Clinical Oncology Society of Australia

FINANCIAL TOXICITY IN CANCER CARE

A COSA Think Tank

26 May 2023

CONTENTS

SUMMARY

Overarching issues

The COSA Financial Toxicity in Cancer Care Think Tank highlighted a range of issues that contribute to the issue of financial toxicity in cancer care. These issues include but are not limited to:

- the increasing cost of delivering healthcare, which in turn is influenced by:
  - increasing complexity and duration of cancer care
  - workforce shortages and issues of demand exceeding supply for healthcare services and products
- the fragmented nature of the health system, which makes navigation difficult and results in delays, inefficiencies and variability
- variability in costs and impact of cost for different population groups (e.g. people in rural and regional areas, priority population groups, people living with metastatic disease, people with rare cancers, people living with other chronic health problems or co-morbidities, people with long-term treatment and care needs, including care related to treatment toxicity and side-effects)
- limited time and resources available to discuss / identify the financial impact of cancer care for patients and carers during active treatment and as part of follow-up / survivorship care
- difficulties in accurately predicting the financial impact of cancer over time (direct and indirect costs) because of the complexity and individual nature of cancer care
- lack of coordination between health, financial, welfare and legal systems, which means services are not accessed even where they are available.

Key issues the Financial Toxicity Roadmap needs to address

The Think Tank identified a number of issues related to financial toxicity that would benefit from national action, including:

- reducing out-of-pocket costs of healthcare (across the cancer care continuum from diagnosis through to survivorship / long-term care / palliation), including costs in both the public and private systems
- improving transparency about costs of cancer care through clear, easy-to-understand information to support a) informed choice and b) help-seeking
- increasing and improving the consistency of financial and psychosocial information and support for patients and carers at risk of and experiencing financial distress, and increasing awareness of available information and support
- understanding and developing strategies to help patients and carers navigate the challenge of work / employment during and after diagnosis and treatment for cancer (across all types of work and work contracts)
- clarifying and advocating for improvements in a range of policy issues related to issues listed above (healthcare, finance and insurance, workplace, government income support / Centrelink eligibility).

Priorities for action

Think Tank participants identified a range of priorities for action to be considered through a national Financial Toxicity Roadmap, including:

- normalising the conversation about financial health, risks of financial toxicity and the impact of cancer on finances, noting that:
  - the issue extends beyond the cost of treatment and is impacted by factors such as waiting times, travel requirements and duration of treatment

    - the conversation extends beyond a discussion about the cost of a specific intervention or treatment
- collective pan-cancer / cross-sector advocacy to increase awareness and support calls for action
- provision of consistent and transparent information to enable informed decision making, with clear signposting to financial support and services:
    - development of a centralised information and support hub to support informed choice and decision making about the costs of cancer care with signposts to financial support and services (a starting point is to map available services and information)
    - strategies for early detection of financial toxicity and early action / intervention to address financial toxicity where it occurs, including consideration of when, where and by whom assessment and discussion of risk and impact should occur
- provision of equitable and accessible financial support (including income support for people who are unable to continue working) and services for people at risk of or experiencing financial distress
- workplace reform to enable employees and employers to support people with cancer and their carers (including parents of children with cancer), with a key priority being improvements in job security
- improvements and better use of innovative delivery and payment models to address financial toxicity to: a) reduce costs; and b) lessen the burden of large upfront payments
- better use of data to understand the financial impact of cancer and more interventional / policy research to inform strategies to lessen the financial impact of cancer
- development of a stakeholder map to show the range of people and organisations to be engaged and involved in actions to improve financial toxicity.

Potential actions

Ideas for actions to address priority issues are summarised in the table overleaf. These ideas will form the basis of the first version of the *Financial Toxicity in Cancer Care Roadmap* (Version 1.0).

Commitments

All Think Tank participants provided an individual commitment to progress ideas emerging from the Roadmap and expressed an interest for continued involvement in discussions and activities through:

- continuing to support the Financial Toxicity Working Group and Roadmap development
- sharing insights and Roadmap outputs
- using research to better understand and develop strategies to address financial toxicity
- increasing use of available data to better understand financial toxicity
- increasing use of available interventions to better serve patient / client concerns around financial toxicity
- involvement in advocacy and awareness raising (Roadmap specific and building in financial toxicity to organisation-level advocacy).

Next steps

The COSA Financial Toxicity Working Group will review the proposed Roadmap activities and identify opportunities for COSA leadership. It is acknowledged that solutions and future efforts will require a whole-of-sector approach.

Summary of potential actions to address financial toxicity in cancer care

Collective advocacy (cross-sector / pan-cancer)

- Reinforce / add weight to national healthcare and cancer care reform agendas (e.g. MBS/PBS and primary care reform, telehealth, value-based healthcare)
- Highlight issues of financial toxicity in cancer care as part of state-based / service-level cancer plans
- Specific calls for action to progress Roadmap actions (e.g. changes in payment / reimbursement models)
- **Early activities:**
  - joint position statement / white paper with reinforcement of calls for action in individual organisation advocacy activity
  - identify organisations and leaders who want to work together to drive change (including parliamentary and industry 'champions')

Health service delivery*	Information and support	Financial services	Workplace reform†	Research

• Innovative payment models e.g. upfront gap payment only (similar to HiCAPS), retrospective reimbursement for new interventions
• Innovative healthcare delivery models to reduce costs e.g. telehealth, chemo at home, nurse practitioners
• Early / proactive identification of financial distress:
  ○ tools (e.g. distress thermometer)
  ○ health professional education
Supported by referral to information and support
	• Centralised pan-cancer information and support hub with clear links to available financial services and supports
	Will require:
	  ○ *mapping available services*
	  ○ *keeping information up to date*
	  ○ *promotion to health services and health professionals*
	• Financial service navigation support (peer support, financial navigators, digital support)
		• Strengthen awareness and understanding within cancer / health systems of available financial services and supports
		• Simplify mechanisms for accessing financial support provided by e.g. financial institutions, Disability Support Pension, life insurance, health insurance, superannuation
			• Universal job security and right to return
			• Return to work support for employees (patients and carers) and employers
			• Investigate employment law and options (mutual leave allocations / government underwriting)
				• Longitudinal research and data analysis needed to understand the long-term impact of cancer on financial health
				• Health economic modelling to be built into new models of cancer care to demonstrate value
				• Ongoing research to identify efficiencies and redundancies that will reduce overall cost (e.g. de-escalation trials, annual medication reviews, reductions in treatment toxicity)
				• Research that designs and evaluates the impact of various interventions

Cross-cutting activities

Strengthen overall awareness of financial toxicity at all levels: community, patients, health services, government, financial services

Reduce complexity and increase transparency

Enable access to information and services for everyone affected by cancer

*Includes delivery of acute and long-term / survivorship care; †Need to consider all types of work, contracts and workplaces including self-employed

INTRODUCTION

Financial toxicity in cancer care describes the impact of changed financial circumstances due to a cancer diagnosis and its care. Financial toxicity is emerging as a significant issue for people affected by cancer but is not universally well recognised or understood. National and international research is seeking to understand the issue of financial toxicity, but little has been done to date to develop and implement solutions.

