for NoE sites at the country level and examples of survivorship service organization in your country.

Based on the experience of the consortium members, a list of potential partners was identified whose participation in the project was considered to be beneficial (see below in part “Collaborating stakeholders of the NoE”).

Clear guidelines for cured patients, close cooperation between network participants, and well-organized governance to keep the network sustainable were created during the meetings and brainstorming sessions.

The list of experts who are members of the network is attached in the Annex at the end of the document.

## Scope of the NoE

### I. Definition of survivorship

The following ESMO definition was adopted by the JANE Community:

“*Survivorship* applies to people living after a diagnosis of cancer with a focus on patients after treatment with curative intent or long-term remission in line with ESMO guidelines. Survivorship focuses on health and the physical, psychological, social, and economic issues affecting people after the end of the primary cancer treatment.



Figure 1 Aspects of survivorship involving NoE activities

The four identified aspects of survivorship to be covered by the NoE (Fig. 1) are listed and explained below:

1. Cancer (personalized follow up, prevention and early detection of second cancer, genetic counseling, etc.).
2. Adverse Events (cardiovascular, respiratory disorders, endocrinopathies, post-systemic therapy, cognitive decline, functional loss and pain disorders requiring rehabilitation, sexual dysfunction, infertility, and reproduction-related problems, etc.).
3. Psychological distress (eg. mental health damage as an effect of cancer disease, addictions, distress associated with sexual dysfunction and infertility, etc.).
4. Social aspects (eg. unemployment, workplace stigma, problems with insurance, mortgages, loans, etc.).

## II. Definition of the scope of the Survivorship Network of Expertise

The mission of the NoE is to identify unmet needs in the area of survivorship and find solutions to achieve improvements in the defined aspects connected with cancer per se, adverse events, and psychological and social issues.

*Potential issues and aspects to cover and improve by NoE:*

- organization of personalized primary cancer follow-up and detection of disease recurrence;



- prevention and early detection of second primary cancers;
- prevention, early detection, and treatment of late sequelae and side effects related to primary cancer treatments;
- management of psychological, social, professional/vocational, and financial issues related to cancer survivorship

Detailed issues/needs/services for the four identified areas of survivorship are as follows:

**I. Related to cancer *per se*:**

- Diagnostics - recurrence, second primary malignancies, subsequent (secondary) malignancies: breast cancer, colon cancer, skin cancers besides thyroid, lung cancer; importance of screening (colon, breast cancer), self-examination as for skin cancers, sarcomas], and comorbid conditions – different screening strategies;
- Individualized checklist for the patient including follow-up and description of the role of the oncologist and GP. Care after cancer treatment is differently organized by different national health care systems. The “Cancer survivor Smart Card” should be implemented - especially in the adult survivor population, as a complement to existing pediatric population projects (<https://siope.eu/activities/joint-projects/survivorship-passport/>);
- Prevention, including primary prevention (as healthy lifestyles and secondary prevention);
- Rehabilitation (including medical, social, psychological, and vocational rehabilitation after primary cancer and second primary cancers)
- Nutritional support;
- Genetic counseling (in cancer survivors who meet the criteria for genetic testing but have not yet had this performed or in cancer survivors who had genetic counseling and testing previously but because of a new cancer diagnosis [personal or family] additional testing is needed [e.g., availability of expanded molecular analyses])
- Quality of life assessment

**II. Related to adverse events** – sequelae of cancer treatment, long-term surveillance, and services should be provided with individual checklists or a survivorship passport:

- Cardiovascular disorders (atherosclerosis, hypertension, hyperlipidemia, coronary artery disease, valvular disease, cardiomyopathy, heart failure, stroke, etc.);
- Respiratory disorders (pneumonitis, fibrosis, bronchiolitis obliterans syndrome, pulmonary hypertension, etc);

- Endocrinopathies (hypothyroidism, hyperthyroidism, hyposomatotropism, hypopituitarism, obesity, metabolic syndrome, diabetes mellitus, gonadal dysfunction etc);
- Acute and late oral complications (oral infection (viral, bacterial, and fungal), oral mucositis, salivary dysfunctions, dental problems, oral hemorrhage, jaw osteonecrosis, trismus, etc)
- Postchemotherapy cognitive decline (after brain radiotherapy). Cancer-related cognitive impairment (CRCI) and chemotherapy-induced cognitive impairment (CICI);
- Neurological disorders. Epilepsy, cerebrovascular insults, polyneuropathy, motoric/sensory dysfunction, carotid stenosis;
- Functional loss and pain disorders that require rehabilitation. Preventive, restorative, supportive, and palliative rehabilitation. Care provided by a pain management specialist. Care related to post-treatment complications e.g., lymphedema, aromatase inhibitor-associated musculoskeletal syndrome (AIMSS), postmastectomy pain syndrome, etc.;
- Sexual dysfunction as an effect of direct treatment to the genital organs (e.g., surgery or radiation therapy impacting the testes, penis, ovaries, and vagina) as well as treatment with chemotherapy/hormonal treatment which has an impact on hormone deficiencies. Other issues connected with sexual dysfunction are permanent ostomy, older age, lack of a partner, poorer body image, etc.;
- Infertility and problems with reproduction (ways and opportunities for fertility and reproductive hormone preservation);
- Alopecia;
- Musculoskeletal problems (osteoporosis, degenerative changes, amputations, problems with prosthesis, osteonecrosis, etc);
- Visual and hearing problems (hyperacusis, hearing loss, visual impairment, blindness, cataract);
- Urogenital dysfunction: renal impairment (glomerular, tubular), unilateral nephrectomy, chronic cystitis, cystectomy;
- Infertility and problems with reproduction Reproductive counseling should be proactive and encouraged because it is beneficial to the patient's mental health, quality of life, and treatment adherence. More adequate and accurate information to patients should be given, as well as appropriate fertility preservation approaches should be offered;

III. **Related to psychological distress** – psychological/psychiatric support:

- Mental health damage as an effect of cancer disease (anxiety and depression connected with such symptoms as tension, restlessness, jitteriness, autonomic hyperactivity, hypervigilance to symptoms and events, insomnia, distractibility, shortness of breath, emotional numbness, apprehension, worry; fear of recurrence; post-traumatic stress; poor self-image related to, for example, alopecia, extremity amputations, mastectomy, etc.);
- Addictions. Cancer patients and survivors who have comorbid psychiatric disorders are also more likely to be addicted to nicotine and alcohol and need counseling;
- Sexual dysfunction, low sexual self-esteem, body image, and mental health.

