

SPECIAL ARTICLE

ESMO expert consensus statements on the screening and management of financial toxicity in patients with cancer

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Background: Financial toxicity, defined as both the objective financial burden and subjective financial distress from a cancer diagnosis and its treatment, is a topic of interest in the assessment of the quality of life of patients with cancer and their families. Current evidence implicates financial toxicity in psychosocial, economic and other harms, leading to suboptimal cancer outcomes along the entire trajectory of diagnosis, treatment, supportive care, survivorship and palliation. This paper presents the results of a virtual consensus, based on the evidence base to date, on the screening and management of financial toxicity in patients with and beyond cancer organized by the European Society for Medical Oncology (ESMO) in 2022.

Methods: A Delphi panel of 19 experts from 11 countries was convened taking into account multidisciplinary, diversity in health system contexts and research relevance. The international panel of experts was divided into four working groups (WGs) to address questions relating to distinct thematic areas: patients with cancer at risk of financial toxicity; management of financial toxicity during the initial phase of treatment at the hospital/ambulatory settings; financial toxicity during the continuing phase and at end of life; and financial risk protection for survivors of cancer, and in cancer recurrence. After comprehensively reviewing the literature, statements were developed by the WGs and then presented to the entire panel for further discussion and amendment, and voting.

Results and discussion: A total of 25 evidence-informed consensus statements were developed, which answer 13 questions on financial toxicity. They cover evidence summaries, practice recommendations/guiding statements and policy recommendations relevant across health systems. These consensus statements aim to provide a more comprehensive understanding of financial toxicity and guide clinicians globally in mitigating its impact, emphasizing the importance of further research, best practices and guidelines.

Key words: cancer, financial toxicity, assessment tools, sociodemographic factors, health insurance coverage, survivorship

INTRODUCTION

Advances in cancer research and their translation to enhanced cancer control and improved cancer care have led to substantial improvements in survival for many cancers. In the United States, there are now 18.1 million cancer survivors, while in Europe there are over 12 million patients living with and beyond cancer.^{1,2} At the same time, the burden of cancer remains high, and according to estimates, there were about 4 million new cancer cases (excluding

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nonmelanoma skin cancer) within Europe in 2020, and over 18 million new cases worldwide.³ The specific physical, psychological, social, existential and economic challenges that are unique to those living with and beyond cancer must be addressed, in order to ensure that cancer survivors live long, healthy and productive lives. This includes 'financial toxicity', which is a common side-effect of cancer.

Current evidence implicates financial toxicity in psychosocial, economic and other harms and affects decisions that can lead to suboptimal cancer outcomes. It is relevant in the delivery of quality cancer care and the affordability of cancer services, antineoplastic medicines and palliation. Thus, it is a topic of interest in the delivery of quality cancer care, and salient to delivering population health impact as part of the universal health coverage (UHC) target of the United Nations.⁴ UHC encompasses the three dimensions of service availability, coverage and protection of patients from financial hardship, including as it is defined for financial toxicity at the patient level. No high-quality UHC for cancer care can be delivered unless all patients have affordable access to essential interventions for enhanced cancer control, by means of protection from financial distress and the risk of impoverishment. Tackling financial toxicity is instrumental to UHC and to deliver highest quality care.

For the purpose of the expert consensus statements, financial toxicity was defined as both the objective financial burden and subjective financial distress from a cancer diagnosis and its treatment.⁵⁻⁸ Financial toxicity is a negative patient- and family-level impact of the cost of cancer. It is the combined impact of out-of-pocket (OOP) costs, indirect costs, financial adjustments, depletion of assets and the changing financial circumstances of an individual and their household due to cancer, from its diagnosis to treatment, supportive and palliative care and throughout survivorship. Financial toxicity adversely affects the overall patient experience of health care, including access to and compliance with life-saving therapies. As such, financial toxicity is prognostic and deserves consideration at the same level of treatments, and not simply as a collateral issue.

This paper presents the results of a virtual consensus, based on the evidence base to date, on the screening and management of financial toxicity in patients with and beyond cancer organized by the European Society for Medical Oncology (ESMO) in 2022. Nineteen experts from 11 countries compiled a total of 25 consensus statements, which answer 13 questions on financial toxicity. These are presented below as follows. Work package (WP) 1 includes evidence summaries. WP2 and WP3 are practice recommendations/guiding statements. Finally, WP4 includes policy recommendations. Details about the methodology for the consensus as well as in-depth discussion of select statements are presented in [Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>.

WP1: PATIENTS WITH CANCER AT RISK OF FINANCIAL TOXICITY

QUESTION 1: What are the intrinsic factors associated with experiences of financial toxicity, and how do they interact with each other?

STATEMENT 1A: Irrespective of subjective or objective measurements of financial toxicity, intrinsic factors associated with financial toxicity include: being female, extreme age ranges, ethnic minorities, lower (household) annual income, loss of income during treatment and no or inadequate health insurance coverage (in countries where this is relevant). Although these intrinsic factors have been repeatedly reported to be significantly associated with financial toxicity, it is likely that many may interact with each other, and with other extrinsic factors. Level of evidence (LoE): II

DISCUSSION: It is important to acknowledge the complexities involved in examining and identifying risk factors of financial toxicity. For example, younger age, female gender, race and ethnic minorities and type of health insurance schemes not comprehensive for cancer care (in countries where this is relevant) are associated with less security in the employment, lower income level and lower financial reserves or coping mechanisms. To explore these complexities further, gender and age are discussed here. (Age as a risk factor is discussed further in [Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>. Socioeconomic factors are discussed in Question 3.)

In the United States, a secondary data analysis of a randomized trial examining whether the use of paper-based encounter decision aids supported women's decisions about breast cancer surgery found that younger (age <65 years), non-white women with breast cancer experience higher financial toxicity up to 12 months after surgery in women with breast cancer compared to their older and white counterparts.⁹ Female patients are often exposed to higher rates of catastrophic health expenditure.¹⁰ This may be due to the health-seeking behaviour of female patients, who may seek care more often and thus incur more health expenditure than males. Compared to male patients, female patients may generally have lower incomes and less employment security.^{11,12}

STATEMENT 1B: People of low socioeconomic status (SES) are more likely to experience financial toxicity when affected by cancer. SES is a measure of social standing, position or class of an individual or group and is usually assessed using occupational, economic and/or educational criteria of the individual, their household or the small area in which they live. Unemployment and reduced work participation during anticancer therapies are also related to financial toxicity. The extent to which employer or social welfare mitigation strategies (such as paid sick leave) may alleviate this has rarely been investigated. LoE: II

DISCUSSION: Systematic reviews, including studies from both high-income countries (HICs) and low- and middle-income countries (LMICs), have concluded that lower SES is associated with higher levels of financial toxicity.¹³⁻¹⁵ The financial impact of cancer among those of low SES can be significant. For example, in Iran, low SES was a risk factor for catastrophic health expenditure among people affected by cancer.¹⁶ In the United States, low SES was significantly associated with financial toxicity at 1 week, 12 weeks and 12 months after surgery in women with breast cancer.⁹ In this secondary data analysis of a randomized trial examining whether the use of paper-based encounter decision aids supported women's decisions about breast cancer surgery, SES was categorized by examining (i) insurance status, (ii) highest educational attainment and (iii) federal poverty level. (Employment is further discussed in [Supplementary Materials](https://doi.org/10.1016/j.esmoop.2024.102992), available at <https://doi.org/10.1016/j.esmoop.2024.102992>.)