The Clinical Oncology Society of Australia (COSA) held a session on financial toxicity at its Annual Scientific Meeting in 2020. This session catalysed the establishment of a Financial Toxicity Working Group (a sub-group of the COSA Survivorship Group). Working Group members represent a broad range of expertise from around Australia, including consumers (see Appendix I for membership).

The Financial Toxicity Working Group has started by defining and understanding the problem, including:

- defining financial toxicity through the development of the COSA Statement on Financial Toxicity
- scoping current activities and services through a national survey of health professionals in Australia.

The Working Group is now focusing its efforts on seeking solutions and developing innovations to address financial toxicity associated with cancer and its treatment.

COSA Think Tank on Financial Toxicity in Cancer Care

On 26 May 2023, COSA convened a National Think Tank on Financial Toxicity in Cancer Care. The one-day event brought together around 40 cancer consumers, health professionals, researchers, policy makers, and representatives from private health organisations, not-for-profit organisations, finance and industry (see Appendix II). Funding for the Think Tank was provided through an educational grant from MSD Australia.

The interactive Think Tank agenda (see Appendix III) provided an opportunity to:

- reflect on key issues underpinning financial toxicity in cancer care
- identify innovative strategies and solutions to address these issues
- highlight opportunities to leverage existing initiatives and act collectively to drive change
- agree on short-term priorities and longer-term ambitions
- generate cross-sector commitment from participants to effect change.

Pre-workshop survey

Ahead of the Think Tank, a short survey was emailed to Financial Toxicity Working Group members, Think Tank invitees, members of COSA Council, and a select group of international experts (a total of 95 people in Australia and 30 from overseas). The survey asked four open-ended questions:

1. What big issues should we be talking about / tackling if we are serious about addressing cancer-related financial toxicity in Australia?
2. Big issues need big ideas. What 'outside the box' ideas do you have that could help drive a new way of thinking about how to address cancer-related financial toxicity?
3. Are you involved in or planning activities to address financial toxicity that others could learn from? (If so, please provide details)
4. Please nominate one priority you would like to see the Financial Toxicity Roadmap address. *Priorities can be in the areas of policy, service delivery, research, education or advocacy.*

A total of 37 survey responses were received (see Appendix IV for a breakdown of respondents). Responses were analysed thematically, and themes presented as a basis for discussions at the Think Tank.

FINANCIAL TOXICITY IN CANCER CARE: CONTEXT

The Think Tank opened with a series of short presentations to set the context for discussions.

Enduring work and careers for those living with cancer

Sue Woodall, cancer survivorship advocate and Founder of Live Work Cancer

The opening presentation from Sue Woodall, Founder of *Live Work Cancer*, provided a lived experience perspective on cancer-related financial toxicity.

At the time of her diagnosis with breast cancer, Sue was at the pinnacle of her career and was 18 months into an Executive role with a supportive team and manager. She was the sole income earner in her household. Sue was unprepared for the impact of intensive treatment and its side effects on her ability to work, and her contract was mutually terminated 15 months after diagnosis.

Sue experienced a >30% reduction in her income over 2-years and a > 40% decrease in disposable income due to out-of-pocket costs.

Sue reflected on the fact that her experience is not unique. She also recognises that, prior to her diagnosis, she would not have had the knowledge or empathy to provide the support needed to a colleague or employee with cancer. Sue's experience has driven her to seek and understand evidence of the impact of cancer on work and earnings, and to establish a program to help people navigate cancer while working, studying, or planning re-entry into work. This program supports not only the employee but also employers who are seeking to support colleagues affected by cancer.

Sue presented data highlighting the significant impact of cancer on:

- individual income (due to reduced hours, time off work, ceasing work permanently)
- entitlements (annual leave, sick leave)
- superannuation contributions (as a result of lost work / income)
- superannuation level (due to super draw-down, essentially postponing financial toxicity).

Sue reflected on the inadequacy of support currently available. As an example, she noted that income protection insurance is good but not accessible to all, has a waiting period, only covers a portion of salary and paid in arrears.

In closing, Sue highlighted the opportunity and need to do more for people with cancer: both supporting the person affected and the employer.

COSA Statement on Financial Toxicity

Professor Raymond Chan, Chair, Caring Futures Institute Director and Dean (Research), Flinders University
Chair, COSA Financial Toxicity Working Group

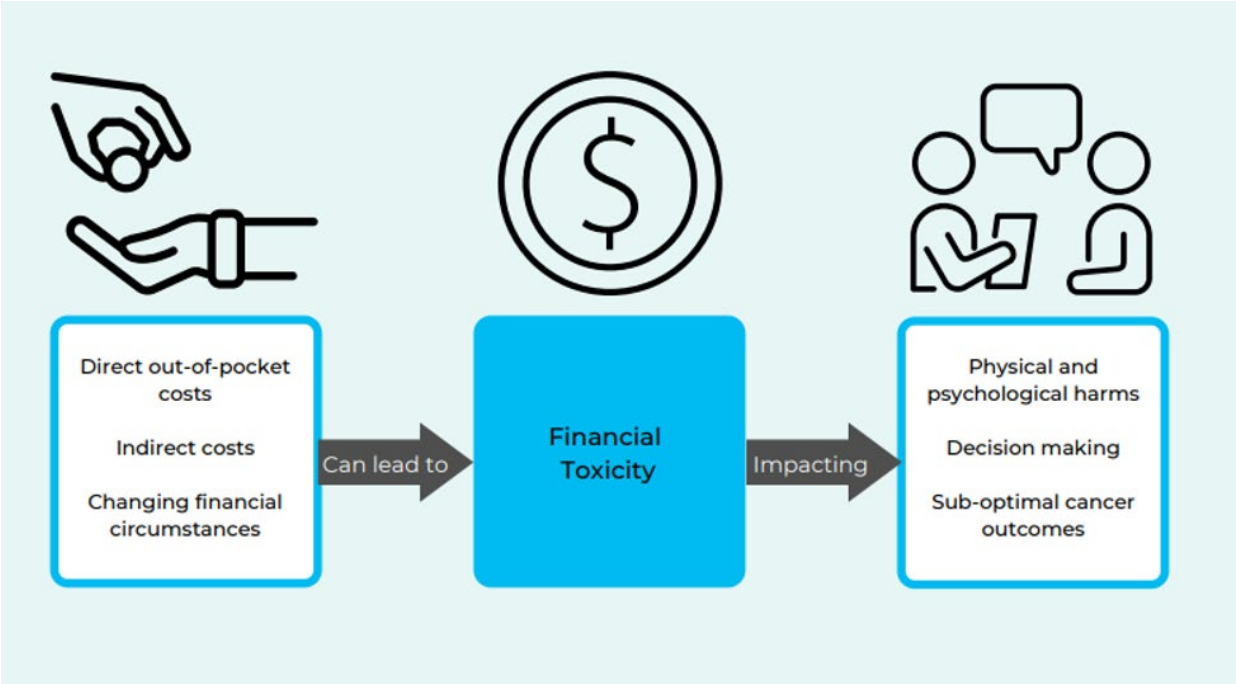
Ray Chan provided a brief overview of COSA's definition of financial toxicity and reflected on the causes and impacts of financial toxicity for people affected by cancer.