IV. **Related to social issues** – a social advisor should be provided:

Problems, that occur are mainly related to a higher risk of unemployment and workplace stigma; return to work/social life, integration and problems in obtaining life, health, and travel insurance; mortgages or loans (Right To Be Forgotten)

Possible solutions:

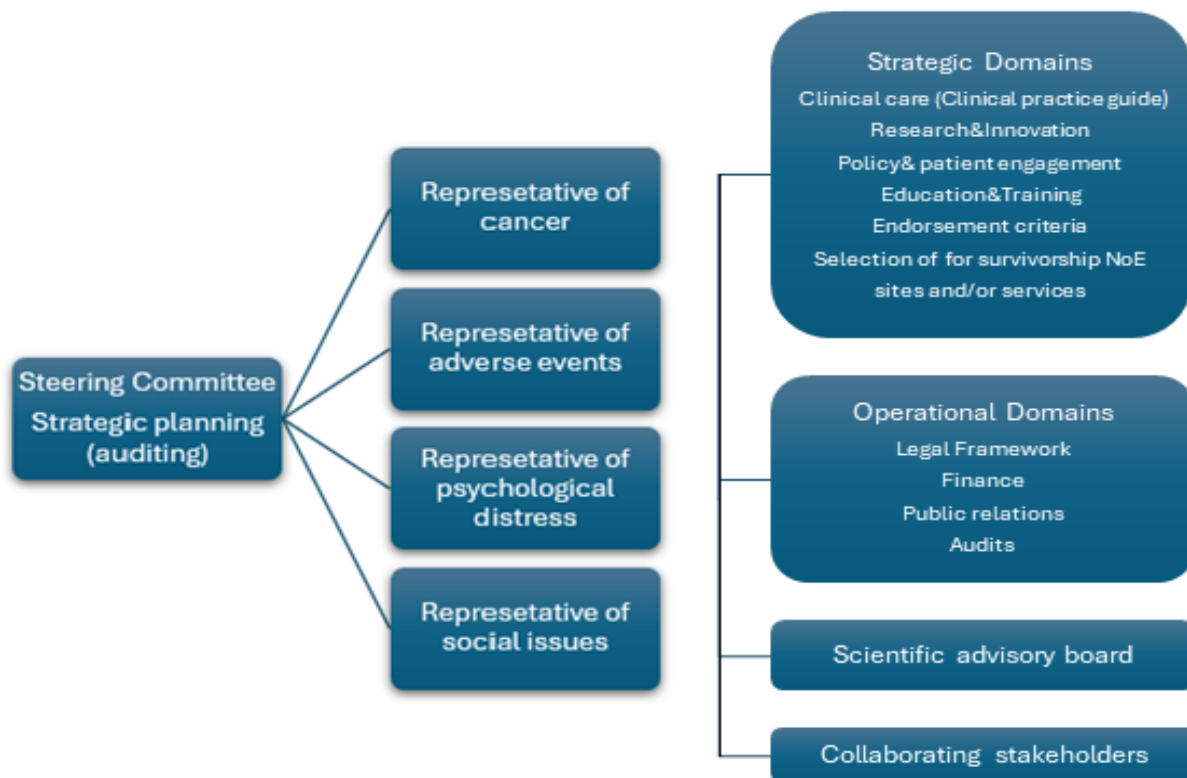
- Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment while supporting cancer survivors with short-term and long-term limitations in their ability to work.
- Implementation of the “right to be forgotten,” protecting the collection of medical data – this should be implemented by national regulations independently of NoE.
- Improving access to adequate and affordable health insurance.
- Career counseling, vocational rehabilitation.

To better organize the NoE, several consensus statements and guidelines (attached below) should be followed, e.g. ESMO, NCCN, Italian Alliance Against Cancer (ACC), European Cancer Organization (ECO, the Survivorship and Quality of Life Network), European Academy of Cancer Sciences (EACS), and the EU Cancer Mission. Collaboration with other societies (European or national), for example, the European Society of Cardiology is very important in terms of the harmonization and improvement of standards of care at the local and national level. During Joint Action JANE, the team prepared the universal recommendations for the Survivorship NoE, exploiting these guidelines. Collaboration with members of existing organizations provides an opportunity to standardize recommendations, guidelines, and the approach to cancer care across EU countries.

## Governance of the NoE

WP7 is dedicated to improving survivorship care organizations across the EU. This governance proposal describes the structure, responsibilities, and steps that define the shared goals and cooperation model, including specific strategies to ensure interaction with MS, other EU networks, (Comprehensive Cancer Centers (CCC), and patients. Collaboration between governance and leading organizations, such as the European Cancer Organization (ECO), and the European Commission, which have experience in the field of survivorship, is needed to improve practices in this area and fulfill unmet needs.

### Proposed model of the NoE's governance structure:



### Steering Committee

A diverse, interdisciplinary Steering Committee (SC) will be established to govern the NoE activities. The committee will include expert representatives from the four different areas of survivorship: cancer per se, adverse events, psychological distress, and social issues. The SC will play a key role in providing guidance, strategic direction, and monitoring the identified activities of the NoE. The tasks of the SC will include:

*Strategic planning.* Setting the strategic direction and goals of the NoE on Survivorship in its mission to recognize and fulfill needs in critical unmet areas with a high priority for improvement.

*Decision making.* The committee will make important decisions regarding NoE policies, initiatives, programs, and endorsement criteria. This might include approving research projects, fundraising strategies, awareness campaigns, and support programs.

*Leadership* – The SC will elect a chair and co-chairs in the four areas who will lead and facilitate discussions, decision-making, and collaboration within the committee. They will play a crucial role in the formation of the scientific advisory board (SAB). Its primary function would be to assess potential candidates for the Survivorship Domains based on their qualifications, expertise, and alignment with the Survivorship NoE goals.

Regular meetings (at least twice per year) will be conducted to discuss progress, challenges, and decisions. Collective decision-making will ensure comprehensive input and ownership.