STATEMENT 1C: Studies indicate that those who live in larger households, or with dependents, or in social isolation are more likely to experience financial toxicity. Similarly, living alone or being single may also be linked with financial toxicity, but evidence is less extensive. Family and friends may play a role in helping alleviate financial hardship due to cancer, but evidence on this is currently limited. **LoE: III**

DISCUSSION: Various aspects of household structure have been found to be associated with increased likelihood of experiencing financial toxicity in studies from a variety of settings. A meta-analysis of quantitative data from LMICs reported a 17% increased likelihood of objective financial toxicity among patients who live in a household comprising more than four people.¹⁴ A further review of data from India confirmed the finding.¹⁷ Living with dependents has also been found to be related to increased risk of financial toxicity.¹⁵ It seems likely that these findings are explained by pre-existing financial resources having to stretch further in larger households, so any cancer-related financial effects have a proportionately greater impact. At the other extreme, in a few studies in HICs, people with cancer who are single or live alone have been reported to be more often vulnerable to financial toxicity or face financial barriers.^{18,19} This could reflect more limited financial resources in single-person household. ([Supplementary Materials](https://doi.org/10.1016/j.esmoop.2024.102992), available at <https://doi.org/10.1016/j.esmoop.2024.102992>, discusses the potential role of household structure, family and friends in minimizing financial toxicity.)

QUESTION 2: What are the health- and disease-related factors associated with financial toxicity (and how do they interact with each other)?

STATEMENT 2A: There are only a few studies that examined cancer type as a risk factor for financial toxicity, and overall, there is no strong evidence that any single cancer type is a risk factor. There is also scarce evidence of cancer stage or advanced disease as a risk factor for financial toxicity. **LoE: III**

DISCUSSION: A 2019 systematic review of 74 studies conducted in the United States and representing 598 751

patients found no consistent evidence that any single cancer site, histology or stage were risk factors for financial toxicity.²⁰ Of all studies reviewed, 30 reported clinical risk factors, and of those, only 8 reported some comparison across types of cancer and stage. Patients with thyroid, ovarian and lung cancer were found to be more likely to report that cancer caused financial problems than survivors of other cancers.²¹ Lung and colon cancer patients were more likely to have OOP costs greater than US\$5000 than breast cancer patients.²² Patients with lung cancer and colorectal cancer have been found to have the highest probability of bankruptcy 5 years after diagnosis, while breast and prostate cancer had the lowest, although not negligible overall.²³ Other studies found higher financial burden²⁴ or more productivity losses²⁵ in patients affected with cancers to be associated with poorer prognosis (e.g. brain, stomach, liver, lung, oesophagus and pancreatic cancer).

A review of 25 studies including 14 from the United States, 2 Europe, 2 Canada, 2 Australia and 5 Asia, representing 271 732 cancer survivors, did not find strong (if any) evidence that cancer type or stage of disease were determinants of financial toxicity.²⁶ Another review of qualitative and quantitative studies from countries with UHC (excluding the United States) that included 30 quantitative studies found that only 8 examined cancer types and stage as risk factors.^{27,28} Most studies found no significant association of financial toxicity with cancer type among patients with ongoing disease or survivors.²⁸⁻³¹ The lack of evidence on cancer type is despite there being strong associations between risk of various cancers and lower SES as discussed in Question 1. Further research is needed to address this important gap in the evidence base. (Advanced stages of several individual cancer types are discussed further in [Supplementary Materials](https://doi.org/10.1016/j.esmoop.2024.102992), available at <https://doi.org/10.1016/j.esmoop.2024.102992>.)

STATEMENT 2B: Systemic anticancer therapies, including chemotherapy and targeted therapies, can represent as risk factors for financial toxicity, while radiation therapy and surgery are not consistently shown as risk factors. Exceptions may exist for some cancer types, and for some populations for whom the travel burden associated with these treatments may be considerable. **LoE: III**

DISCUSSION: A review of 74 United States studies, representing 598 751 patients, found that having chemotherapy was consistently reported as a risk factor, while radiation and oncology surgery were not consistently reported as risk factors for financial toxicity.²⁷ Having chemotherapy was associated with higher self-reported percentage of income spent on OOP costs,³² OOP costs being $\geq 20\%$ of income,³³ higher short-term disability costs,³⁴ higher likelihood of unemployment³⁵ and financial decline,³⁶ and worse financial impact score,²⁴ financial burden^{37,38} and financial problems in survivorship.³⁹ Only a few reported radiation as a risk factor for OOP costs being $\geq 20\%$ of income,³³ and financial problems in survivorship.⁴⁰ A few studies also reported duration or intensity of treatment as risk factors for financial toxicity, for example, more

intense end-of-life care,⁴¹ having a higher number of hospitalizations,⁴² transplantation⁴³ and longer treatment.⁴⁴

A meta-analysis of 31 studies conducted in LMICs reached similar conclusions about chemotherapy being a risk factor for financial toxicity, but not radiation therapy or surgery.⁴⁵ In particular, chemotherapy was associated with catastrophic health expenditure defined as OOP costs >10% of income in a study from Ethiopia⁴⁶ and 30% of income in another study from Malaysia.⁴⁷ In Australia, however, receiving surgery and radiation was found to be associated with higher travel cost burden in Australian patients.⁴⁸ (The evidence on other cancer treatments including radical prostatectomy as a risk factor for financial toxicity is discussed in [Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>.)