COSA statement on Financial Toxicity in Cancer Care

COSA endorses the following definition of financial toxicity:

"*The negative patient-level impact of the cost of cancer. It is the combined impact of direct out-of-pocket costs and indirect costs and the changing financial circumstances of an individual and their household due to cancer, its diagnosis, treatment, survivorship and palliation, causing both physical and psychological harms, affecting decisions which can lead to suboptimal cancer outcomes*."

Ray reflected on the contribution to financial toxicity of direct and indirect costs of cancer across the cancer care continuum. He noted that cancer and financial toxicity affect people from all backgrounds and socioeconomic status and that the experience is highly individual. Ray also emphasised that, while literature focuses on the psychological burden of financial toxicity, it is also important to be aware of the impact on physical wellbeing, and the fact that financial considerations can influence decision making and lead to poorer cancer outcomes.



Tackling financial toxicity: views of health professionals

Professor Louisa Gordon, QIMR Berghofer Medical Institute, member of the COSA Financial Toxicity Working Group

Louisa opened her presentation by reflecting on the current financial environment in Australia. Inflation is increasing, and health costs are high and increasing over time. Relative to other household expenses, consumers are paying more for health and medical expenses, driven in part by increases in insurance premiums.

Louisa reiterated issues around the impact of financial toxicity on the health and wellbeing of people with cancer. She highlighted that cost is an independent determinant of quality of life and reflected on mounting evidence of poorer quality of life for people with financial stress, and the relationship between financial issues and adherence to or delays in presentation, diagnostic tests, treatment and other care.

Louisa presented a summary of findings from a survey of health professionals undertaken in 2021 to understand knowledge, opinions and current practices in relation to financial toxicity in cancer care. Responses were received from 277 health professionals[1] from across Australia.

[1] Noting that this is a small proportion of all health professionals and likely represents the views of people with an interest in financial toxicity

Key findings from the 2021 survey included:

- respondents felt a high proportion of their patients were experiencing some form of financial toxicity
- mixed results on whether HCPs talk about financial toxicity / who raises the issue / views on who is responsible (strong role currently for social workers)
- respondents were comfortable discussing financial toxicity with patients (indicates likely bias towards those interested in the topic)
- time in consultations is often a barrier to discussion
- strategies used when financial toxicity is identified include referring people to information and practical supports including to social workers (which is challenging given low number of social workers and limited resources)
- overwhelming response to whether financial toxicity screening should occur was 'No'; surprising result that could be a result of time pressure or a lack of resources / supports for patient referral.

IDENTIFYING 'THE BIG ISSUES' IN FINANCIAL TOXICITY

Survey responses

The pre-Think Tank survey identified a range of healthcare and broader system issues contributing to financial toxicity in cancer care (Table 1). Survey responses highlighted a lack of transparency, lack of awareness / information as well as complexities and inconsistencies between services, healthcare settings and Governments.

Table 1: Financial toxicity in cancer care: the big issues (survey responses; n=37 with additional refinements from the Working Group)

HEALTHCARE COSTS		
Treatment-related costs	**Survivorship-related costs**	**Specific populations**
• High-cost tests and treatments / cumulative cost over time • Differences between public / private / non-bulk-billed services • Medicare safety net complexities • Gap payments • Lack of Medicare item numbers for allied health referrals • Non-medical costs (e.g. parking, accommodation, childcare) • Cost of off-label / unfunded treatments • Variability in healthcare delivery models (e.g. hospital-based vs home-based care)	• Rehabilitation services • Fertility treatments • Breast reconstruction • Mental health care • Allied health services • Other medical and dental services for toxicity and co-morbidity management	• Carers • Regional and rural patients • Financially disadvantaged people • People who do not qualify for benefits / support • Adolescents and young adults
LACK OF AWARENESS LACK OF TRANSPARENCY COMPLEXITY INCONSISTENCY		
BROADER SYSTEM ISSUES		
Work / employment	**Insurance / financial institutions**	**Policy / Government**
• Loss of income (all cause) • Job security • Employer understanding • Return to work models • Maximising income	• Cost of insurance • Wait times, inclusions, exclusions • Issues for specific patients (e.g. AYA, metastatic disease) • Hardship provisions (banks) • Addressing insurance entitlements and debts • Erosion of superannuation balances • Administrative challenges accessing insurance / superannuation	• Cost shifting between states and Commonwealth • Lack of clarity and challenges accessing Centrelink payments due to administrative burden • Centrelink payment eligibility • Medicare safety net / Medicare rebates • Financial hardship options

Think Tank insights

Participants were asked to reflect on the survey responses and write down 2–3 big issues that the Financial Toxicity Roadmap should address. Responses were gathered and grouped during the workshop and have been subsequently refined and themed (Table 2: summary; Table 3: detail).

The issues raised highlight the significant need for policy reform to address issues of cost and the need for greater transparency and reduced complexity of information around the costs of cancer care and available services. Responses also highlight the requirement for multisector activity to address the issues highlighted, with challenges identified in health (public and private sectors), financial, social support, legal and employment sectors.

Table 2: Financial toxicity in cancer care: the big issues (summary of workshop insights)

Overarching issues
• Increasing costs of delivering healthcare, increasing complexity of cancer care, and challenge of demand exceeding supply for medical services and products • Fragmented health system makes navigation difficult and results in delays, inefficiencies and variability • The complexity and individual nature of cancer care and duration of treatment means it is difficult to accurately predict the financial impact of cancer over time • Challenge of equity of access (e.g. for people in rural and regional areas, priority population groups, people living with metastatic disease, people with rare cancers, people living with other chronic health problems or co-morbidities, people with long-term treatment and care needs, including care related to treatment toxicity and side-effects) • Workforce shortages across the healthcare system and resultant challenges around duration and frequency of appointments, overreliance on a limited number of healthcare professionals and lack of support staff • Lack of coordination between health, financial, welfare, and legal systems means available services are not accessed