Regular updates on progress, milestones, and outcomes will be communicated to the NoE leadership and stakeholders.

*Auditing.* A consensus will be reached on the form of auditing to be implemented.

## **Strategic domains**

*Clinical care subcommittee* - This subcommittee will focus on optimizing the quality of care provided to patients after cancer. It will explore strategies to enhance patient outcomes and survivorship care. It will include the representatives of the four areas of survivorship.

*Research & Innovation subcommittee* - This subcommittee will conduct extensive research and analysis to identify challenges, advancements, and gaps in the field of survivorship. The main role of this section is to develop guidelines to improve research on survivorship.

*Education and training subcommittee* - Responsible for educational initiatives related to survivorship, this subcommittee will develop materials for healthcare professionals, patients, and the public. Its focus will be on enhancing awareness and knowledge.

*Policy subcommittee* - Dedicated to influencing policy decisions in the realm of survivorship, this subcommittee will collaborate with relevant authorities to advocate for improved policies that benefit patients and healthcare practitioners.



*Endorsement criteria subcommittee* - The objectives and targets of this subcommittee will provide expert advice on integrating healthcare models across the EU (with a strong focus on cooperation between primary care and specific survivorship care in comprehensive cancer centers) in the field of survivorship.

*Subcommittee for the election of survivorship NoE sites and/or services* - The aim of this subcommittee is to select particular sites and/or services based on standardized criteria and inclusion criteria.

## **Operational domains**

*Strategic planning subcommittee* - This subcommittee would oversee the allocation of resources, including budget, personnel, and equipment, to ensure that the organization has the means required to carry out its initiatives effectively. The Strategic planning subcommittee and *Finance Subcommittee* will work together on network budget planning.

*Advocacy and public relations subcommittee* - This subcommittee will be responsible for advocacy efforts, which could involve lobbying for policy changes, raising awareness about survivorship, and building relationships with key stakeholders in the healthcare community. Regular engagement with external stakeholders, such as patient advocacy groups, medical societies, and industry partners, will provide well-rounded perspectives and foster collaboration. It would oversee efforts to engage and support individuals affected by survivorship, which could include patient and caregiver support programs, educational initiatives, and awareness campaigns.

*Finance Subcommittee* - This subcommittee will be an advisory voice for the NoE's long-term financial management principles, budgeting, and financial reporting processes. The subcommittee will ensure strong recommendations to the NoE on financial matters. Ongoing reporting mechanisms will maintain transparency and accountability.

Each subcommittee chair will be selected to serve a two-year term which may be renewed on the recommendation of the NoE.

## **The Scientific Advisory Board**

A group of independent experts and researchers, including representatives of other EU initiatives, as European networks (e.g., ERNs), projects (e.g., EU-CAYAS-NET), and research groups with specialized knowledge in the field of survivorship, will provide independent advice to the NoE. It will evaluate the effectiveness of research programs connected with survivorship, the implementation of guidelines and existing approaches, and make suggestions to strengthen the NoE's overall functioning as well as possible research studies. The primary purpose of the SAB will be to provide scientific guidance,

expertise, and strategic direction to organizations, institutions, or initiatives focused on the area of patients after cancer. The SAB would be a critical component of the NoE for advancing research and finding solutions. Their expertise and oversight will contribute significantly to the quality and impact of scientific endeavors in this critical area of oncology.

In addition to their advisory role, SAB members may contribute to educational initiatives, conferences, and workshops related to survivorship. They may also engage in public outreach to raise awareness about survivorship and research efforts.

## Endorsement criteria for NoE participants

### I. The general approach of the endorsement criteria for survivorship NoE sites.

Achieving comprehensive, coordinated management and care for cancer survivors requires coordination and organization across health systems. Healthcare models should integrate cooperation with primary care and/or specific survivorship care at CCCs. The NoE sites should provide:

- surveillance and management of somatic effects of primary cancer and chronic medical conditions;
- surveillance and management of psychological effects of cancer;
- surveillance and management of social, work-related, and financial effects of cancer; surveillance for recurrences and second primary cancers;
- promotion of cancer prevention and overall health and well-being.

### II. Mandatory requirements for the selection of survivorship NoE sites should be:

#### 1. General requirements:

- Multidisciplinary (MDT) approach to anticipate, personalize, and implement cancer survivors' follow-up, complication management, and tertiary prevention in care pathways.
- Coordination of survivorship management with local/community healthcare professionals, especially GPs. Involvement of patients and voluntary patient organizations (representatives) and collaboration with advocacy groups in planning and implementing the services.
- Education programs addressing cancer survivorship aim to improve patients' understanding of illness and the consequences of cancer treatment as well as social aspects of survivorship,

including recommendations on health promotion/prevention, and to increase patient empowerment.

- Provision of information materials on survivorship which are readable, up-to-date, and available in different national languages.
- Preparation of an individualized survivorship card for all patients after therapy with curative intent or long-term remission. A personalized survivorship plan should be created based on the patient's specific characteristics (including comorbidities, lifestyle), cancer, and treatment details.
- Systematic administration of a patient requirements questionnaire for all patients after treatment with curative intent, including health, socioeconomic and psychological outcomes (PROMs), and needs.

## 2. Related to cancer per se:

- Individualized follow-up plan/checklist to detect recurrences/secondary malignancies is available for all patients and describes who should take care of patients with cancers after treatment (role of the oncologist and GP. Where differently organized by national health care systems, a professional coordinator should be implemented). The follow-up model should provide for rapid re-entry to specialized cancer care, if required
- Prevention (including systematic assessment of smoking and alcohol addiction and referral to relevant addiction services; physical activity - assessment/referral; nutrition/body composition); availability of an active approach to overall healthy living in the fields of diet (nutritional support), tobacco use, alcohol, exercise delivered to all patients at the NoE site; support for patients to quit smoking.
- Genetic counseling/oncogenic care is available to all appropriate patients (in cancer survivors who meet the criteria for genetic testing but have not yet had this performed or in cancer survivors who had genetic counseling and testing previously but because of a new cancer diagnosis [personal or family] additional testing is needed (e.g., availability of expanded molecular analyses).
- Rehabilitation after therapy is described and available for all patients, including vocational rehabilitation.