STATEMENT 2C: A limited number of studies have examined the association between symptoms or symptom burden and financial toxicity. Most of these studies found significant associations with psychological symptoms but less commonly with physical symptoms. However, there is lack of clarity with respect to the recall period for financial toxicity and symptoms. There is also less evidence to confirm that symptoms are risk factors for financial toxicity or outcomes of financial toxicity. **LoE: III**

DISCUSSION: In a review of articles published between 2000 and 2018, including nine studies (six from the United States) that involved >11 000 patients, a weak-to-moderate association of measures of financial distress and strain with depression, anxiety, psychological distress, stress and fear of recurrence was found.⁷ Of the studies that measured financial distress or strain specifically related to cancer, higher financial stress (defined as the impact of the cancer diagnosis on household ability to make ends meet) and strain (feeling about financial situation since cancer diagnosis) were found to be associated with higher depression, anxiety and overall distress.⁴⁹ Several indicators of financial difficulties due to cancer were found to be associated with depression (using up savings due to cancer) and stress (using up savings and difficulty paying bills due to cancer).⁵⁰ Having financial distress due to cancer has been independently associated with depression (depressed mood) and worry about recurrence.²⁴ Moreover, those reporting a higher number of financial problems due to cancer were more likely to experience overall psychological distress. Having cancer-related financial problems has also been found to be associated with worry about recurrence in long-term survivors.²¹ (Physical symptoms including symptom burden and financial toxicity are discussed in [Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>.)

STATEMENT 2D: Financial toxicity may be more likely to occur close to the time of diagnosis when patients are undergoing primary treatment. Studies that reported objective measures of financial toxicity, such as OOP costs, found them to be higher at the time closer to diagnosis or treatment and as patients approach end of life. However, the evidence is not consistent, and it is unclear how prevalent financial toxicity is in long-term survivors. **LoE: III**

DISCUSSION: A few studies found that a greater financial burden is experienced closer to diagnosis, with the burden declining after treatment completion.¹⁹ Studies found higher OOP costs in the first 12 months from diagnosis or from end of treatment,^{42,51} higher probability of borrowing/going into debt within 12 months from the last treatment⁵² and higher financial burden or financial problems in survivors who were within the first few years from diagnosis, compared with longer-term survivors. Three studies reported higher financial toxicity closer to the time of the cancer diagnosis.²⁶ It is worth noting, however, that in these studies^{11,24,40,53} survivors were asked if they experienced financial burden or problems ever, and not at the time of the survey. Therefore, it is unclear if longer-term survivors are less likely to experience financial burden or problems, or if they are less likely to recall.

Based on a sample of patients with multiple myeloma in the United States surveyed on average 3 years from the end of treatment, survivors reported spending 36% of income in OOP costs in the first year of treatment and 28% in the year closest to the survey time.⁴⁴ Another study found that survivors with more recent treatment had higher psychological hardship (i.e. ever worry about medical bills) than those further away from treatment.¹¹ In addition to these two United States studies, a study from Canada reported that a recent prostate cancer diagnosis was associated with higher OOP and time costs compared with a more distant one.⁵⁴ Six studies have reported results concerning time since diagnosis as a risk factor for financial toxicity.²⁰ Of these, two studies of patients with advanced cancer⁵⁵ and head and neck cancer⁵⁶ did not find time since diagnosis, or since start of treatment, to be a significant risk factor for distress or difficulties caused by cost of cancer care. As time from diagnosis or time since the end of the hospital stay increased, the likelihood of reporting financial difficulties related to disease or its treatment has been found to decrease.¹⁴ However, the significance of these findings was not reported. (Financial toxicity in longer-term survivors is discussed further in [Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>.)

QUESTION 3: What are the extrinsic factors associated that cause financial toxicity and how do they interact with each other?

STATEMENT 3A: Generally, the higher the OOP costs of the patient are, the higher is the magnitude of financial toxicity, unless there is financial risk protection and other mitigation and coping strategies offered by the publicly funded health system or private health insurance and social security, or charitable programmes and non-governmental organizations' assistance are available. Irrespective of OOP payments, patients with cancer experience financial toxicity given the impact of disease on the economic situation of their household. **LoE: III**

DISCUSSION: The diagnosis of, treatment for and survival following cancer impose an economic burden on patients with cancer and their household.^{5,6} They bear OOP

expenditures, which are the direct medical and non-medical costs of treatment borne by the patient's household that are not reimbursed by health insurance.⁵⁷ Direct medical costs are costs incurred for medical products and services ranging from chemotherapy, targeted agents to immunotherapy, and from surgery to rehabilitation as well as supportive care. Direct non-medical costs, meanwhile, refer to costs for non-medical services associated with inpatient and outpatient care, such as transportation and accommodation costs as well as auxiliary care at home.⁵⁸

How much direct and indirect costs contribute to financial toxicity may depend on where the patient is along the cancer care continuum and the extent of insurance coverage. For example, a prospective cohort study using a longitudinal design in Germany found that at baseline 48.8% of OOP costs were connected to hospital stays dropping to 15.4% after 3 months.⁵⁹ In comparison, transportation accounted for 38% and 62.8% at baseline and after 3 months. Moreover, direct non-medical expenditures have been found to be the main source of financial toxicity for patients with comprehensive health insurance coverage both private and public.¹³ (An overview of OOP costs in HICs as well as LMICs is available in [Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>.)

STATEMENT 3B: Under comprehensive cancer care within UHC, financial barriers to access and direct payments to obtain health care are probably modest. However, in numerous countries, certain cancer medications (often new and very expensive) often lack public funding, leading to financial challenges unless covered by private insurance or other complementary schemas. Patients with cancer in publicly funded health systems may still face direct non-medical costs as well as indirect costs, some of which may be mitigated by coverage of benefits due to sickness, therapy and unemployment payment. **LoE: IV**

DISCUSSION: Publicly funded health systems vary in terms of the adequacy of financial risk protection they provide to their respective beneficiaries or populations given the scope of benefits and proportion of costs they cover.⁶⁰ In many of the health systems of Western Europe, for example, cancer care is delivered free at the point of service⁶¹ and, OOP costs for non-prescription medication (for symptom management) and some medical equipment are modest.⁶² At the same time, social welfare benefits such as sick paid leave and unemployment payment are available, which has been associated with reduced financial toxicity.⁶³ Nonetheless, the patient with cancer still faces direct non-medical costs such as transportation and accommodation for treatment at a regional/comprehensive cancer facility, which may add up and be sizable especially where OOP costs are not capped.⁶⁴ A review of financial toxicity in publicly funded health care systems found the prevalence of financial toxicity ranging between 7% at 12 months for patients with colorectal cancer in Australia and 39% in Ireland.⁶⁴ (OOP costs in other publicly funded health systems are discussed in [Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>.)

