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# Cancer survivorship: A positive side-effect of more successful cancer treatment

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## ABSTRACT

Over the past decades, early diagnosis, new drugs and more personalised multi-modality treatment have led to impressive increases in survival rates of patients with cancer. This success in treating cancer has resulted in a large and rapidly increasing number of cancer survivors, yet life after cancer is often compromised by a broad spectrum of late adverse treatment effects. Some encounter cardiovascular, second malignancies, cognitive or other morbidities which impair normal life in an important way. Some patients are confronted with societal discrimination due to slower performance, chronic fatigue or partial inability and these things can adversely affect employment, education, insurance or mortgage opportunities.

In 2012, the European Organisation of Research and Treatment of Cancer (EORTC) Survivorship Task Force was created to focus research efforts on late morbidity of cancer treatment and its impact on society. On 30–31st January 2014, the 1st EORTC Cancer Survivorship Summit was organised to facilitate interaction between clinicians, researchers, social workers, patients, insurers, bankers and policy makers. This important event addressed the needs of cancer survivors, and new collaborations between academic groups, patient advocates, financial and political representatives were formed to guide future European research and health policies in this field. This special issue of the European Journal of Cancer is entirely dedicated to this Summit and addresses, respectively, second malignancies, cardiovascular disease, cognitive dysfunction, infertility/sexuality and psycho-social problems following cancer treatment.

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## 1. Introduction

Over the past decades, the introduction of screening, new drugs and more personalised multi-modality treatments have led to impressive increases in survival rates of patients with cancer. This success in treating cancer has resulted in a large and rapidly increasing number of cancer survivors. Currently,

there are over 13 million cancer survivors in the United States and close to 30 million survivors worldwide [1,2]. Some five million are survivors of breast cancer and there are also over three million survivors each of prostate and colorectal cancers. In the United States and Europe the overall 5-year relative survival rate for all cancers combined has increased steadily over the past few decades and reached 66.1% for

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patients diagnosed from 1999 to 2006 [3]. Cure is now a reality for the majority of patients suffering from breast, colorectal and testicular cancer, Hodgkin's disease or children's leukaemia, with survival rates reaching 90%. Also many other cancer patients are now successfully treated. Even in the metastatic setting, salvage and maintenance treatments create long-term control and reduce this mortal cancer into a chronic disease.

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## 2. Cancer survivors face a host of issues

Cancer patients face numerous challenges which were unforeseen in the 70's, when a diagnosis of cancer was seen as a death sentence. Clinical trials were focused on more aggressive treatment to increase survival. Since the 90's, starting mainly in paediatric oncology, cancer survivorship issues became clearer, and new trials trying to reduce treatment toxicity were introduced. Still, long-term toxicity data remain scarce.

Many cancer survivors face secondary problems for which neither standard oncology follow-up care nor society as a whole is well prepared. Some patients encounter disabling neurological problems, second malignancies, severe cardiovascular or other morbidities, which impair normal life in an important way. Some patients are confronted with difficulties of societal discrimination due to slower performance, chronic fatigue, partial inability or credit history, and these things can interfere with their efforts to gain employment, receive an education, insurance or a mortgage to purchase a home.

The increasing number of reports on morbidity and mortality due to physical and mental impact of cancer treatment raises questions concerning the classical follow-up of cancer patients by cancer specialists. Following the example of paediatric oncology, preventive care plans are being developed for adult cancer survivors in an effort to reduce morbidity and early mortality due to late effects. However, many questions regarding risk assessment and potential interventions still stand open.

Given the steadily growing volume of cancer survivors, the definition of follow-up after cancer treatment urgently needs renewed discussion in order to reduce the economic impact of high secondary medical consumption due to late adverse effects. Restructuring follow-up needs to be discussed among cancer specialists, psychologists, social workers, and also epidemiologists, general practitioners, policy makers and health insurers so that appropriate guidance is available for future cancer survivors.

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## 3. EORTC Cancer Survivorship Task Force

The EORTC (European Organisation for Research and Treatment of Cancer) is a pioneer in cancer care. It has created European-wide collaborations that are responsible for a large number of modern cancer treatment protocols. For over 50 years the EORTC has contributed to better outcome and quality of life for patients with cancer, and the existing EORTC network and expertise together with an extensive database of clinical studies performed over these five dec-

ades can also be of great value in increasing our understanding of the situations and needs of cancer survivors. The EORTC wants not only to contribute by collecting detailed information on late morbidity and mortality, but also by helping to improve data-collection, statistical modelling, and international cooperation across Europe. In order to address the needs of cancer survivors, high quality research of late effects is needed, and this requires access to large clinical cohorts of homogeneously treated cancer patients who have been prospectively followed for many years. Such long term follow-up can only be achieved by independent academic research organisations operating within a Pan-European framework.

The mission of the EORTC Cancer Survivorship Task Force is to identify the needs of cancer survivors and provide guidance for their proper management. A team of interested investigators has joined this Survivorship Task Force and aims to evaluate the most common problems in cancer survivors and construct research initiatives within the different EORTC disease oriented research groups as well as other international working parties.

First, though, we should define what is meant by a cancer survivor, because there is some variability in the definitions. For example, the United States National Cancer Institute (NCI) defines a cancer survivor as any person with cancer, starting from the moment of diagnosis [4]. For its estimates on cancer prevalence, the International Agency for Research on Cancer (IARC) categorises it according to three different phases of cancer care: initial treatment (within one year), clinical follow-up (two to three years) and cure (four to five years) [2].