## 3. Related to adverse events

- Long-term surveillance and services should be provided for the early detection of sequelae of cancer treatment with an individual/personalized checklist or survivorship passport (the list of possible long-term side effects is in the Annex at the end of the document).

- Systematic screening for pain is implemented and access to pain specialists provided.
  - A plan related to sexual dysfunction and fertility should be provided.
4. Related to psychological aspects
- Psycho-oncology service and psychiatric support should be provided
  - Addiction-fighting support should be available
  - Fertility counseling and preservation.
5. Related to social issues
- A social advisor should be provided by the NoE site, which can counsel in terms of social benefits, employment rights, housing needs, etc.
  - Access to insurance, mortgages, etc. – avoidance of financial toxicity for those living beyond cancer.
  - Vocational/professional counseling.

The main aims of sites belonging to the NoE on survivorship in social care are presented in Table 1. The care in this issue should cover:

- **promotion, coordination, and implementation of social care research in cancer survivorship;**

Health service research on the provision of social care should be organized, paying specific attention to integrated approaches and continuity of social care from a long-term perspective.

Social care research efforts should also cover the social participation of survivors and the social impact on relatives towards the design of personalized social interventions, especially for vulnerable groups (e.g., patients who are elderly, disabled, have multimorbidities, are from minorities, have low socioeconomic status, etc.).

The members need to lead the (local, and regional) development and update of guidance (e.g., guidelines, handbooks, etc.) related to the provision of social care.

- **ensure universal access to a “social coach”** in case of identification of social needs/screening tools. The social coach should
- pay attention to/screen for the patient’s socioeconomic and socio-demographic status (health literacy, vulnerability, social environment, access to social support, etc.)
- assess overall quality of life
- provide information or refer survivors to support services:

- social benefits related to work incapacity (conditions and administrative procedures);
- rights regarding loans and insurance;
- implementation of the Right To Be Forgotten;
- return-to-work pathways (roles and duties of patients and employers), including advice about communications within the work environment (colleagues, line manager, human resources, etc.);
- career counseling (including vocational rehabilitation);
- existing services for home care, housing, childcare, etc.;
- mobility.

This information or activities should be provided by the “social coach” or any specialist/expert to whom the social coach can refer the patient. The social coach needs to use (or develop and regularly update) manuals (e.g. a social map), gathering all local social security conditions, labour market regulations, legal and financial rules, etc.

The long-term follow-up should be organized as the financial and social impact of cancer survivorship often appears months or years after the end of treatment. Socio-professional reintegration plans should be foreseen and planned across years, in parallel to the medical follow-up.

#### **List of minimum standards for cancer survivorship social care**

- ❖ detect the social care needs of patients and relatives, with attention to vulnerable groups
- ❖ develop, conduct, and promote cancer survivorship social care research
- ❖ ensure the availability of guidance for referring to social services outside the hospital
- ❖ ensure that all patients have access to a social coach
- ❖ implement social care plans and ensure long-term social support and follow-up

Table 1 **minimum standards for cancer survivorship social care**

### **III. Additional requirements**

- Employers, legal advocates, and health care providers should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in their ability to work – return to work is a key strategy for rehabilitation in cancer patients
- Research related to survivorship
- Long-term quality of life assessment
- Integration of technology, including digital companions, to facilitate remote monitoring, education, and self-management.

- Additional tools should be implemented for children/adolescent survivorship
  - Transition of care from pediatric oncology to adult medicine should be organized to guarantee adequate long-term follow-up and setting up of appropriate interventions.

#### IV. Standardized international solutions - national/EU services

- Survivorship passport/Cancer survivor Smart Card implementation
- PanEU database - virtual European Cancer Patient Digital Center for monitoring survivors' health condition
- National legislation should be implemented in terms of the "Right to be forgotten".

## Services provided by the NoE

### I Planning Survivorship NoE Deliverables

1. The desired deliverable of the NoE must cover the 4 aspects included in the survivorship definition (Fig 1).
2. Services provided by the NoE require reliable coordination and organization across health systems to achieve comprehensive, coordinated management and care for cancer survivors.
3. NoE should be implemented at the national or EU level in collaboration with healthcare providers appointed by MS for survivorship and further contact directly with the CCC infrastructure in each country.
4. The NoE services provided will include:
  - General guidelines related to oncological survivorship
  - Guidelines for recurrences and second primary cancers
  - Guidelines for the effects of primary cancer and chronic medical conditions;
  - Guidelines for psychological effects of cancer;
  - Guidelines for social, work, and financial effects of cancer;
  - Guidelines for cancer prevention and overall health and well-being promotion.
5. The NoE should provide recommendations to organize/develop:
  - An MDT approach to anticipate, personalize, and implement cancer survivor follow-up, complication management, and tertiary prevention in care pathways.
  - Coordination of survivorship management with national healthcare professionals, especially GP organizations/societies. Involvement of patients and voluntary patient

- organizations (representatives) and collaboration with advocacy groups in planning and implementing services.
- Education programs on cancer survivorship aiming to improve patients' understanding of illness and the consequences of cancer treatment as well as social aspects of survivorship, including recommendations on health promotion/prevention and increasing patient empowerment.
  - Provision of information materials on survivorship which are readable, up-to-date, and available in different national languages.
  - An individualized survivorship card/survivorship passport prepared for all patients after therapy with curative intent or long-term remission and implementation of this tool at national and EU levels.
  - Patient requirement questionnaire, which is methodically gathered for all patients after treatment with curative intent, including health, socioeconomic and psychological outcomes (PROMs), and needs.
  - Implementation of a professional coordinator at the healthcare provider level related to survivorship.
6. The NoE should promote digitalization of healthcare to support data collection and the development of quality indicators and collaborate with national cancer registries to establish a standardized approach to data collection and reporting for cancer survivorship issues.
  7. The NoE should map ongoing programs regarding survivorship within public health care systems (i.e., university courses and training programs for GPs) and existing organizations to understand current considerations about survivorship
  8. The NoE should map and analyze the different care pathway experiences and models considering the high variability among countries (e.g., in relation to oncological network structures, centralization versus decentralization approaches, and hub-and-spoke models), and promote best practices.
  9. The NoE should support the development of multilevel programs within the public health care systems (i.e., university courses and training programs for GPs, to train GPs and specialists in all aspects of oncological survivorship).
  10. The NoE should implement the complex rehabilitation process for cancer survivors.
  11. The NoE should determine the methodology of recommendations/guidelines, i.e., define rules and criteria for the composition of multidisciplinary expert panels, involve stakeholders engaged in survivorship oncology care, establish the indicators for evaluating evidence, define the format of the recommendations/guidelines, implement a process of external review, and ensure periodic



