## Table S1: Detailed search strategies for all databases/search engine

### a) EMBASE (via Ovid)

malignant neoplasms/ or carcinoma.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
 (cancer\* or carcinoma\* or malignan\* or neoplasm\* or tumo?r\*).ti,ab.
 (financial\* adj9 (hardship\* or stress\* or burden\* or distress\* or strain\* or toxicity\* or catastrophic\* or consequence\* or impact\*)).ti,ab. 4. physical examination/ or palpation/
 (economic\* adj5 (hardship\* or burden\* or strain\* or consequence\* or impact\*)).ti,ab. 6. "clinical breast examination\*".ti,ab.
 1 or 2
 3 or 4
 5 and 6
 exp United Kingdom/
 7 and 8
 limit 9 to english language

#### b) Google Scholar

"financial" AND "cancer" AND ("united kingdom" OR "england" OR "scotland" OR "wales" OR "northern ireland")

#### c) MEDLINE (via Ovid)

1. neoplasms/ or carcinoma.mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

2. (cancer\* or carcinoma\* or malignan\* or neoplasm\* or tumo?r\*).ti,ab.

3. (financial\* adj9 (hardship\* or stress\* or burden\* or distress\* or strain\* or toxicity\* or catastrophic\* or consequence\* or impact\*)).ti,ab.

4. (economic\* adj5 (hardship\* or burden\* or strain\* or consequence\* or impact\*)).ti,ab.

5. 1 or 2

6. 3 or 4

7. 5 and 6

8. exp United Kingdom/

9.7 and 8

10. limit 9 to english language

### d) Scopus

((TITLE-ABS-KEY (financial\* W/9 (hardship\* OR stress\* OR burden\* OR distress\* OR strain\* OR toxicity\* OR catastrophic\* OR consequence\* OR impact\*)) OR TITLE-ABS-KEY (economic\* W/5 (hardship\* OR burden\* OR strain\* OR consequence\* OR impact\*))) AND TITLE-ABS-KEY (cancer\* OR carcinoma\* OR malignan\* OR neoplasm\* OR tumo\*r\*) AND TITLE-ABS-KEY ("united kingdom") AND LANGUAGE (english))

### e) Web of Science

#1	cancer* or carcinoma* or malignan* or neoplasm* or tumo\$r* (Topic)
#2	TS=((financial* near/9 (hardship* or stress* or burden* or distress* or strain* or toxicity* or
	catastrophic* or consequence* or impact*)))
#3	TS=((economic* near/5 (hardship* or burden* or strain* or consequence* or impact*)))
#4	#2 OR #3
#5	#4 AND #1
#6	TS=(United Kingdom)
#7	#5 AND #6
#8	(#5 AND #6) AND LA=(English)

Study	Inclusion criteria	Exclusion criteria
<b>Study</b> <b>Population</b>	<ul> <li>Inclusion criteria</li> <li>ONLY those living in the United Kingdom (including England, Scotland, Wales, and Northern Ireland)</li> <li>Cancer patients (those who are under treatment, including patients with initial treatment after diagnosis and people with on-going treatment* for advanced cancer)</li> <li>Cancer survivors (those who finished initial**/hospital treatment). Other terms: cancerfree survivors, disease-free survivors</li> <li>Family members of cancer patients/survivors (whether giving care to patients/survivors or not). Other terms: carer, caregiver</li> </ul>	<ul> <li>Exclusion criteria</li> <li>Non-human subjects</li> <li>Cancer patients/survivors or carers reside in any countries rather than the UK</li> </ul>
	NOTE * On-going treatment is different from follow-up treatment. The latter is for cancer-free survivors and normally includes hormone therapy and/or periodic check-up (last 5-10 years) ** Initial/hospital treatment: Treatment provided after diagnosis and before discharge (cancer-free). It often lasts up to 9-12 months, depends on type of cancer and stage of cancer at diagnosis	
Exposure (the issue)	<ul> <li>Financial toxicity (refers to both the objective financial burden and subjective financial distress) experienced by the population of interest***</li> <li>Other terms: financial hardship/stress/burden/distress/strain/catastrophic, economic burden/consequence/impact/strain</li> <li>NOTE *** Patient perspective: the review only focuses on the issue (financial toxicity) from the population of interest's perspective. Studies report the patient-level data of the issue will be included</li> </ul>	<ul> <li>Studies report the economic burden of the disease, financial impact of the treatment, drug etc. from the society or payer perspective</li> <li>Studies report the cost of treatment, drug without discuss the experience of patients/survivors bearing that cost</li> <li>Cost-effectiveness analysis of treatment/drug</li> </ul>