STATEMENT 3C: Cancer patients who live in rural or remote areas, farther away from specialist treatment centres, experience financial toxicity more often and to a greater extent. Those patients who have to travel long distances to specialized cancer treatment centres given the spatial clustering of health care facilities faced increased costs and higher risks of financial toxicity. **LoE: III**

DISCUSSION: Several systematic reviews have concluded that, compared with those who live in urban/metropolitan areas, cancer patients and survivors who live in remote/rural and underserved areas more often experience financial toxicity.^{13,17,27,64} Furthermore, a range of studies report that those who live farther away from treatment centres are more likely, than those who live closer, to spend a significant proportion of their household income on cancer-related health care expenditure or experience catastrophic health expenditure.⁶⁵⁻⁷⁰ These associations have been found in LMICs and HICs as well as in countries with predominantly private- and predominantly publicly funded health care systems. In Australian studies, patients who live in remote or rural areas are more likely than those living elsewhere to report travel, accommodation and food associated with undergoing specialist care as their greatest expense.⁷¹

The centralization of and distribution of specialized services using the hub-and-spoke design, wherein services are distributed between an anchor tertiary facility (hub) and secondary facilities (spokes), may likewise expose the patient to financial toxicity. Although treatment is received faster at the spoke when it is closer to the patient's residence,⁷² distance from the oncological centre (hub) can be exacerbated by poor transportation infrastructure and lack of motorized transport, which further increases the time required for travel ([Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>, discusses further the link between long distance travel for cancer treatment and financial toxicity). More research is needed about the impact of the hub-and-spoke model on patient outcomes and financial toxicity.

WP2: MANAGEMENT OF FINANCIAL TOXICITY DURING THE INITIAL PHASE OF TREATMENT AT THE HOSPITAL/ AMBULATORY SETTINGS

QUESTION 4: When and how should cancer patients undergo a financial toxicity assessment?

STATEMENT 4: Health care providers should make a preliminary assessment of financial impact of disease and treatment on the patient and their household at diagnosis or before the start of treatment. As the data on long-term survivors are lacking, whether there is a need for these assessments to continue over time needs further research. A reasonable approach, which requires further validation, might be based on a sequential strategy, starting with the use of a simple set of questions from instruments developed to evaluate quality of life (QoL) as a screening tool, and then using a specific, longer validated questionnaire for

further comprehension of the financial problems by the initial single question. **LoE: V**

DISCUSSION: As we evaluate the physical, psychosocial symptoms, the sense of isolation and the spiritual pain, the distress related to financial problems should always be evaluated in routine clinical practice starting with a screening tool. However, many questions are still open on what approach how frequently the evaluation of financial toxicity has to be carried out. Instruments developed for broader evaluation of QoL may be used as simple screening tools to trigger further investigation of the financial problems and distress and to understand whether an initial estimation of financial toxicity may be predictive of patients' outcome. If screening is positive, it should be followed by an in-depth assessment of financial distress faced by the patient to identify which domain is impacted and lead to appropriate, tailored intervention.

For simple screening, it is worth citing the European Organisation for Research and Treatment of Cancer (EORTC) core questionnaire (QLQ C-30) (version 3) that includes one single item (number 28) 'in the past week has your physical condition or medical treatment caused you financial difficulties?'. Possible answers through a Likert-like scale: 'not at all, a little, quite a bit, very much' explore whether financial difficulties due to cancer and its treatment arose.⁷³ Similarly, the Edmonton Symptom Assessment System (ESAS)-Total Care (TC) where a single item exploring financial hardship has been produced and validated in the Italian version 'have you had financial worries related to your illness in the past month?'. Possible answers are given through a numerical rating scale from 0 to 10.⁷⁴ (Supplementary Materials, available at <https://doi.org/10.1016/j.esmooop.2024.102992>, discusses further the advantages and disadvantages of using instruments developed for broader evaluation of QoL in financial toxicity screening.)

Following the sequential strategy, specific, longer validated instruments to measure financial toxicity could be employed (Table 1). The first and more diffuse of these instruments is the COmprehensive Score for financial Toxicity (COST) instrument, which is validated in many languages with 12 items and a scoring system ranging from 0 to 44.^{42,75} Item 12 is not scored and was intended as a summary item and designed to be used as a standalone screening question [D Cella (personal communication)].

The Patient-Reported Outcome for Fighting Financial Toxicity (PROFFIT) instrument, meanwhile, includes 16 items, of which 7 estimate the degree of financial toxicity producing a global score ranging from 0 to 100, and 9 represent single items exploring possible determinants of financial toxicity.^{76,77} Both COST and PROFFIT consider patients with various types of cancer as their target population. Another instrument, the Subjective Financial Distress Questionnaire (SFDQ) including 14 items, has been recently produced in India and validated in a cohort of patients with head and neck cancer undergoing radiotherapy.⁷⁸ All these instruments were built as patient-reported outcome measures that allow direct reporting by the patients, not mediated by health professionals' interpretations.⁷⁹

(Further discussion on financial toxicity assessment can be found in [Supplementary Materials](https://doi.org/10.1016/j.esmooop.2024.102992), available at <https://doi.org/10.1016/j.esmooop.2024.102992>.)

QUESTION 5: In the diagnostic phase of cancer, how might the economic impact of examinations be reduced for patients?

STATEMENT 5A: A formal, temporary cost exemption of the diagnostic pathway when a cancer is suspected should be offered to all patients and access to services should be free of charge. **LoE: V**

STATEMENT 5B: Clinicians are advised to 'choose wisely' and avoid low-value diagnostics and therapeutics, to reduce costs for patients and/or payers: examinations that are not essential to the treatment plan should be discouraged. Navigation into services should be offered by relevant health care professionals. **LoE: V**

DISCUSSION: The initial phase of cancer treatment typically consists of costly diagnostic evaluations. The diagnostic pathway, when the presence of tumour is suspected, may involve complex imaging studies, laboratory tests, specialist consultations and histological and biomolecular examination of the tissue specimen. In this phase, the patient is usually not covered by the cost exemptions that apply with diagnosis. The multiple examinations that are requested to reach diagnosis and staging should be affordable and be obtained in a timely fashion. The lack of coverage can delay the decision to seek medical attention and receive the examinations indicated.^{4,80} Late referral and late diagnosis are considered strictly related to poor clinical outcomes.^{39,81}

Receipt of care across several subspecialty teams can exacerbate the complex logistical challenges required for multidisciplinary cancer treatment.⁸² Patients face uncertainty about where to seek information and support services.⁸⁰ Inclusion of diagnostics as part of the assured benefit packages for cancer care would be beneficial. (Supplementary Materials, available at <https://doi.org/10.1016/j.esmooop.2024.102992>, highlights the importance of an adequate diagnostic process.)

QUESTION 6: How could the economic impact for patients with high disease burden, low performance status and/or severe comorbidities be reduced?

STATEMENT 6: Appropriate and timely early access to palliative care should be offered to all patients, especially to those with advanced cancer, and for whom oncological therapies can produce substantial toxicity with rather modest to negligible clinical benefits. Accordingly, low-value treatments should be discouraged, especially when resulting in additional OOP or other indirect costs for patients.