- updates. The NoE should create a comprehensive plan for disseminating and implementing the developed guidelines and recommendations.
12. The NoE will collect and analyze existing expertise and organizational strength to build powerful resources to underpin a new future. The NoE should explore innovative approaches for guideline implementation, such as digital tools, decision support systems, and quality improvement initiatives. These strategies can facilitate the adoption of and adherence to clinical practice guidelines and improve the overall quality of cancer survivorship.
  13. The NoE should promote the development of specific studies for prospective data collection for long-term aspects of survivorship.
  14. The NoE should promote initiatives to raise awareness among the public and healthcare professionals of the importance of clinical studies related to survivorship.
  15. The NoE should define a research strategy to prioritize different research topics for cancer survivorship and promote research on long-term survivorship care. This includes studying the physical, psychological, and social late effects of cancer and its treatment in patients, as well as developing interventions and guidelines for comprehensive survivorship care plans tailored to patients' specific needs.
  16. The NoE should create a curriculum for cancer training related to survivorship, working with the certification organizations of each professional discipline with a strong stake.
  17. The NoE should promote the identification of health providers for survivorship excellence.

## Synergies with the NoE

The NoE on Survivorship is designed to work synergistically with MS, other NoEs, existing EU organizations, patients across the EU, and societies involved in cancer care and research (OEI, ECO, ESMO, EORTC, ESSO). There are several existing CPGs and previous experiences (listed below in Table no. 2) that present guidelines and modes of survivorship care. The collaborative approach and integrated action that the network proposes provide a coherent, unified strategy to improve standards of care for patients after cancer.

**Member States:** Each participating MS plays a vital role in the network by contributing local expertise, resources, and data. MS are encouraged to align their national cancer strategies with the network's objectives, facilitating cross-border collaboration and standardization of care. This cooperation enhances the overall effectiveness of the network and supports the implementation of best practices across different healthcare systems.



**Networks:** The NoE on Survivorship interacts with other NoEs, such as the NoE on Omics, on Hi-Tech Medical Resources, on Palliative Care, on AYA, and on Poor Prognosis Cancer). This interplay fosters information exchange, coordinated research efforts, and shared resources. Additionally, collaboration with EUNetCCC will provide a background to create a checklist for patients, including follow up and a description of who should take care of patients with cancer after treatment (the role of oncologists and GPs, as differently organized by national health care systems) and support the implementation of the Cancer Survivor Smart Card

**Patients in the EU:** Networking with patients across the EU is crucial to the mission of the NoE on Survivorship. Patient involvement helps to determine the real needs after cancer treatment. This provides an opportunity to adapt the network's activities to the unmet needs of a diverse patient population across the EU. In addition to medical care and health system organization, some social and economic problems remain unmet. Engaging societies involved in economic issues improves the organization of socio-economic care.

**Organizations and Societies:** Collaboration with key organizations and societies, such as the OECl, ECO, ESMO, EORTC, and ESSO, is crucial to the NoE strategy. These organizations provide a platform for exchanging best practices, clinical guidelines, and innovative research findings. Their involvement strengthens the network's ability to implement care after treatment.

Title	Suggested part	Published by	Link to entire Publications
Cancer cure and consequences on survivorship care: Position Paper from the Italian Alliance Against Cancer (ACC) Survivorship Care Working Group	Entire Publication	Dove press	<a href="https://pubmed.ncbi.nlm.nih.gov/36340999/">https://pubmed.ncbi.nlm.nih.gov/36340999/</a>
Survivorship Care for Cancer Patients	Chapter 2	Springer	<a href="https://link.springer.com/chapter/10.1007/978-3-030-78648-9_2">https://link.springer.com/chapter/10.1007/978-3-030-78648-9_2</a>
CanCon Policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States	Chapter 7	CanCon	<a href="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</a>
ESMO Expert Consensus Statements on Cancer Survivorship: promoting high-quality survivorship care and research in Europe	Entire Publication	Annals of Oncology	<a href="https://www.annalsofoncology.org/article/S0923-7534(22)03792-9/fulltext">https://www.annalsofoncology.org/article/S0923-7534(22)03792-9/fulltext</a>
NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Survivorship	Entire Publication		<a href="https://www.nccn.org/guidelines/guidelines-detail?category=3&amp;id=1466">https://www.nccn.org/guidelines/guidelines-detail?category=3&amp;id=1466</a> Guidelines Detail (nccn.org)
Cancer survivorship: an integral part of Europe's research agenda	Entire Publication	Molecular Oncology	<a href="https://pubmed.ncbi.nlm.nih.gov/30552794/">https://pubmed.ncbi.nlm.nih.gov/30552794/</a>
Challenges and solutions to embed cancer survivorship	Entire Publication	Molecular Oncology	<a href="https://pubmed.ncbi.nlm.nih.gov/34053182/">https://pubmed.ncbi.nlm.nih.gov/34053182/</a>
ASCO Cancer Treatment and Survivorship Care Plans	Entire Publication	ASCO	<a href="https://www.cancer.net/sites/cancer.net/files/cancer_survivorship.pdf">https://www.cancer.net/sites/cancer.net/files/cancer_survivorship.pdf</a>
ESMO Patient Guide Survivorship	Entire Publication	ESMO	<a href="https://www.esmo.org/content/download/117593/2061518/file/esmo-patient-guide-survivorship.pdf">https://www.esmo.org/content/download/117593/2061518/file/esmo-patient-guide-survivorship.pdf</a>
Late effects, long-term problems, and unmet needs of cancer survivors	Entire Publication	International Journal of Cancer	<a href="https://pubmed.ncbi.nlm.nih.gov/35657637/">https://pubmed.ncbi.nlm.nih.gov/35657637/</a>
European Groundshot—addressing Europe's cancer research challenges: a Lancet Oncology Commission	Section 13	Lancet Oncol	<a href="https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(22)00540-X/fulltext">https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(22)00540-X/fulltext</a>
REPORT on strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy	part IV	European Commission	<a href="https://www.europarl.europa.eu/doceo/document/A-9-2022-0001_EN.html">https://www.europarl.europa.eu/doceo/document/A-9-2022-0001_EN.html</a>
European PanCareFollowUp Recommendations for surveillance of late effects of childhood, adolescent, and young adult cancer	Entire publication	EJC - Science Direct	<a href="https://www.ejca.org/ViewFullText.aspx?doi=10.1016/j.ejca.2022.03.001">The PanCareFollowUp Care Intervention: A European harmonized approach to person-centered guideline-based survivorship care after childhood, adolescent, and young adult cancer (ejcancer.com)</a>
Children's Oncology Group long-term follow-up up (COG LTFU) guidelines			<a href="http://www.survivorshipguidelines.org/">http://www.survivorshipguidelines.org/</a>