Costs of healthcare	Lack of information / transparency	Lack of / inconsistent support	Work / employment	Policy
• High-cost tests and treatments • Out-of-pocket expenses • Inconsistencies between public and private settings • Costs associated with long-term care / survivorship care (including toxicities)	• Lack of cost information / transparency • Need for financial toxicity screening • Lack of easy / early access to financial advice / support • Issues of financial, health and cancer literacy • Need to normalise the conversation about financial health and the impact of cancer on finances	• Inadequacies and complexity of income support • Lack of understanding / awareness about available financial support	• Impact of cancer on ability to work • Inadequate entitlements for people unable to work due to cancer • Inconsistencies in return-to-work policies and support • Issues with employer / workplace awareness and support	• Issues related to Medicare / MBS / PBS • Inconsistencies and challenges related to financial policies • Need to move from cost to value-based healthcare

Table 3: Financial toxicity in cancer care: the big issues (detailed workshop insights)

Theme	Sub-theme	Issues
Costs of healthcare	**High-cost diagnostic tests and treatments**	Examples include novel imaging modalities, genomic testing, novel medicines Cancer research is delivering innovative treatments, but there is often a lag between evidence of benefit and reimbursement
	Out-of-pocket expenses	Increasing out-of-pocket expenses caused by, for example, decreased GP bulk billing, lack of Medicare item numbers for allied health Ongoing indirect costs for all affected: transport; parking; childcare, reduced income during and after treatment High travel and accommodation costs for people in rural and regional areas
	Inconsistencies between public and private settings	Importance of considering and understanding perspectives of public and private providers Funding models in the private setting may limit availability of some options (e.g. day oncology; access to care-coordination / allied healthcare) Limited funding of public services may compel patients to access care with higher costs
	Costs associated with long-term care / survivorship care	Ongoing and long-term costs (>20 years) (e.g. late effects, treatment toxicity, costs of living with and managing cancer, psychosocial support) Ongoing financial impact related to workplace and career progression Ongoing travel and accommodation costs associated with follow-up care
Lack of information / transparency	**Lack of information / transparency about costs**	Lack of upfront transparency about costs including out-of-pocket costs 'Bill shock' related to requirement for upfront payment and high-cost tests and treatments Lack of predictability of costs across the care continuum Information provided influenced by assumptions made about an individual's financial circumstances Lack of information at point of diagnosis about timing and costs of treatment and pros and cons of receiving care in public vs private setting Confusion / lack of clear signposts: as a patient, you don't know what you don't know Key need to normalise the conversation about financial health and the impact of cancer on finances Moral dilemma for health professionals of discussing high-cost tests and treatments with patients; discussion may be based on a judgement call on who can / cannot afford high-cost tests and treatments
	Screening for financial toxicity	Lack of routine screening to identify people at risk of financial toxicity means issues are usually picked up late
	Lack of easy / early access to financial advice / support	Lack of clear pathways to / sources of financial advice and support (for health professionals, health services, patients and carers) Need for information to be provided early and across the cancer care pathway; easily accessed and understood by all populations

Theme	Sub-theme	Issues
	Issues of health, financial and cancer literacy	Ongoing challenges with financial and health literacy for patients, carers, specific populations Poor understanding of out-of-pocket costs amongst health professionals Lack of cancer / health literacy for people making decisions about entitlements influences speed of decision making Complexity creates challenges for GPs and patients in navigating critical options
Lack of / inconsistent support	**Inadequacies and complexity of income support**	Lack of adequate income / social support protection Complexity of systems create barriers and make it difficult to understand entitlements and access financial support
	Lack of understanding / awareness about financial support	Complexity leads to delays in accessing financial support options / entitlements for patients and carers / family: hardship payments; bridging support Lack of awareness in financial services of complexities and long-term issues and impact of cancer Challenge of managing existing debts / loans Lack of education and awareness about rehabilitation opportunities under Group Life Insurance / Income Protection
Work / employment (including patients and carers)	**Impact of cancer on ability to work (patients and carers)**	Income loss due to inability to work / changes in ability to work to the same level Lack of employment security during and following treatment Loss of momentum in education and early career can have long term impacts
	Inadequate entitlements for people unable to work due to cancer	Lack of a clear pathway and services facilitating return to work (e.g. bridging finance options, psychological help, pre-/rehabilitation)
	Inconsistencies in return-to-work policies and support	Inadequate sick leave entitlements for employees with cancer diagnosis Lack of clear workplace policies about cancer and return to work
	Issues with employer / workplace awareness and support	Too few employers equipped to manage / support employees with cancer Stigma in community and workplaces: people with cancer may be seen as ‘damaged goods’
Policy	**Issues related to Medicare / MBS / PBS**	Current processes for reimbursement of health services via the MBS and PBS are not always fit for purpose (includes speed with which payments are made, lack of MBS items for some key services, lack of quality research to support reimbursement decisions for new treatments / interventions, lack of timely access to data about costs and outcomes of existing treatments) Health system incentivises high patient throughput not time spent with patients or quality of care

Theme	Sub-theme	Issues
	Inconsistencies and challenges related to financial policies	Inability to use tax system to help Lack of consistency around means testing for co-contribution to private care Lack of cancer-specific insurance options Challenges around early access to savings and superannuation: delays financial toxicity
	Continued focus on value-based healthcare	Assessment for reimbursement of healthcare interventions may not always capture everything of value to patients Need to change the language from expense to investment / cost to affordability

POTENTIAL ACTIONS TO ADDRESS FINANCIAL TOXICITY IN CANCER CARE

Pre-workshop survey insights

The pre-workshop survey identified a range of ideas and examples of existing activity that could be used to address the issues identified (Table 4).

Table 4: Ideas to address financial toxicity in cancer care (survey responses)

Healthcare funding models	Information and support
• Bundled cancer care packages / bundled billing in private services • Billing caps • Revise / demystify the Medicare Safety Net (PCPA, RCA activity) • Reduce / subsidise treatment costs • Annual medication review • Cancer passport with allied health sessions • Support for health / practical needs (e.g. My Aged Care) • Proactive assistance schemes (PATS, lymphoedema garments) • Funding for consumer-centred healthcare services wherever appropriate and possible (e.g. hospital in the home; care closer to home)	• Normalise the conversation • Increase health professional awareness and skills to talk to patients about financial concerns and refer for support • Financial assessment tool • Financial navigators / coordinators • Financial counselling (free / subsidised / pro bono) • App-based information • Public awareness campaign: benefits of public cancer care
Financial services	**Workplace solutions**
• Low-interest loans • Pause student loans • Expand eligibility for the Disability Support Pension (e.g. to include parents of children with cancer) • Mandatory income protection through super • Childcare support / income support • Avoid managed care policies (US model) • Sponsorship from commercial partners / banks	• Universal chronic disease / paid cancer leave • Improved return-to-work programs • Mutual leave fund • Employer insurance (similar to work-related accident insurance) to cover chronic disease and cancer leave
	Research
	• Make health payment data available for researchers • Funding for de-escalation trials

Group discussion

Participants self-selected into small groups to discuss strategies to address issues in six domain areas:

1. Costs of delivering cancer care
2. Costs of survivorship / long-term care
3. Workplace and employment
4. Financial services and support
5. Financial care models and services
6. Awareness

Participants were asked to identify innovative strategies to enable change in each area and to consider how these strategies could be enabled. Ideas are summarised in Table 5, themed according to the topic area. Further detail is provided in Tables 6–10. These strategies will be considered by the COSA Financial Toxicity Working Group and will form the basis for the first draft of the *Financial Toxicity in Cancer Care Roadmap*.