LoE: V

DISCUSSION: Use of health care and, therefore, costs increase steadily in the last year of patients' life: spending in this phase of the disease trajectory accounts for a disproportionate share of total health care spending. Patients with low performance status, intercurrent acute events and severe comorbidities are typically those at higher risk of death

Table 1. Selection of instruments specifically developed to measure financial toxicity of cancer

| Abbreviation of the instrument | Author, year, reference | Country of origin | Original language | Translations | Target population | No. of items |
|--------------------------------|--|-------------------|-------------------|---|---|--------------|
| COST | de Souza et al., 2014 ⁷⁵ de Souza et al., 2017 ⁷² | USA | English | 14 available (Chinese—simplified, Chinese—traditional, English, French, German, Greek, Hindi, Indonesian, Italian, Korean, Malay, Marathi, Portuguese, Spanish) | Patients with cancer (various types) | 12 |
| PROFFIT | Riva et al., 2021 ^{76,77} | Italy | Italian | English (ongoing linguistic validation and cross-cultural adaptation) | Patients with cancer (various types) | 16 |
| SFDQ | Dar et al., 2022 ⁷⁸ | India | Indian | English | Patients undergoing radiotherapy for head and neck cancer | 14 |

COST, COmprehensive Score for financial Toxicity; PROFFIT, Patient-Reported Outcome for Fighting Financial Toxicity; SFDQ, Subjective Financial Distress Questionnaire.

and have been shown to be also more likely to face higher OOP spending and to be at higher risk of financial difficulties.⁵⁵ Treatment spending in combination with inability to regain employment and income resulting from progressive disease and debility may contribute to the association between advanced disease and greater financial burden.

Many novel treatments, especially new drugs, extend life only marginally and have low success rates, yet are very expensive. Early access to palliative care for patients with advanced cancer tends to lead to better health outcomes and a more cost-effective use of resources, reducing levels of overtreatment, and optimizing health spending, including at the patient level.⁸³

QUESTION 7: Should every patient experiencing or at risk of suffering financial toxicity have right for financial counselling during his/her stay at the hospital/ambulatory setting?

STATEMENT 7: Financial toxicity is an extra burden for a patient, possibly affecting therapeutic outcomes and causing distress for the patient and their families. Thus, it is both ethically and medically reasonable to offer financial counselling to a patient suffering from any form of financial toxicity following screening for financial toxicity. Counselling might produce benefit. Counselling should be given by a dedicated professional (like a social worker) who can assess the patient's economic situation, knows thoroughly the social security system of the jurisdiction and is aware of modalities to help the patient in his/her economic situation.

LoE: III

DISCUSSION: There is solid evidence that financial burden is associated with negative physical and psychological effects and can result in excess mortality.²³ Accordingly, assessment of cancer patient's economic situation and financial counselling based on that assessment should be an integral part of the treatment procedure.⁸⁴ The reasons are both medical and ethical. Since the financial burden may affect survival rate in several ways and be potentially detrimental to QoL, it is necessary to help a patient to find relief for their economic situation and for the distress it causes. A patient may concentrate solely on coping with cancer and could not properly manage their possibly disastrous and complicated economic situation.⁸⁵ Some of the strategies to cope with financial burden may

compromise patient health and well-being.⁸⁶ The other reason is ethical. Justice is one of the fundamental principles of biomedical ethics.⁸⁷ The patient's economic situation should not prevent them from getting the best available treatment (see [Supplementary Materials](#), available at <https://doi.org/10.1016/j.esmooop.2024.102992>, for further discussion).

WP3: FINANCIAL TOXICITY DURING THE CONTINUING PHASE AND AT END OF LIFE

QUESTION 8: Are new treatments (e.g. targeted therapies, immunotherapy, antibody–drug conjugates, etc.) increasing financial toxicity?

STATEMENT 8: The very high cost of new cancer medicines contributes to financial toxicity when insurance coverage is absent or partial, and when co-payments are required. In publicly funded health systems, this occurs frequently when expensive new agents are prescribed for off-label indications, which may not be covered except in certain cases. Treatment toxicities of new treatments, some of which can be severe or persistent, can adversely impact on acute and long-term care needs and function, and may generate additional financial burdens. **LoE: II**

DISCUSSION: The United States list price of new anti-cancer therapies, especially targeted therapies and immunotherapy, now exceeds US\$100 000/year.^{88,89} Cost prices in other countries vary and are usually lower than the United States price, but are still very expensive.^{90,91} Additional costs derive from cost of medicine administration and costs associated with the prevention and management of adverse effects of treatment. In addition, genomic testing to identify patients eligible for specific therapies is now routine. As of 2020, ~27% of patients had conditions that were potentially amenable to genome-informed therapies, half of which were molecularly targeted therapies.⁹² Beyond therapies with licensed indications, commercial genomic tests routinely identify actionable mutations and present data supporting off-label therapeutic approaches.

Financial toxicity is often exacerbated when expensive new therapies are recommended for off-label use where the likelihood of insurance coverage (of any kind) is diminished.⁹³ Many new treatments are associated with

acute and long-term toxicities which in a minority of patients can be severe or persistent.⁹⁴ These toxicities can adversely impact on acute and long-term care needs and function, consequently adding to financial burden and toxicity.^{95,96} (The role of health financing and individual financial exposure with new treatments is discussed in [Supplementary Materials](https://doi.org/10.1016/j.esmoop.2024.102992), available at <https://doi.org/10.1016/j.esmoop.2024.102992>.)

QUESTION 9: What is the contribution of cancer drug prices to direct costs?

STATEMENT 9: The cost of cancer medicines accounts for almost one-third of the direct medical costs of cancer in Europe, under an UHC schema. For individual patients and their families, the relative contribution of drug costs to their total burden of medical and non-medical costs is a function of the extent of health care coverage and social welfare benefits and varies considerably depending on individual country policies. **LoE: II**

DISCUSSION: According to the most recent published data, total expenditures for cancer care in Europe in 2018 was €103 billion, of which medicines accounted for €32 billion.⁹⁷ Spending on informal care was €26 billion. At the patient level, costs include medical costs (comprising cost of medications, medical investigations and procedures and professional carers) and non-medical costs [that include lost income, transportation costs and costs of (social unskilled) carers]. The relative contributions of these two cost elements are variable depending on the (national) health insurance coverage of medical costs and the extent of welfare benefits and supports afforded to patients in different countries.^{58,98,99}

According to a report by the Organisation of Economic Cooperation and Development (OECD) on access to cancer medicines, while patients access oncology medicines for self-administration free of charge in 13 countries, they are subject to a fixed co-payment with cap (in Australia and Ireland) or without cap (in France, Hungary and Italy).¹⁰⁰ Elsewhere, patients are subject to co-insurance with cap (in Denmark, Germany, Sweden and the USA, for example) or co-insurance without cap (in the case of Latvia). Even when welfare support is available, they are often difficult to identify and access, limited in scope and delayed in payment.^{101,102} Patient advocacy services are often very helpful to assist patients in accessing welfare benefits.¹⁰³

QUESTION 10: How can palliative health care teams address patient and caregiver distress and uncertainty from financial toxicity at the end of life?