Table 2. Several clinical practice guidelines and previous experiences/other actions

# Collaborating stakeholders of the NoE

## I. Proposed NoE sites at the country level in different EU countries:

1. **Poland:** Survivorship issues are included in the Polish National Oncological Strategy. The main aim of the survivorship plan is to organize the National Network of Oncology between main hospitals to help collaboration between the Polish Oncological Society and the National Oncological Council. The NoE sites proposed three hospitals:

- Maria Skłodowska-Curie National Research Institute of Oncology (hospital in Warsaw and hospital in Gliwice)
- Lower-Silesian Oncology Center (hospital in Wrocław).

The national consultant for clinical oncology and the national consultant for pediatric oncology and hematology will be involved as stakeholders. The Polish National Oncological Strategy includes a network “Follow-up” which is responsible for identifying unmet needs and finding solutions to improve care at the national level.

2. **Spain:**

- HUVM (Hospital Universitario Virgen Macarena) has coordinated the Cancer Strategy in the region of Andalusia since 2021. The main strategy includes as a pivotal objective the creation of a common protocol for long-term survivor care for the whole region. Guidelines have been developed in coordination with Primary Care Centers throughout the region (published in 2023).
- SEGUIM Unit, Pediatric Cancer Center Barcelona, Hospital Sant Joan de Déu. SEGUIM is a unit dedicated to cancer survivorship care. It is the leading pediatric cancer care facility in the country, with more than 800 survivors of pediatric cancer. SEGUIM is a multidisciplinary unit that integrates a pediatrician, advance practice nurse, a psycho-oncologist and a social worker. It coordinates with the different specialties to monitor and treat late effects of cancer and treatment. SEGUIM liaises with the primary health care system in order to engage the GPs in cancer survivor care. The unit also facilitates the transition of pediatric cancer survivors over 18 years of age to adult oncology services. Hospitals that provide care for patients after cancer treatment in a unified system are listed below:
  - Hospital Salamanca
  - Hospital Santiago
  - Hospital Niño Jesús

3. **France:** Unicancer Federation of 18 French comprehensive cancer centers has established a common core curriculum for the follow-up of cancer survivors in the French CCCs involving a self-questionnaire for needs assessment and screening of sequelae (pain, nutrition, physical activity, psychological effects, social and occupational aspects, etc.). The CCCs involved in survivorship care are listed below:
  - Centre Léon Bérard, Lyon Specific programs being implemented to ensure systematic follow-up of treatment sequelae (PASCA (adults) and SALT (childhood and AYA))
  - Gustave Roussy, Villejuif, Paris for adult survivors of childhood and TYA cancers in complete remission at 5 years post-end of treatment
  - Centre François Baclesse, Caen;
  - Institut du Cancer, Montpellier.
  
4. **Croatia:** The University Hospital Centre Zagreb, <https://www.kbc-zagreb.hr/> is the largest health institution in the Republic of Croatia, considering the number and diversity of health services it provides. It is a good partner for collaboration and promotion of survivorship activities.

Survivorship has been recognized in Croatia as an important topic in the Croatian National Strategic Framework against Cancer ([https://narodnenovine.nn.hr/clanci/sluzbeni/2020\\_12\\_141\\_2728.html](https://narodnenovine.nn.hr/clanci/sluzbeni/2020_12_141_2728.html)). The strategic framework mentions the importance of survivorship and the need for services to support cancer survivors. It emphasizes the need for psychosocial support, rehabilitation services, and follow-up care to monitor for cancer recurrence and manage the long-term effects of cancer and its treatment.

Also, in 2022, the Croatian Parliament unanimously decided to introduce a National Cancer Survivors Day commemorated on the first Sunday of June each year. The initiative, proposed by the Health Committee of the Parliament and supported by all 126 members present, aims to focus on the large population of cancer survivors in Croatia and emphasize the importance of prevention and healthy living.
  
5. **Slovenia:** Institute of Oncology, Ljubljana <https://www.onko-i.si/eng> - a comprehensive national cancer center, which carries out services required for cancer prevention and treatment, as well as rehabilitation and palliative care of cancer patients. It is a good partner for collaboration and promotion of survivorship activities.

6. **Italy:** Istituto Nazionale dei Tumori, Milan <https://www.istitutotumori.mi.it/> - the center is dedicated to the cure of cancer and is divided into different departments that come together in medical oncology, hematology, surgery, and radiotherapy. The center also has several specialized clinical services, including for example the Adolescent and Young Adult Oncology Program, Genetic consultation, Psycho-oncology, Pain Clinic, and Palliative Care Program, which are dedicated to survivorship.