Table 5: Financial toxicity in cancer care: potential actions (summary)

<table>
<tr><th colspan="5">Collective advocacy (cross-sector / pan-cancer)</th></tr>
<tr><td colspan="5">

Reinforce / add weight to national healthcare and cancer care reform agendas (e.g. MBS / PBS and primary care reform, telehealth, value-based healthcare)
Highlight issues of financial toxicity in cancer care as part of state-based / service-level cancer plans
Specific calls for action to progress Roadmap actions (e.g. changes in payment / reimbursement models)
Early activities:

joint position statement / white paper with reinforcement of calls for action in individual organisation advocacy activity
identify organisations and leaders who want to work together to drive change (including parliamentary and industry ‘champions’)

</td></tr>
<tr><th>Health service delivery*</th><th>Information and support</th><th>Financial services</th><th>Workplace reform†</th><th>Research</th></tr>
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Innovative payment models e.g. upfront gap payment only (similar to HiCAPS), retrospective reimbursement for new interventions
Innovative healthcare delivery models to reduce costs e.g. telehealth, chemo at home, nurse practitioners
Early / proactive identification of financial distress:

tools (e.g. distress thermometer)
health professional education

Supported by referral to information and support
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Centralised pan-cancer information and support hub with clear links to available financial services and supports

Will require:

mapping available services
keeping information up to date
promotion to health services and health professionals

Financial service navigation support (peer support, financial navigators, digital support)

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Strengthen awareness and understanding within cancer / health systems of available financial services and supports
Simplify mechanisms for accessing financial support provided by e.g. financial institutions, Disability Support Pension, life insurance, health insurance, superannuation

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Universal job security and right to return
Return to work support for employees (patients and carers) and employers
Investigate employment law and options (mutual leave allocations / government underwriting)

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Longitudinal research and data analysis needed to understand the long-term impact of cancer on financial health
Health economic modelling to be built into new models of cancer care to demonstrate value
Ongoing research to identify efficiencies and redundancies that will reduce overall cost (e.g. de-escalation trials, annual medication reviews, reductions in treatment toxicity)
Research that designs and evaluates the impact of various interventions

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</tr>
<tr><th colspan="5">Cross-cutting activities</th></tr>
<tr><td colspan="5">Strengthen overall awareness of financial toxicity at all levels: community, patients, health services, government, financial services
Reduce complexity and increase transparency
Enable access to information and services for everyone affected by cancer</td></tr>
</table>

*Includes delivery of acute and long-term / survivorship care; †Need to consider all types of work, contracts and workplaces including self-employed

1. Costs of delivering cancer care

Participants highlighted the rapid pace of change in cancer research and development of new interventions and treatment options. The ongoing need for MBS and PBS system reform was highlighted, together with the ongoing impact of supply and demand as a driver for cost. It was noted that these are national and system-wide issues that go beyond the cancer sector. It was agreed that, while the Roadmap can and should advocate for change from a cancer perspective, the Roadmap focus should also include shorter-term pragmatic ways to reduce the impact of the cost of cancer care on people affected.

Table 6: Potential actions to address the impact of costs of delivering cancer care on financial toxicity

Aim	Ideas	Activity needed
Innovative payment models	• Change administration of upfront payment so patients only pay the gap fee rather than the full cost (similar to HiCAPS system): ○ system already exists for other areas of health and dental care ○ short-term action requiring practical implementation	**Advocacy:*** Insurance companies / care providers / Government
	• Retrospective reimbursement for medicines or tests that were not funded at time they were prescribed but subsequently are approved for government funding	**Advocacy:*** Government / Industry
	• Shorten the time between approval and reimbursement decisions	**Advocacy:*** Add specific consideration of financial toxicity as part of coordinated advocacy to influence MBS / PBS reform; encourage implementation of managed access programs
Health care delivery models	• Telehealth: ○ adopt telehealth into routine care to reduce unnecessary costs of travel, parking, accommodation, childcare, time off work (learn from COVID-19 pandemic models)	**Advocacy:*** Government (MBS item for telehealth) **Service delivery**: continue to embed telehealth
	• Chemo-at-home: ○ services are available but uptake is low	**Information:** Raise awareness about chemo-at-home options
	• Nurse Practitioners: ○ highly motivated and skilled group of workers who can provide care at lower cost	**Advocacy:*** Work with CNSA to continue to promote the value of Nurse Practitioners

Aim	Ideas	Activity needed

Informed choice and navigation	• Increase understanding and awareness of public and private options and costs to support informed decision making:
	  ○ increase knowledge, skills and tools available to GPs in presenting options (not just about whether a person has private health insurance or GP's personal referral networks)
	  ○ empower patients and carers to ask about options and associated costs
	  ○ ensure navigation systems include sufficient focus on support regarding financial impact of cancer
	  ○ adapt the model used for Allied Health Care Management Plans to include financial advice / counselling
	  ○ promote and encourage use of financial counselling services that are available and accessible (e.g., free services through cancer councils)
		Information:
		• Community awareness raising on asking for options; cancer-specific information
		• Information on referral options
		• Inclusion of 'financial impacts' in patient navigation
		Education: GP education on presenting referral options

Value-based care	• Research:
	  ○ understand opportunities to reduce the duration and number of treatments / interventions needed
	  ○ use data to better understand costs associated with delivery of quality cancer care and to identify redundancies and efficiencies
	  ○ undertake research to strengthen value-based delivery models (see below)
		Research:
		• Support de-escalation trials
		• Review of data / health economics
		• Research into value-based service delivery
		Service delivery:
		• Health system performance reporting to support evidence-informed practice change

	• Value-based service delivery:
	  ○ continue to embed Optimal Care Pathways (OCPs)
	  ○ cancer-focused annual medication reviews to find efficiencies and reduce costs
	  ○ invest in prevention / pre-habilitation
	  ○ use evidence to determine 'value' in clinical/treatment decision making
		Service delivery:
		• Leverage and support Australian Cancer Plan activity (OCPs)
		• Leverage and support state-based value-based care initiatives

*Advocacy activity can be undertaken by individuals and organisations; a starting point may be to make recommendations to COSA Council

2. Costs of survivorship care / long-term cancer care

Discussions about the costs of survivorship care / long-term cancer care incorporated:

- costs associated with long-term treatment protocols
- costs associated with managing long-term sequelae of cancer treatment
- costs associated with managing ongoing care for people living with cancer.