STATEMENT 10: Because of the high prevalence of financial distress among patients with far advanced cancer, in addition to present physical and psychological distress, it needs to be assessed in all cases. When financial distress is identified, management approaches should include financial counseling, assistance with social welfare entitlements and mobilization of other strategies to cope with distress. **LoE: III**

DISCUSSION: As previously described, OOP expenses increase during the end-of-life phase of cancer care, and the demands of care from family members commonly add to further reduction in income. Financial assessment includes an evaluation of available resources, costs of care and family income. Material financial burden needs to be distinguished from anxiety about anticipated future material financial burden.^{5,6,104} Screening tools such as the COST may need to be adapted for examining financial toxicity in patients at end of life or bereaved caregivers.⁴²

When financial distress is identified, expenses should be evaluated and categorized as essential or discretionary. Discretionary expenses should be carefully evaluated to help identify wasteful expenses that can either be deleted or reduced.

A clear need for periodic assessment of financial challenges, including an audit of social welfare benefits and entitlements, at multiple time points during the cancer continuum has previously been highlighted.¹⁰⁵ In many instances, social welfare benefits are not optimized because of lack of knowledge regarding available entitlements, or difficulties and delays in application. In cases of need, patients and their families may benefit from advice regarding other sources of charitable support elsewhere. This evaluation can be carried out by a social worker and may benefit from the assistance of a financial planner if this service is available. (Strategies to address financial distress are discussed in [Supplementary Materials](https://doi.org/10.1016/j.esmoop.2024.102992), available at <https://doi.org/10.1016/j.esmoop.2024.102992>.)

WP4: FINANCIAL RISK PROTECTION FOR SURVIVORS OF CANCER AND DURING CANCER RECURRENCE

QUESTION 11: Do we need continued long-term assessment for financial challenges during survivorship?

STATEMENT 11: We must prioritize the provision of person-centred care with a focus on assessing the socioeconomic challenges that may arise in the aftermath of cancer. This involves understanding the impact of these challenges and devising practical solutions. A risk-based approach necessitates tailored assessments, with frequency determined by factors such as the cancer stage, the risk of cancer recurrence and the potential for late complications, including secondary cancers. **LoE: III**

DISCUSSION: A number of pan-European initiatives have recognized that the challenges and needs of cancer survivors must be addressed as a matter of urgency.¹⁰⁶ The European Code of Cancer Practice¹⁰⁷ co-created by cancer patients, cancer survivors and cancer health professionals sets out a series of 10 rights that cancer patients and those living beyond cancer should expect from their health services, in order to receive best quality care. Rights 7-10 of the Code call out the requirement to address issues that are specific to those living with and beyond cancer—Quality of Life (Right 7), Integrated Supportive and Palliative Care (Right 8), Survivorship and Rehabilitation (Right 9) and Reintegration (Right 10). Embedded within Right 10

(Reintegration) is the right to protection from financial challenges, including financial toxicity for cancer survivors.¹⁰⁸

In addition to the financial challenges that those living with and beyond cancer and their families and carers face, we also highlight the potential for financial discrimination and how best this can be mitigated with reference to The Right to be Forgotten (RTBF),¹⁰⁹ a cancer survivor-focused initiative that has gained significant momentum over the past number of years. Numerous studies have described the continued financial challenges (including economic, psychological, societal and behavioural challenges) experienced by cancer survivors.^{21,25,110-114} (Details about the long-term assessment for financial challenges during survivorship and RTBF are discussed in [Supplementary Materials](#), available at <https://doi.org/10.1016/j.esmoop.2024.102992>.)

The 'Right to be Forgotten' grants cancer survivors the right to live without discrimination based on past cancer diagnoses post-deemed 'cured'. In financial contexts, the RTBF advocates for overlooking oncological history by insurers and banks after a defined post-treatment period, aligning with survivors' current health status. Jurisdiction-specific laws vary; in some countries (France, the Netherlands, Portugal, Romania, Spain), survivors need not disclose their cancer history after 5-10 years after treatment. In Belgium, disclosure is mandatory but cannot be used to deny services. Unlike the European Union (EU) General Data Protection Regulation (GDPR), the RTBF in cancer emphasizes disregarding rather than deleting data. Balancing the RTBF with accurate medical records is crucial for health care providers and researchers relying on comprehensive histories.¹¹⁵

QUESTION 12: How should/can we build survivorship care delivery models to incorporate strategies for financial risk protection?

STATEMENT 12A: Institutions and society should embed the 'Right to be Forgotten' as a legal framework within all European countries to avoid financial discrimination for those living beyond cancer. European health care providers should be aware of the social and legal implications of the financial discrimination that long-term cancer survivors can be exposed to, despite being cured of their disease. **LoE: III**

STATEMENT 12B: Institutions and health authorities need to promote models incorporating long-term follow-up strategies such as leveraging telemedicine for follow-up care, careful use of surveillance testing, remote monitoring systems and emphasis on rehabilitative measures. This would help provide financial risk protection to cancer survivors to improve their clinical outcomes including health-related QoL, thereby enhancing overall quality of care. It is mandatory to incorporate mitigation strategies for financial hardship such as online resources for coverage and reimbursement information, educational opportunities and assistance programmes into cancer survivorship plans. **LoE: III**

STATEMENT 12C: Institutions need to include caregivers as important stakeholder in the survivorship care delivery

model, ensuring optimal psychosocial support, including for financial issues, can help decrease the familial financial burden. **LoE: III**

DISCUSSION: Survivorship care models and creation of survivorship care plans have been proposed to enable a risk-based approach to meet the unique needs of survivors, while efficiently applying health care resources. Care delivery models for survivorship and/or incorporation of relevant information into survivorship care plans need to be improved to help provide risk-stratified, easily accessible and affordable care to those living beyond cancer.¹¹⁶ Unfortunately, there is a critical lack of information on long-term outcomes, including survival and costs, associated with these survivorship care models. ([Supplementary Materials](#), available at <https://doi.org/10.1016/j.esmoop.2024.102992>, briefly discusses England's National Cancer Survivorship Initiative model for reference.)

In the United States, very often there is suboptimal reimbursement for survivorship-related services, which not only decreases quality of care but also may lead to a substantial cost burden for patients and their families.¹¹⁷ In the EU, particular attention has been dedicated to addressing financial discrimination for long-term cancer survivors. It is unacceptable that long-term cancer survivors can be discriminated against financially, in terms of access to loans, mortgages and insurance due to a previous cancer diagnosis.