## II. Proposed NoE service organizations in different EU countries:

1. **SEOM (The Spanish Society for Medical Oncology)** - proposed back in 2013 an integral plan for the care of long-term survivors (described as cancer in remission for more than 5 years after curative treatment) which included clinical guidelines for the management of these patients, depending on the type of cancer. SEOM has also created a website called Oncosaludable which is freely accessible to survivors and their family members and has useful information for long-term survivors regarding healthy lifestyles after the disease, specific health issues such as skin health, alarming symptoms to be aware of, etc. SEOM also has a working group centered on long-term survivorship.
2. **RETI (The Registry of Long-term Survivors)** - The Spanish Registry of Children with Tumours (RETI-SEHOP) is a science project, which is a collaboration between the Spanish Association of Pediatric Hematology and Oncology (SEHOP) and the Universitat de València, where the Research Group acting as the Central Team of the Registry is located. It is a reference benchmark project for child cancer, which contributes to the fight against cancer in childhood through the study of the survival of children with cancer in Spain and its international comparison; the study of the incidence and its tendencies; and collaborating to the study of the causal risk factors.
3. **INCa (The French National Cancer Institute)** - established under the French Public Health as the State health and science agency to specialize in cancer control. The Institute operates under the dual auspices of the French Ministry of Health and Solidarities and the French Ministry of Higher Education, Research and Innovation. It provides an integrated approach encompassing all cancer-control aspects (health, scientific, social, and economic) and intervention areas (prevention, screening, care, research) to benefit patients and their relatives. This ambitious strategy aims to significantly reduce the burden of cancer in the daily lives of French people. It follows on from the successive Cancer Plans and continues the collective mobilization established in the fight against cancer. This strategy revolves around four priorities:

- to improve prevention;
  - to limit after-effects and enhance the quality of life;
  - to fight against cancers with poor prognosis;
  - to ensure that progress benefits everyone.
4. ACC (Alliance Against Cancer, Alleanza Contro il Cancro) - In Italy, ACC is currently developing a survivorship care program involving 23 tertiary centers. The aim of the project is to create a shared online platform and an app to generate a personalized survivorship care plan for each patient. Data about cancer diagnosis, cancer treatments, and patient characteristics (such as age, sex, comorbidities, and lifestyle) will be entered into the platform, which will provide a precise integrated assessment of cancer and cancer treatment sequelae. On this basis, a customized care plan will be available for the patient. Through this project, a coordinated approach among the different cancer centers is being developed, unifying survivorship definition and follow-up care.
  5. ECO (European Cancer Organisation) - The organization was created to reduce the burden of cancer and improve outcomes and the quality of care for cancer patients, through multidisciplinary and multiprofessionalism. As the not-for-profit federation of member organizations working in cancer at a European level, ECO convenes oncology professionals and patients to agree on policy, advocate for positive change, and be the united voice of the European cancer community.
  6. European PanCare Follow-up - The overall aim is to improve the quality of life for survivors of childhood and adolescent cancer by bringing evidence-based, person-centered care to clinical practice in the real world. PanCareFollowUp brings together experts in clinical guidelines, person-centered care, intervention development, and assessment to develop and test two interventions to improve survivorship care. The project launched on 01 Jan 2019, bringing together partners from Austria, Belgium, Czech Republic, Denmark, Ireland, Italy, the Netherlands, Sweden, Switzerland, and the United Kingdom.
  7. OECI - The Organisation of European Cancer Institutes - The mission is to bring together the cancer research and care institutions of the EU to create a critical mass of expertise and competence with the view of building and maintaining a consensus on the best models of oncology, developing concrete affordable and realistic solutions to effectively combat cancer, and fostering the widest deployment of oncology models and solutions to improve the quality of life for the patients in the EU.

8. Polish National Oncological Strategy and Survivorship Plan - (clarified above)
9. Ministries of Health of each country of the EU
10. Possible inclusion of additional stakeholders will also be activated (e.g. insurance companies, general practitioners' societies, legal experts, etc.).

# Annex

## Leading experts

Leading experts scoping the field of survivorship across Europe have been identified, to cover 4 survivorship aspects (as described above):

### 1. Experts on Cancer aspects:

- Lorna Zadavec Zaletel, Slovenia Institute of Oncology Ljubljana, radiotherapy dept. radiation oncologist and specialist at the Follow-up clinic.
- Carlos Miguez, Spain Radiotherapy Oncology Department of Macarena University Hospital Radiotherapy oncologist.
- Régine Kiasuwa, Belgium National Institute of Public Health (Sciensano) Department of Epidemiology and Public Health Cancer Center; Health Policy Scientist.
- Nicola Di Flora and Francesco de Lorenzo FAVO Italy.
- Winette van der Graaf, Dept Medical Oncology, Netherlands Cancer Institute, Amsterdam, The Netherlands.
- Piotr Rutkowski Maria Sklodowska-Curie National Research Institute of Oncology Warsaw Poland Department of Soft Tissue/Bone Sarcoma and Melanoma.
- Dr Ines Vaz-Luis, Breast Cancer Unit, Medical Oncology Department, Gustave Roussy and Cancer Campus, Villejuif, France;
- Monica Terenziani; Pediatric Oncologist at Fondazione IRCCS Istituto Nazionale dei Tumori Milano and Chair Of AIEOP for Late Effects (Associazione Italiana Ematologia Oncologia Pediatrica) Italy.
- Tarsila Ferro; Quality management / Catalan Institute of Oncology (ICO), Director, Italy.
- Jesús González Barboteo; Palliative Care Dept, Deputy Head of department Catalan Institute of Oncology L'Hospitalet, Spain.
- Paweł Wiechno, medical oncologist, Maria Sklodowska-Curie National Research Institute of Oncology Warsaw Poland Department of Urological Cancers
- Marc YCHOU; Institut du Cancer de Montpellier (ICM) - Unicancer network, France.
- Mario Šekerija; Croatian Institute of Public Health, Croatia.
- Prof. Antonis Kattamis Head, Division of Pediatric Hematology-Oncology; First Department of Pediatrics, National and Kapodistrian University of Athens, 'Aghia Sophia' Children's Hospital Papadiamantopoulou and Thivon, Athens, Greece
- Andres Morales, Head of Oncology Department; Pediatric Cancer Center, Sant Joan de Déu Hospital, Barcelona, Spain.