Table S2: Detailed inclusion and exclusion criteria

Study	Inclusion criteria	Exclusion criteria	
Outcomes	Primary main outcome	Outcomes not listed	
	Financial well-being		
	• Health-related quality of life		
	• Additional mental health conditions such as		
	depression and anxiety		
	Secondary main outcomes		
	Benefit/welfare benefit		
	Counselling service		
	• Any other support with purpose to ease FT		
Study	• United Kingdom (including England, Scotland,	• Any other countries	
context	Wales, and Northern Ireland)	• Any other countries	
Publication	Published at anytime	None (no time	
type	• English language only	restriction)	
	• Any types, including grey literature	Non-English articles	
		• Publications that do not	
		have an available full-	
		text version or are	
		duplications of other	
		publications	

Appendix 1: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #		
TITLE					
Title	1	Identify the report as a scoping review.	Page 1		
ABSTRACT					
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Page 2		
INTRODUCTION					
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Page 3		
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Page 4		
METHODS					
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Review protocol exists but was not registered		
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Page 4, 5		
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Page 4		
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Table S1, supplementary information		
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Page 5		
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Page 5		
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made	Page 5		

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Page 5, 6
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Page 6 Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Page 6, 7 Table 1
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 2, 3
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Page 7, 8
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Page 9, 10
Limitations	20	Discuss the limitations of the scoping review process.	Page 11
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Page 10
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Page 24

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

<sup>†</sup> A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

<sup>‡</sup> The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

## Appendix 2: Data charting template (used in Covidence)

# **1. GENERAL INFORMATION**

### Study ID

Lead author - Surname only (e.g., Amir)

### Year of publication

#### Title

*Title of paper / abstract / report that data are extracted from* 

### Type of publication

- Peer-reviewed article
- Grey literature (e.g., report)

#### **Geographic coverage**

If UK-wide, tick all options. If study is a review/sys review that have more locations, note in the 'other' field

- England
- □ Scotland
- □ Wales
- □ Northern Ireland
- □ Other

#### Authors' affiliation

Note where the authors work (and their position if available). e.g., university, hospital

# 2. CHARACTERISTICS OF INCLUDED STUDIES

## a) Methods

# **Objectives/research questions**

#### Study design

- Randomised controlled trial
- Cohort study
- $^{\circ}$  Cross sectional study
- Systematic review
- Qualitative research
- Narrative review
- Scoping review
- Mixed methods
- Others

### b) Participants (skip in case of rev/sys rev)

#### **Studied population**

- Patients
- □ Survivors
- Carers/family members
- □ Other

### Type of cancer (that patients/survivors have/had)

### Total number of participants

#### Participants' characteristics

(e.g., age, socio-economic groups) This is not the data from table 1 but the inclusion criteria for participants

### Method of recruitment of participants

- Phone (random dial)
- $\square$  Mail (postal study)
- □ Online
- □ In-person recruitment (at hospital, support centre, etc.)
- □ Other

#### Setting of the recruitment (Specify)

*E.g.*, hospital, cancer registry, cancer forum, support centre etc.

### c) Included studies (specifically for rev/sys rev)

## How many studies from UK were included in the rev/sys rev?

Number only

#### Which studies were included?

Author, year, title. Note is the original study was in this scoping review or not (e.g., Amir 2012 xyz, IN/NOT IN).