In September, the EU revised the Consumer Credits Directive prohibiting the use of health information, including cancer, for creditworthiness after a maximum of 15 years. At the ESMO Congress in Madrid, member states were urged to adopt a 5-year period when implementing this directive.¹¹⁸ ESMO is actively involved in developing a non-binding EU Code of Conduct. This initiative aims to unite stakeholders, establish a shared vision for the financial sector and health representatives and provide clear guidance for fair access to financial services for cancer survivors.

QUESTION 13: Can we deliver targeted financial and employment support strategies?

STATEMENT 13A: Governments need to develop and implement proactive return-to-work plans for cancer rehabilitation needs and related sickness absence benefits. We need to also ensure employment accommodations, such as the ability to work remotely, flexible work schedules and accommodations at workplace to help address specific disabilities in order to help the patient and caregiver to continue performing productively in their employment, in a safe and non-discriminating environment. **LoE: III**

STATEMENT 13B: It is mandatory to promote studies to better understand the costs incurred by survivors, including time and indirect costs as well as the prevalence, effectiveness and cost-effectiveness of workplace accommodations on health and retention of employees who are cancer survivors. **LoE: IV**

STATEMENT 13C: A harmonized normative framework should be set up at a global level with a goal to avoid

Table 2. Overview of working packages and consensus statements

| Questions | Statements |
|---|---|
| WP1: Patients with cancer at risk of financial toxicity | |
| 1 What are the intrinsic factors associated with experiences of financial toxicity, and how do they interact with each other? | <p>A: Irrespective of subjective or objective measurements of financial toxicity, intrinsic factors associated with financial toxicity include: being female, extreme age ranges, ethnic minorities, lower (household) annual income, loss of income during treatment and no or inadequate health insurance coverage (in countries where this is relevant). Although these intrinsic factors have been repeatedly reported to be significantly associated with financial toxicity, it is likely that many may interact with each other, and with other extrinsic factors. LoE: III</p> <p>B: People of low socioeconomic status (SES) are more likely to experience financial toxicity when affected by cancer. SES is a measure of social standing, position or class of an individual or group and is usually assessed using occupational, economic and/or educational criteria of the individual, their household or the small area in which they live. Unemployment and reduced work participation during anticancer therapies are also related to financial toxicity. The extent to which employer or social welfare mitigation strategies (such as paid sick leave) may alleviate this has rarely been investigated. LoE: III</p> <p>C: Studies indicate that those who live in larger households, or with dependents, or in social isolation are more likely to experience financial toxicity. Similarly, living alone or being single may also be linked with financial toxicity, but the evidence is less extensive. Family and friends may play a role in helping alleviate financial hardship due to cancer, but evidence on this is currently limited. LoE: III</p> |
| 2 What are the health and disease-related factors associated with financial toxicity (and how do they interact with each other)? | <p>A: There are only a few comparative studies that examined cancer type as a risk factor for financial toxicity, and overall, there is no strong evidence that any single cancer type is a risk factor. There is also scarce evidence of cancer stage or advanced disease as a risk factor for financial toxicity. LoE: III</p> <p>B: Systemic anticancer therapies, including chemotherapy and targeted therapies, can represent as risk factors for financial toxicity, while radiation therapy and surgery are not consistently shown as risk factors. Exceptions may exist for some cancer types, and for some populations for whom the travel burden associated with these treatments may be considerable. LoE: III</p> <p>C: A limited number of studies have examined the association between symptoms or symptom burden and financial toxicity. Most of these studies found significant associations with psychological symptoms but less commonly with physical symptoms. However, there is lack of clarity with respect to the recall period for financial toxicity and symptoms. There is also less evidence to confirm that symptoms are risk factors for financial toxicity or outcomes of financial toxicity. LoE: III</p> <p>D: Financial toxicity may be more likely to occur close to the time of diagnosis when patients are undergoing primary treatment. Studies that reported objective measures of financial toxicity, such as out-of-pocket (OOP) costs, found them to be higher at the time closer to diagnosis or treatment and as patients approach end of life. However, the evidence is not consistent, and it is unclear how prevalent financial toxicity is in long-term survivors. LoE: III</p> |
| 3 What are the extrinsic factors associated that cause financial toxicity and how do they interact with each other? | <p>A: Generally, the higher the OOP costs of the patient, the higher is the magnitude of financial toxicity, unless there is financial risk protection and other mitigation and copying strategies offered by the publicly funded health system or private health insurance and social security, or charitable programmes and non-governmental organizations' assistance programmes are available. Irrespective of OOP payments, patients with cancer experience financial toxicity given the impact of disease on the economic situation of their household. LoE: III</p> <p>B: Under comprehensive cancer care within universal health coverage (UHC), financial barriers to access and direct payments to obtain health care are probably modest. However, in numerous countries, certain cancer medications (often new and very expensive) often lack public funding, leading to financial challenges unless covered by private insurance or other complementary schemas. Patients with cancer in publicly funded health systems may still face direct non-medical costs as well as indirect costs, some of which may be mitigated by coverage of benefits due to sickness, therapy and unemployment payment. LoE: IV</p> <p>C: Cancer patients who live in rural or remote areas, further away from specialist cancer treatment centres experience financial toxicity more often and to a greater extent. Those patients who have to travel long distances to specialist treatment centres given the spatial clustering of health care facilities faced increased costs and higher risks of financial toxicity. LoE: III</p> |
| WP2: Management of financial toxicity during the initial phase of treatment at the hospital/ambulatory settings | |
| 4 When and how should cancer patients undergo a financial toxicity assessment? | <p>Health care providers should make a preliminary assessment of the financial impact of disease and treatment on patient and his/her household at the diagnosis or before the start of treatment. As the data on long-term survivors are lacking, whether there is a need for these assessments to continue over time needs further research. A reasonable approach, which requires further validation, might be based on a sequential strategy, starting with the use of a simple set of questions from instruments developed to evaluate quality of life (QoL) as a screening tool, and then using a specific, longer validated questionnaire for further comprehension of the financial problems by the initial single question. LoE: V</p> |
| 5 In the diagnostic phase of cancer, how might the economic impact of examinations be reduced for patients? | <p>A: A formal, temporary cost exemption of the diagnostic pathway when a cancer is suspected should be offered to all patients and access to services should be free of charge. LoE: V</p> <p>B: Clinicians are advised to 'choose wisely' and avoid low-value interventions, including diagnostics and therapeutics, to reduce costs for patients and/or payers: examinations that are not essential to the treatment plan should be discouraged. Navigation into services should be offered by relevant health care professionals. LoE: V</p> |
| 6 How could the economic impact for patients with high disease burden, low performance status and/or severe comorbidities be reduced? | <p>Expensive treatments with a negligible impact on survival or QoL should be avoided. Appropriate and timely early access to palliative care should be offered to all patients, especially to those with advanced cancer, and for whom oncological therapies can produce substantial toxicity with rather modest benefits. LoE: V</p> |