Discussions highlighted the need to advocate for financial hardship provisions and services (e.g. mortgage relief) to be accessible by everyone affected by cancer, regardless of where they are in the cancer care pathway.

Table 7: Potential actions to address the impact of costs of cancer survivorship / long-term care on financial toxicity

Aim	Ideas	Activity needed
Innovative payment models	• Universal cap on cancer costs that does not stop after 12 months and includes hospital costs. • Passport for allied health services to support access to more sessions (e.g. up to 20) and bundle a range of services and specialities • Disability / chronic disease payment through Centrelink for people who no longer qualify as a 'cancer patient' but may have ongoing chronic conditions requiring support	**Advocacy:** Insurance companies / care providers / Government

Innovative survivorship care delivery models	• Survivorship centres / clinics:
	  ○ include financial planning support, advice and counselling
	  ○ MBS item number to cover financial planning consultations
	• Adopt telehealth into routine survivorship / follow-up / long-term care to reduce unnecessary costs of travel, parking, accommodation, childcare, time off work (learn from COVID-19 pandemic models)
	• Include digital link to Medicare (similar to vaccination record) that includes notes about e.g. prostheses etc
		Advocacy: Government (MBS item for telehealth)
		Service delivery:
		• Continue to embed telehealth
		• Leverage and support Australian Cancer Plan activity (telehealth)

	• Research:
	  ○ longitudinal research on the impact of financial toxicity over time; requires better access to and use of data and health economic modelling
	  ○ clinical research to reduce long-term effects of treatment / treatment toxicity
		Research:
		• Data review / health economics, incl. PROMs/PREMs / registries
		• Clinical research

Aim	Ideas	Activity needed
Informed choice and navigation	• Develop and maintain service directories (national / state and territory / local) • Optimise referral pathways	**Information**: Centralised information and support hub **Service delivery:** Leverage and support Australian Cancer Plan activity (OCPs, Navigation)

3. Workplace / employment

Participants highlighted the need to recognise that not everyone is in a 'traditional' employment role and that any actions arising from the Roadmap must be accessible to casual / contract workers and the self-employed as well as those on permanent employment contracts. It was also noted that actions relevant for people with cancer may have broader application to people with other chronic health conditions, and vice versa.

Table 8: Potential actions to address the impact of cancer on work / employment

Aim	Ideas	Activity needed

Universal job security and income support	• Universal job security:
	  ○ Change employment law to recognise the impact of cancer and protect employee rights to return to work after a 12-month leave period (with option for a further 12 months with negotiated conditions)
	  ○ In the UK, the definition of 'disability' includes cancer as part of the discrimination law
		Advocacy: Changes to employment law with protections for patients and employers

	• Mutual leave fund for cancer: ○ similar model to work cover	**Further modelling:** Model / work-up options ahead of Government advocacy

Return-to-work programs	• Range of activities including:
	  ○ rehabilitation support and coaching for individuals
	  ○ education programs for workplaces / other employees to increase awareness and reduce stigma of cancer (including cancer as a chronic illness, episodes of care)
	  ○ Different ways to return and adjustments to support that
		Advocacy: Pan-cancer alliance / advocacy: look to organisations that have implemented change, find leaders or organisations who want to work together on this; develop parliamentary and industry 'champions'

4. Financial information and support

An underpinning theme in the discussion about financial information and support was 'Prevention is better than cure', highlighting the need to pre-empt and address financial concerns before they become a significant burden.

Table 9: Strategies to improve financial information and support for people affected by cancer

Aim	Ideas	Activity needed

Informed choice and navigation	• Financial navigators:
	  ○ Intervene at the point of referral to educate patients about available options and associated costs
	  ○ Option for 'financial health navigators' between primary and secondary care assisting in this process to identify and pre-empt financial considerations before a patient ends up in financial distress
		Further modelling: Review available options: e.g. extension of existing systems used by health insurers BEFORE decision is made to have care in the public / private system

	• Information:
	  ○ Create a centralised information and support hub about treatment options and costs with links to sources of information, advice and support, to which all health professionals can refer patients
	  ○ Web-based portal / 'one-stop shop' with all of the information that is needed
	  ○ Bring together and link available resources so people can find them easily ('no wrong door' model)
		Information: Pan-cancer information and support hub

	• Education and training
	  ○ Include information about how to sensitively raise the issue of financial distress with patients and families as part of health professional education and ongoing professional development
	  ○ Reinforce the importance of not making assumptions about what patients can afford and offer all patients all options to support patient informed choice
		Education: Range of options including medical student / registrar / nursing education and ongoing CPD

Financial and health literacy	• Increase awareness and understanding about the differences between public and private care; requires current and accessible information • Will contribute to removing the stigma around asking for and accessing support	**Information:** Pan-cancer information and support hub
Identifying people at risk of financial distress	• Adopt and routinely use existing QoL / Distress / financial toxicity screening tools to incorporate financial toxicity, e.g. NCCN distress thermometer includes a question about whether person has concerns about money • Incorporating FT discussions in screening can help to reduce stigma. • Should be repeated regularly • Requires the health professionals/ identified personnel (e.g. navigators) to know how to act / what to do if the patient indicates concerns and where to refer for financial support • Are there other ways to identify 'red flags' that indicate a patient is headed towards financial distress (e.g. via financial institutions, similar to how domestic violence is flagged; likely to be significant privacy issues and concerns to be overcome)	**Research:** Develop and pilot a suitable brief screening tool to assess feasibility and implementation (including who would administer the tool and frequency of administration)

5. Financial models and services

A key recommendation arising from the discussion about financial models and services was to change the language from 'cost' of cancer services and care to 'affordability'.

Table 10: Potential actions to reduce the financial impact on people affected by cancer

Aim	Ideas	Activity needed

Innovative funding models	• Approaches to address gap payments
	  ○ address inconsistencies in state / federal approaches to co-funding
	  ○ public/private partnership models to address service gaps
	  ○ community funding: 'patients helping patients' – option for those who can afford it to pay a little more
		Research: Feasibility study to determine options available to address gap payments
		Advocacy: coordinated calls to expand innovative payment models into demonstration sites and wider implementation

	• Taxation ○ revisit options for tax deductions to offset medical expenses	

Informed choice and navigation	• Early identification
	  ○ Early identification of questions and concerns is important
	  ○ Provide tips / strategies for health professionals to use to start the conversation early (e.g. 'has your income dropped' or 'is money / cost a concern you'?); this can be a trigger for referral to a third party e.g. financial counsellor / cancer care coordinator / social worker
		Service delivery: Systematic application of validated tools to screen for financial toxicity and appropriate response options

	• Increased awareness of and referral pathways to financial support services:
	  ○ clinicians need to know what to do if a patient identifies financial concerns / distress
	  ○ option for a role for peer navigators
	  ○ option for app-based information to help people identify financial concerns and signpost information and support services
		Information: Pan-cancer information and support hub (starting with mapping available information and resources)

Financial supports	• Increase awareness of available supports:
	  ○ Services available through financial institutions
	  ○ Services available through life insurance policies (income protection, TPD)
		Information: Pan-cancer information and support hub (starting with mapping available information and resources)

6. *Awareness*

Overarching comments around awareness of financial toxicity:

- unless there is a ground swell, it's hard to prompt policy change
- it is hard to understand financial toxicity until you've been through it
    - people take out life insurance / health insurance when they are well, but are less likely to do so if they do not understand the potential impact; awareness raising is needed to drive financial planning for future impact
- it is essential to normalise the conversation around financial health and financial literacy
- income security is the most important factor in people's economic wellbeing following a cancer diagnosis and affects overall wellbeing.