### d) Exposure (Financial Toxicity)

#### Used terms

*The terms were used to describe the problem (e.g., financial hardship, stress)* 

#### **Exposure description**

*Give a detailed description of the studied problems here* 

### Tools used to measure FT

If validated tool, note the name (e.g., COST, EUQOL). Otherwise, record the questions & answer options

## Subjective financial distress sub-category

*What aspect(s) did the included study look at?* 

- □ Material
- □ Psychosocial
- Behavioral

#### e) Outcomes

#### What are the outcomes?

- Financial well-being/situation
- □ Health-related quality of life
- $\square$  Additional mental health conditions such as depression and anxiety
- Employment (work/retirement)
- □ Benefit/welfare
- $\square$  Any other support with purpose to ease FT
- □ Others

### **3. RESULTS**

#### **Key findings**

Summary the key findings of the study

#### **Future research/recommendations**

This is normally mentioned in the limitation, end of discusison section

### **Conclusions of the research**

#### **Final thought**

Anything you think that is important but was not captured by this form

### Appendix 3: List of excluded reviews and justification for the exclusions

This list includes 30 articles that were excluded after full-text review with justification for the exclusion of each. The list does not contain articles excluded due to duplicate or during the title and abstract screening.

#### Ineligible population: One review was excluded

 Cook NS, Landskroner K, Shah B, Walda S, Weiss O, Pallapotu V. Identification of Patient Needs and Preferences in Pigmented Villonodular Synovitis (PVNS) Using a Qualitative Online Bulletin Board Study. Advances in therapy. 2020;37(6):2813-28.

#### Ineligible exposure (no data on FT): Ten reviews were excluded

- 2. Agarwal A, Livingstone A, Karikios DJ, Stockler MR, Beale PJ, Morton RL. Physician-patient communication of costs and financial burden of cancer and its treatment: a systematic review of clinical guidelines. BMC cancer. 2021;21(1):1-10.
- 3. Bordonaro R, Piazza D, Sergi C, Cordio S, Tomaselli S, Gebbia V. Out-of-pocket costs in gastrointestinal cancer patients: Lack of a perfectly framed problem contributing to financial toxicity. Critical Reviews in Oncology/Hematology. 2021;167:103501.
- 4. Carreira H, Williams R, Dempsey H, Stanway S, Smeeth L, Bhaskaran K. Quality of life and mental health in breast cancer survivors compared with non-cancer controls: a study of patient-reported outcomes in the United Kingdom. Journal of Cancer Survivorship. 2021;15(4):564-75.
- 5. Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. Bmj. 2004;328(7454):1470.
- Colomer-Lahiguera S, Ribi K, Dunnack HJ, Cooley ME, Hammer MJ, Miaskowski C, et al. Experiences of people affected by cancer during the outbreak of the COVID-19 pandemic: an exploratory qualitative analysis of public online forums. Supportive Care in Cancer. 2021;29(9):4979-85.
- Coumoundouros C, Ould Brahim L, Lambert SD, McCusker J. The direct and indirect financial costs of informal cancer care: a scoping review. Health & Social Care in the Community. 2019;27(5):e622-e36.
- Herring B, Lewis-Smith H, Paraskeva N, Harcourt D. Exploring the experiences and psychosocial support needs of informal carers of men with breast cancer: a qualitative study. Supportive Care in Cancer. 2022;30(8):6669-76.
- Longo CJ, Fitch MI, Loree JM, Carlson LE, Turner D, Cheung WY, et al. Patient and family financial burden associated with cancer treatment in Canada: a national study. Supportive Care in Cancer. 2021;29(6):3377-86.
- Marti J, Hall PS, Hamilton P, Hulme CT, Jones H, Velikova G, et al. The economic burden of cancer in the UK: a study of survivors treated with curative intent. Psycho-Oncology. 2016;25(1):77-83.

 Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. BMJ. 2002;325(7370):929.