Continued

| Table 2. Continued | | |
|--|---|--|
| Questions | Statements | |
| 7 | Should every patient experiencing or at risk of suffering financial toxicity have right for financial counselling during his/her stay at the hospital/ambulatory setting? | Financial toxicity is an extra burden for a patient, possibly affecting therapeutic outcomes and causing distress for the patient and their families. Thus, it is both ethically and medically reasonable to offer financial counselling to a patient suffering from any form of financial toxicity following screening for financial toxicity. Counselling might produce benefit. Counselling should be given by a dedicated professional (like a social worker) who can assess the patient's economic situation, knows thoroughly the social security system of the jurisdiction and is aware of modalities to help the patient in his/her economic situation. LoE: III |
| WP3: Financial toxicity during the continuing phase and at end of life | | |
| 8 | Are new treatments (targeted therapies, immunotherapy, antibody–drug conjugates, etc.) increasing financial toxicity? | The very high cost of new cancer medicines contributes to financial toxicity when insurance coverage is absent or partial, and when co-payments are required. In publicly funded health systems covering for cancer care, this occurs more frequently when expensive new agents are prescribed for off-label indications. Treatment toxicities of new treatments, some of which can be severe or persistent, can adversely impact on acute and long-term care needs and function, and may generate additional financial burdens. LoE: II |
| 9 | What is the contribution of cancer drug's prices to direct costs? | The cost of cancer medicines accounts for almost one-third of the direct medical costs of cancer in Europe, under an UHC schema. For individual patients and their families, the relative contribution of drug costs to their total burden of medical and non-medical costs is a function of the extent of health care coverage and social welfare benefits and varies considerably depending on individual country policies. LoE: II |
| 10 | How can palliative health care teams address patient and caregiver distress and uncertainty from financial toxicity at the end of life? | Because of the high prevalence of financial distress among patients with far advanced cancer, in addition to present physical and psychological distress, it needs to be assessed in all cases. When financial distress is identified, management approaches should include financial counselling, assistance with social welfare entitlements and mobilization of other strategies to cope with distress. LoE: III |
| WP4: Financial risk protection for survivors of cancer and during cancer recurrence | | |
| 11 | Do we need continued long-term assessment for financial challenges during survivorship? | We must prioritize the provision of person-centred care with a focus on assessing the socioeconomic challenges that may arise in the aftermath of cancer. This involves understanding the impact of these challenges and devising practical solutions. A risk-based approach necessitates tailored assessments, with frequency determined by factors such as the cancer stage, the risk of cancer recurrence and the potential for late complications, including secondary cancers. LoE: III |
| 12 | How should/can we build survivorship care delivery models to incorporate strategies for financial risk protection? | A: Institutions and society should embed the 'Right to be Forgotten' as a legal framework within all European countries to avoid financial discrimination for those living beyond cancer. European health care providers should be aware of the social and legal implications of the financial discrimination that long-term cancer survivors can be exposed to, despite being cured of their disease. LoE: III B: Institutions and health authorities need to promote models incorporating long-term follow-up strategies such as leveraging telemedicine for follow-up care, careful use of surveillance testing, remote monitoring systems and emphasis on rehabilitative measures. This would help provide financial risk protection to cancer survivors to improve their clinical outcomes including health-related QoL, thereby enhancing overall quality of care. It is mandatory to incorporate mitigation strategies for financial hardship such as online resources for coverage and reimbursement information, educational opportunities and assistance programmes into cancer survivorship plans. LoE: III C: Institutions need to include caregivers as important stakeholder in the survivorship care delivery model, ensuring optimal psychosocial support, including for financial issues, can help decrease the familial financial burden. LoE: III |
| 13 | Can we deliver targeted financial and employment support strategies? | A: Governments need to develop and implement proactive return-to-work plans for cancer rehabilitation needs and related sickness absence benefits. We need to also ensure employment accommodations, such as the ability to work remotely, flexible work schedules and accommodations at workplace to help address specific disabilities in order to help the patient and caregiver to continue performing productively in their employment. LoE: III B: It is mandatory to promote studies to better understand the costs incurred by survivors, including time and indirect costs as well as the prevalence, effectiveness and cost-effectiveness of workplace accommodations on health and retention of employees who are cancer survivors. LoE: IV C: A harmonized normative framework should be set up at a global level with a goal to avoid discrimination, ensure equitable access to employment opportunities and financial services and protect the rights of cancer survivors. LoE: IV |

WP, work package.

discrimination, ensure equitable access to employment opportunities and financial services and protect the rights of cancer survivors. **LoE: IV**

DISCUSSION: Cancer survivorship may be associated with loss of employment and labour-market earnings. Most studies suggest that it is difficult for a patient's economic situation to return to their pre-diagnosis levels.¹¹⁹ Productivity and disability losses for the patient as well as

caregivers add to the financial hardship that results from medical OOP costs for cancer survivors.^{117,120} Patient access to paid leave can help decrease financial hardship, thereby leading to improved health, better QoL and reduced stress.⁶³ Employment interventions or workplace flexibility options and multidisciplinary interventions to enhance return to work, in conjunction with psychological and physical interventions, can help mitigate financial hardship by

providing financial and psychological protection to those living beyond cancer.¹²¹ These approaches will require policy-level changes at the level of employers and possibly a need for adjustment in payment and reimbursement structures.¹²² Additionally, inequities within the financial service landscape for cancer survivors have been highlighted such as job discrimination or reduced access to travel or life insurance, bank loans and adoption services which can further exacerbate financial toxicity.^{109,123,124}

DISCUSSION

To the authors' knowledge, these are the first consensus statements on the risk factors for financial toxicity, management of financial toxicity in initial treatment settings, during survivorship and at end of life as well as financial protection for cancer survivors and recurrence (see [Table 2](#) for an overview of all questionnaires and statements). In the United States, work has been carried out to elaborate on financial navigation, led by social workers or nurse navigators, to deal with financial toxicity.¹²⁵ While financial navigation has applications in other health systems, it is most relevant to the United States setting. These consensus statements apply to a wider range of health systems offering medical oncologists and other clinicians and health professionals a more comprehensive understanding of the problem as well as approaches to alleviate this burden. In addition to further research on the topic to address the potential limited transferability of the United States studies cited in this paper, best practices and guidelines are crucial to build on this effort.

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