The EORTC Cancer Survivorship Task Force will use the term survivorship to describe patients who have completed their primary treatment (maintenance treatment can be ongoing). The initial focus of this initiative will be on adult cancers and primarily lymphoma, breast, colorectal, prostate, gynaecological and testicular cancers. Patients who are not cured but in remission for extended periods of time can be included in this definition in light of the broad emphasis on quality of life (QoL) and treatment related morbidity in this category of chronic patients.

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## 4. Progress beyond the state-of-the-art

Using EORTC clinical research data and long term follow-up, we hope to precisely estimate the magnitude of cancer survivors' problems, individual risk factors and susceptibility. Possible preventive measures and guidelines for proper management are an important goal.

Two main research strategies will be initiated in parallel:

- First, retrospective collection and analyses of cancer survivor data will be developed in a variety of projects. In collaboration with the EORTC QoL Group, special updates with medical, socio-economic and QoL questionnaires will be developed and validated.
- Second, adoption of prospective long term follow-up in current and new clinical trials is needed to allow systematic and comprehensive collection of data related late

side-effects. Translational research will be proposed to identify risk groups on a molecular basis and individual susceptibility.

The strategic plan of the EORTC cancer survivorship project includes:

1. Provide more insight into late adverse effects of modern cancer treatments by stimulating and centrally coordinating diverse research efforts in retrospective analysis of long-term survivors treated in EORTC conducted clinical randomised trials across different tumour-oriented groups.
2. Collect data directly from the patients in various European countries using the EORTC network. Enable surveys on topics such as fatigue, cognitive and reproductive function and other socio-economic and quality of life questions. Integration in prospectively upfront planned long-term follow-up in clinical trials and self-reporting tools will be proposed to improve comprehensive collection of data.
3. Develop QoL core questionnaires for cancer survivors addressing medical, socio-economic and quality of life issues in collaboration with the EORTC QOL Group in order to directly ask cancer survivors about their experiences.
4. Conduct case-control studies for analyses of late mortality and morbidity and their relation to dose and planning of different chemotherapy agents, targeted therapy, hormonal treatment and radiotherapy.
5. Develop prediction scores for risk of different physical and mental late adverse events based on age, sex, country, pre-existing co-morbidity and life-style factors.
6. Collate information on the current management of European cancer survivors and provide insight into barriers to good health care. Improve communication among different academic, national and international working groups performing research on survivor's issues and join forces by sharing data to complete registries and series of long-term data in different countries.
7. Create awareness and guidelines in post-cancer care. Identify barriers, because interaction is needed with primary health care professionals, patient advocates and also insurance, banking, health care industry representatives, politicians and economists, and, after having completed problem definitions and risk profiling follow-up, preventive care programs can then be improved and addressed in terms of cost-effectiveness.
8. Translational research on materials retrospectively retrieved or prospectively collected to identify risk groups and individual susceptibility for developing late effects.
9. Develop an open access website for researchers to communicate, improve data-collection and share patient information on prevention and health promotion, expert opinions, publications and harmonised guidelines. Sponsoring can be communicated and shared on the web-based platform, as can presentations of the outcomes of projects.

10. Through workshops and meetings, the Cancer Survivorship Task Force can convene leading experts and share knowledge to a broader medical community, as well as health care economists, policy makers and patient associations.

11. By being an international initiative, collaboration can take advantage of different national strengths, combine them, and compare morbidity, care plans, and preventive strategies and produce high quality and unique research which is difficult to accomplish in other parts of the world because of the lack of follow-up or treatment accessibility.

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## 5. 1st EORTC Cancer Survivorship Summit

The EORTC Board together with the EORTC Cancer Survivorship Task Force organised the 1st EORTC Cancer Survivorship Summit on 30-31 January 2014 in Brussels, Belgium. Experts in the field of late adverse effects research were brought together alongside policy makers, insurers and cancer survivors to discuss priorities for future research, guideline development and international networking. Meetings held prior to the summit enabled international experts and speakers to discuss and prepare the plenary sessions focused on late effects such as neurological effects, second malignancies, issues concerning fertility and sexuality, as well as cardiovascular complications and psychological and socio-economic impact of cancer treatment.

During the Summit the state of the art, but moreover future research directions, were shared with patient advocates, representatives of insurance companies, policy makers and the rest of the audience via key-note lectures and round table discussions. Speakers from North America and Europe outlined various topics concerning life after cancer and stressed the need for international collaboration and new economic vision. Measures such as survivorship care plans and behavioural and life-style interventions were discussed. Assessment of QoL, optimal methods for data collection and innovative informatics tools were addressed. The closing session illustrated the need for collaboration and organisation of survivorship research in Europe, for which the EORTC, as a multidisciplinary and pan-European organisation, can be of great value.

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## 6. Setting the stage for discussing cancer survivorship issues

The EORTC stresses the importance of survivorship issues and is playing an active role in fostering future research and developing guidelines. By uniting experts in the field and facilitating their interaction with patients, survivors, insurers, bankers and policy makers, future lines of research can be developed faster and be better adapted to the realities of life after cancer. In this new era of successful cancer treatments which have redefined cancer from a lethal to a curable or chronic disease, the EORTC has broadened its scope of responsibility beyond improvement of life

expectancy to include survivorship issues, and by the EORTC Cancer Survivorship Task Force, has combined forces to address survivorship issues prospectively and systematically and guide future research and health policies in Europe in this field.

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**Conflict of interest statement**

None declared.

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