Ineligible outcomes: No review was excluded

Wrong setting: Five reviews were excluded

- 12. Chauhan J, Aasaithambi S, Marquez-Rodas I, Formisano L, Papa S, Meyer N, et al. Understanding the Lived Experiences of Patients with Melanoma: Real-World Evidence Generated through a European Social Media Listening Analysis. JMIR Cancer. 2022;8(2):e35930.
- 13. Huntington S. Cancer-related financial toxicity: beyond the realm of drug pricing and out-of-pocket costs. Annals of Oncology. 2016;27(12):2143-5.
- 14. Jassem J, Penrod JR, Goren A, Gilloteau I. Caring for relatives with lung cancer in Europe: an evaluation of caregivers' experience. Quality of Life Research. 2015;24(12):2843-52.
- 15. Lorgelly PK, Neri M. Survivorship burden for individuals, households and society: Estimates and methodology. Journal of Cancer Policy. 2018;15:113-7.
- 16. Tufman A, Redmond K, Giannopoulou A, Gonzalez-McQuire S, Varriale P, Geltenbort-Rost L, et al. Patient perception of burden of disease and treatment preferences in non-small cell lung cancer: Results from a European survey. Lung Cancer. 2022;168:59-66.

### No full-text available: Fourteen reviews were excluded

- Brearley SG, Craven O, Wilson B, Brunton L, Molassiotis A. Gastro-intestinal cancer patients: How they perceive and cope with disease and treatment-related symptoms over a 12-month period. European Journal of Cancer, Supplement. 2009;7(2-3):234.
- 18. Choon-Quinones M, Zelei T, Barnett M, Keown P, Durie B, Kalo Z, et al. Exploring the true cost of multiple myeloma. American Journal of Hematology. 2020;95(SUPPL 1):S8-S9.
- 19. Corney R, Swinglehurst J, Brett-Smith D. The impact of breast cancer on couple and family relationships of young women. Psycho-Oncology. 2011;20(SUPPL. 2):93-4.
- 20. Cox T, MacLennan S, Scott S. Cancer survivorship and working life. Psycho-Oncology. 2014;23(SUPPL. 3):355-6.
- 21. Higginson IJ, Gomes B, Calanzani N, Gao W, Bausewein C, Daveson BA, et al. Factors associated with the priorities for treatment and care if faced with advanced cancer across seven european countries. Palliative Medicine. 2012;26(4):410.
- 22. Holmes L, Addington-Hall J, Grande G, Payne S, Seymour J, Hanratty B. Transitions between care settings in the last year of life for people living with heart failure, stroke and lung cancer: A qualitative study. Palliative Medicine. 2010;24(4 SUPPL. 1):S190.
- 23. Hyman J, Lucas E. Community cancer programs network-bringing cancer care closer to home. Asia-Pacific Journal of Clinical Oncology. 2014;10(SUPPL. 9):27.
- 24. Mowbray M, Fraser S, Hancock E, Scorgie C. Melanoma patient support-what does your patient want? Melanoma Research. 2016;26(Supplement 1):e59.

- 25. Nelson D, Pascal J, Kane R, McGonagle I, Kenny A, Dickson-Swift V, et al. The psychosocial support needs of people affected by cancer: A comparative study of patient and carer experience in a rural setting. Psycho-Oncology. 2017;26(Supplement 3):80.
- 26. Palmer SK, Collie J. Transplant experience for post-transplant patients who travel for follow-up care. Bone Marrow Transplantation. 2011;46(SUPPL. 1):S448.
- 27. Reaney M, Eek D, Ascoytia C, Scrabis L, Halling K, Black P, et al. Similarities and differences between symptoms and impacts of ovarian cancer as reported by the patients and their caregivers. European Journal of Cancer. 2015;51(SUPPL. 3):S248.
- Scanlon K, Tompkins C, Ream E, Armes J, Harding S. Challenging the concept of self management: Ethnic minority women's experiences of early breast cancer survivorship. Psycho-Oncology. 2013;22(SUPPL. 3):41.
- Tanguay JS, Long J, Knoyle DM, Gibson A. Maximising financial aid for patients in a thoracic oncology clinic in merthyr tydfil. The effect of a clinic-based Welfare Rights Officer. Lung Cancer. 2013;79(SUPPL. 1):S42.
- 30. Younger E, Husson O, Desar IME, Young R, Leahy MG, Oosten A, et al. Health-related quality of life in patients with advanced soft tissue sarcomas treated with chemotherapy: The HOLISTIC study. Annals of Oncology. 2019;30(Supplement 5):v709.