## 2. Experts of adverse events

- Lorna Zadavec. Slovenia Institute of Oncology Ljubljana, Radiotherapy department radiation oncologist, and a specialist at the Follow-up clinic.
- Carlos Miguez. Spain Radiotherapy Oncology Department of Macarena University Hospital Radiotherapy oncologist.
- Alberto Moreno Conde. Spain ICT Innovation & Data Analysis Unit of Macarena University Hospital Telecommunications Engineer.
- Régine Kiasuwa. Belgium National Institute of Public Health (Sciensano) Department of Epidemiology and Public Health Cancer Center Health Policy Scientist.
- Barbara Vischioni. Italy CNAO (National Center for Oncological Hadrontherapy) Radiation Oncologist (Head and Neck).
- Paulina Jagodzinska-Mucha. Maria Sklodowska-Curie National Research Institute of Oncology Warsaw Poland Department of Soft Tissue/Bone Sarcoma and Melanoma.
- G. Pravettoni Department of Oncology and Hemato-Oncology, University of Milano, Milan; 4Applied Research Division for Cognitive and Psychological Science, Istituto Europeo di Oncologia, IRCCS, Milan
- Beatrice Fervers (medical oncologist, epidemiologist) the Prevention Cancer Environment Department in Leon Berard Center, Lyon, France
- Monica Terenziani Fondazione IRCCS Istituto Nazionale dei Tumori di Milano Istituto Tumori di Milano · Dipartimento di Ematologia ed Oncoematologia Pediatrica, Milan, Italy
- Cecilie Kiserud, Head of the Center of Late effects within the oncology department. Clinical oncologist. Norway
- Florence JOLY. Centre François Baclesse (Caen) - Unicancer network France
- Katerina Katsibardi. Pediatric Hematology-Oncology Unit, First Department of Pediatrics, National and Kapodistrian University of Athens, 'Agia Sophia Children's Hospital', Greece
- Antonia Vlachou; Pediatric Hematology-Oncology Unit, First Department of Pediatrics, National and Kapodistrian University of Athens, 'Agia Sophia Children's Hospital', Greece

## 3. Experts of psychological distress

- Rosa María Baños Rivera. Spain. University of Valencia. Clinical Psychologist
- Régine Kiasuwa. Belgium National Institute of Public Health (Sciensano) Dept of Epidemiology and Public Health, Cancer Center, Health Policy Scientist
- L. van de Poll-Franse CoRPSdCenter of Research on Psychology in Somatic Diseases, Department of Medical and Clinical Psychology, Tilburg University, Tilburg, The Netherlands

- G. Pravettoni Department of Oncology and Hemato-Oncology, University of Milano, Milan; 4Applied Research Division for Cognitive and Psychological Science, Istituto Europeo di Oncologia, IRCCS, Milan
- Cecilie Kiserud. Head of the Center of Late Effects within the Oncology Dept. Clinical oncologist. Norway
- Paweł Wiechno, medical oncologist, Maria Skłodowska-Curie National Research Institute of Oncology Warsaw Poland Department of Urological Cancers.
- Bojana Raičković (psychologist). Croatian Institute of Public Health, Croatia
- Ivana Andrijašević (psychologist); Croatian Institute of Public Health, Croatia
- Petra Čukelj (psychologist); Croatian Institute of Public Health, Croatia

#### 4. Experts in social aspects

- Lorna Zadavec Zaletel. Slovenia Institute of Oncology Ljubljana, Radiotherapy Dept. Oncologist and specialist at the Follow-up clinic
- Régine Kiasuwa. Belgium National Institute of Public Health (Sciensano) Department of Epidemiology and Public Health Cancer Center Health Policy Scientist
- Iwona Ługowska Maria Skłodowska-Curie National Research Institute of Oncology Warsaw Poland Early Phase Clinical Trial Unit
- Michi Geissler Sarcoma Patient Advocacy Global Network (SPAGN)
- Françoise Meunier, MD, PhD, FRCP (UK) Right to be Forgotten initiative
- Mark Lawler, survivorship and financial toxicity/health policy of living beyond cancer, Right To Be Forgotten, Queen's University Belfast, UK

## The list of possible long-term side effects

The general list of possible long-term adverse events that should be included in the survivorship individual plan:

- Cardiovascular disorders (atherosclerosis, hypertension, hyperlipidemia, coronary disease, valvular disease, cardiomyopathy, heart failure, stroke, etc.);
- Respiratory disorders (pneumonitis, fibrosis, bronchiolitis obliterans syndrome, pulmonary hypertension, etc);
- Endocrinopathies (hypothyroidism, hyperthyroidism, hypopituitarism, obesity, metabolic syndrome, diabetes mellitus, gonadal dysfunction, etc);
- Acute and late oral complications (Oral infection [viral, bacterial, and fungal]), oral mucositis, salivary dysfunctions, problems with teeth, oral hemorrhage, jaw osteonecrosis, trismus, etc.);
- Postchemotherapy cognitive decline. Cancer-related cognitive impairment (CRCI) and Chemotherapy-induced cognitive impairment (CICI);
- Neurological disorders. Epilepsy, cerebrovascular insults, polyneuropathy, motoric/sensory dysfunction, etc.;
- Functional loss and pain disorders that require rehabilitation. Preventive, restorative, supportive, and palliative rehabilitation. Care provided by a pain management specialist. Care related to post-treatment complications ex. lymphedema, aromatase inhibitor-associated musculoskeletal syndrome (AIMSS), Postmastectomy pain syndrome, etc.;
- Sexual dysfunction as an effect of direct treatment to the genital organs (e.g., surgery or radiation therapy that impacts the testes, penis, ovaries, and vagina) as well as treatment with chemotherapy which has an impact on hormone deficiencies. Other issues connected with sexual dysfunction are permanent ostomy, older age, lack of a partner, poorer body image, etc.;
- Infertility and problems with reproduction (ways and opportunities for fertility and reproductive hormone preservation);
- Alopecia;
- Musculoskeletal problems (osteoporosis, degenerative changes, amputations, problems with prosthesis, osteonecrosis, need for reconstructive surgery, etc.);
- Visual and hearing problems (hyperacusis, hearing loss, visual impairment, blindness, cataract);
- Urogenital dysfunction, renal impairment (glomerular, tubular), unilateral nephrectomy, chronic cystitis, cystectomy, etc.;
- Subsequent (second primary) malignancies. breast cancer, colon cancer, skin cancers besides thyroid, lung cancer; Importance of screening (colon, breast cancer), self-examination as for skin cancers, sarcomas, prevention.