MAKING CHANGE HAPPEN

Participants reflected on short-term actions (Table 11) and longer-term ambitions (Table 12) to be addressed in the Roadmap.

Table 11: Short-term actions to be considered in the Roadmap

Activity	Detail
Normalise the conversation	• Raising awareness of the issue of financial toxicity in cancer care is a critical first step in normalising the conversation • A simple first step is to encourage health professionals to ask one simple question and not make assumptions about who may or may not be at risk
Centralised information and support hub	• Raising awareness has to be supported by signposting available services and resources • Great information exists and services / supports are available, but these can be hard to find • An important early step will be to map available resources and services and bring this information together in a central (pan-cancer) information and support hub
Build the coalition	• Enacting the Roadmap and driving change will require a coalition that cuts across sectors and includes people and organisations involved in cancer services, employment, social care, financial services, government and non-profit organisations • Consumers / people with lived experience will continue to be a powerful voice for change

Advocacy	• A powerful starting point could be a joint position statement from all of the organisations represented at the Think Tank calling for change in key areas
	• Many of the Roadmap activities will require advocacy and outreach to politicians. It will be important to build capacity on how to do this effectively:
	  ○ draw on skills and expertise within the extended network
	  ○ consider seeking support from a skilled lobbyist to provide advice and drive specific initiatives

Cost-neutral strategies	• An early focus on simple or cost-neutral strategies could provide some 'early wins', for example:
	  ○ reframing return to work forms to make them cancer-specific
	  ○ reframing the way in which upfront payments are made for cancer treatment to only cover the gap fee
	  ○ promoting existing tools and resources that incorporate consideration of financial issues (e.g. NCCN distress thermometer, communication skills modules on high-cost tests and treatments)

Table 12: Longer-term ambitions for the Roadmap

Activity	Detail
Reducing complexity	• Make Centrelink payments more accessible • Help patients understand entitlements from superannuation and linked insurance policies • Promote understanding of changes to Disability Support Payments
Increase available financial support	• Advocate for changes in the MBS / PBS system to reduce the time between approval and reimbursement decisions • Advocate for increases in Centrelink payments

STAKEHOLDERS

In addition to the organisations and perspectives represented at the Think Tank, a range of other stakeholder groups were identified as important to inform, enable and implement the Roadmap.

The broad range of stakeholders identified highlights the need to undertake a stakeholder mapping activity as part of the development of the Roadmap, to ensure that all relevant perspectives are considered and to ensure broad awareness and engagement around Roadmap implementation.

- All cancer organisations
- Primary care (RACGP), Nurses (APNA)
- Comprehensive cancer networks in each state
- Government departments:
    - Commonwealth and State / Territory Departments of Health
    - Commonwealth and State / Territory Departments of Social Services
    - Services Australia
        - Centrelink
        - Medicare
- Australian Health and Hospitals Association (AHHA)
- Australian Commission on Safety and Quality in Healthcare
- Employer groups (e.g. Unions, Chamber of Commerce, Small Business Council of Australia, Working Women's Association)
- Superannuation groups
- Health insurance industry
- General insurance industry (life insurance, Insurance Council of Australia)
- Financial Advisors/financial counsellors
- Health Justice Australia – health justice partnerships
- Workplace lawyers (?)
- Regulators – like APRA
- Services and organisations supporting priority population groups (e.g. NACCHO, FECCA, Multicultural Health Alliance)
- Banks / Banking industry
- Pharmaceutical / Biotechnology / Medical devices companies and associated bodies (e.g. Medicines Australia)
- Australian Human Rights Commission
- National Oncology Alliance (NOA)

PRIORITIES

Participants were asked to individually nominate:

- one thing they would like to see the roadmap deliver on (Table 13)
- their commitment to act following the Think Tank (Table 14).

Table 12: Individual views on priorities for the Roadmap

Idea	Detail
Overall goals of the Roadmap	• All cancer patients have a conversation with their healthcare team about financial issues and are provided with relevant information or resources to assist them • Conversations about the financial impact of cancer are normalised at all levels (community, health services, workplaces) • Everyone affected by cancer is given the opportunity to discuss the financial impact diagnosis and treatment, and support is provided to action concerns and reduce the impact of financial issues on decision making
Central information and support hub	• Development of a centralised information and support hub was the most common priority identified by Think Tank participants • Links to the need to comprehensively map (and maintain up to date listings) of available resources
Job / income security	• The need for strategies to address job / income security was the second most common priority identified by Think Tank participants, with strategies including: ○ paid cancer leave at a liveable rate (12 months and open role for a further 12 months) ○ income protection (e.g. through universal income protection, paid leave, Centrelink support) regardless of type of job / status / contract ○ mandatory income insurance for at least 5 years via superannuation ○ ability to access extended financial support to cover the duration of treatment and recovery
Navigation	• Navigation and clearer signposting of financial information and services was a clear priority with ideas including: ○ community-based financial navigators ○ peer support / buddy systems ○ extending use of survivorship care plans to incorporate financial services and supports • Comprehensively consider the evolving role of navigation to allow consumers to make best use of existing resources and supports to reduce FT • Make recommendations and advocacy plans to strengthen navigation into the future to ensure it encompasses financial support in a timely way to help consumers • Informed channelling between public and private
Early action / intervention	• Earlier screening for financial toxicity • Early intervention • Reach consensus and implementation of the best way / whether / by who to do FT screening • Education for health professionals on having difficult conversations • Routine early screening • Further embed financial counselling to address financial toxicity • Improved social support

Idea	Detail
Approaches to reduce costs	• De-escalation trials • A commitment to increasing investment in innovative cancer treatments with low toxicity and therefore reduce the long-term impacts and costs of cancer • Funding reform to minimise time and costs • Leveraging already available models of care, such as telehealth, and nurse practitioners through MBS reform to allow patients to have flexibility in care provision and reduce financial impact
Financial models	• Paying the gap only • Retrospective reimbursement • Better financial support from government for individuals with cancer • Change Medicare: reimbursement/EMSN (not just cancer) • Universal cap on cancer survivorship costs
Role definition	• All care providers across the country working to the top of their scope
Equity	• Equitable delivery of cancer care regardless of socio-economic circumstance • Caring specifically for priority populations
Awareness	• Raise awareness at every level about the costs of cancer • Greater awareness at all levels about the issue of FT

Table 14: Individual commitments

Type of activity	Commitment
Share	Share outcomes of the workshop with Medicines Australia Consumer Action Working Group Take information back to Cancer Australia to be able to leverage and promote within our remit in the implementation of the Australian Cancer Plan, e.g. work to support embedding of the OCPs as standard practice Share the discussion with my team (McCabe centre) and continue research on legal measures Continue the conversation regarding FT with CNSA and collaborate with this group to assist with any actions CNSA can do Proactively engage the OSWANZ membership in related activities
Research	Bring the cost of care and financial toxicity research back to my research group as a new area to focus on (head and neck cancers) Continue to include patient cost information in future research Think about developing some dynamic modelling approaches that can contribute to predicting financial and survivorship trajectory for cancer patients As a researcher, new data collection to monetise the value of social workers (evaluation project) to develop advocacy evidence Design and think about how to measure benefits / monetise back to hospitals for early intervention Submit a grant to get this started (not alone!) Cancer nurse – use discussions to think about how to do impactful research to reduce financial toxicity through innovative models of care
Ongoing involvement	Actively commit to this group Continue to be part of this work and do what I can Continue to contribute to COSA FT working group through reporting the outcome of the Think Tank and development of the Roadmap Ongoing commitment to raise awareness and contribute to the roadmap

Type of activity	Commitment
	Engage with stakeholders from the workshop Continue to be an active member of the FT working group Continued involvement in the COSA FT working group and find out if I can formally join! Continue to contribute to the COSA FT working group Contribute to the COSA FT Working Group Continue to work with the COSA Financial Toxicity Working Group to publish the Roadmap
Advocacy	Happy to be involved with direct communication with politicians in regard to the roadmap Continue to use my consumer voice to advocate for equitable health outcomes, improved health literacy, de-escalation of treatment, improved information and support in a timely manner To continue to prioritise FT as a key BCNA advocacy priority and to look for the opportunity to collaboratively lead advocacy as a consumer issue on behalf of this group Continue to lobby for change in out-of-pocket costs Raise the issue of financial impacts of cancer in all forums that I participate in as a consumer advocate and promote the work being done by COSA and continue to participate in this work Focus the Cancer Council Cancer Care Policy to reflect the issue of Financial Toxicity and channel the expertise in this room into it Advocate through CNSA Publish the National Cancer Care Policy chapter on the financial cost of cancer Build CCA financial toxicity advocacy plan Start advocacy Parliamentary breakfast to table the Roadmap
Connect	Put the idea of a centralised cancer hub to our navigation policy development consultations Continue the conversation and consider opportunities to expand the cancer hub Working towards improved accessible financial information and support and collaborating with other NFPs in this space
Awareness raising	Commitment to drive awareness of life insurance rehabilitation offerings and support about programs that are available Increase education for students and clinicians on awareness of financial issues in medicine and have an understanding of the costs of healthcare – to encourage the conversation around screening for FT Increasing awareness of information and support available Include in Master of Science unit I teach
Interventions	Continue to build and deliver on the Live Work Cancer vision 'Enduring work participation for people with cancer' Investigate / scope a pilot of financial counsellors in regional centres and talk to the state government to include in our next submission to the next Victorian Cancer Plan Work with others to pilot a FT program in clinical / hospital setting I will review all distress thermometer screening data of my patients and particularly focus on financial distress

Next steps

The COSA Financial Toxicity Working Group will review the proposed Roadmap activities and identify opportunities for COSA leadership. It is acknowledged that solutions and future efforts will require a whole-of-sector approach.

APPENDIX I: COSA FINANCIAL TOXICITY WORKING GROUP MEMBERS

Current members:

Michelle Bass, Cancer Council NSW

Professor Raymond Chan, Caring Futures institute, Flinders University, SA (Chair)

David Goldsbury, The Daffodil Centre (Cancer Council NSW/The University of Sydney), NSW

Professor Louisa Gordon, QIMR Berghofer Medical Research Institute, Qld

Kim Hobbs, Oncology Social Work Australia and New Zealand /Westmead Hospital, NSW

Lee Hunt, Consumer representative/Cancer Voices NSW

Dr Deme Karikios, Nepean Hospital, NSW/University of Sydney, NSW

Dr Daniel Lindsay, QIMR Berghofer Medical Research Institute, Qld

Dr Jordana McLoone, UNSW Sydney/Sydney Children's Hospital, NSW

Tri Nguyen, Cancer Council Australia

Amanda Piper, Cancer Council Victoria, VIC

Dr Carla Thamm, Caring Futures Institute, Flinders University SA/ Metro South Hospital and Health Service QLD

Megan Varlow, Cancer Council Australia

Kate Whittaker, Cancer Council Australia

Past members:

Raylene Cox, Cancer Council Australia

Associate Professor Eng-Siew Koh, South Western Sydney Clinical School/University of NSW

Lillian Leigh, Consumer advocate

Laura Muir, Cancer Council NSW

APPENDIX II: THINK TANK PARTICIPANTS

Attendee	Affiliation
Anupriya Agarwal	Specialist Medical Randwick & NHMRC CTC
Melissa Austen	Cancer Australia
Michelle Bass *	Cancer Council NSW
Kathy Bell	COSA Council consumer representative
Nadia Carnevale	MSD
Raymond Chan *	COSA Survivorship and Financial Toxicity Working Group Chair
Megan Clark	Icon Cancer Care
Fran Doughton	COSA
Alison Evans (Facilitator)	Alison Evans Consulting
Dion Forstner	COSA President, GenesisCare
Peter Gartlan	Financial Counsellors of Australia
David Goldsbury *	The Daffodil Centre (Cancer Council NSW and University of Sydney)
Louisa Gordon *	QIMR Berghofer Medical Research Institute
Nicole Heneka	Prostate Cancer Foundation of Australia (PCFA)
Jen Henwood (Scribe)	Sensus Health Group
Kim Hobbs *	Westmead & Oncology Social Work Australia and New Zealand
Lee Hunt *	Consumer advocate / Cancer Voices NSW
Genelle Jessup	MSD
Hayley Jones	McCabe Centre for Law and Cancer
Deme Karikios *	Nepean Cancer Care/Medical Oncology Group of Australia (MOGA)
June Khaw	Hannover RE
Reegan Knowles	Flinders University SA
Lillian Leigh	Consumer advocate
Gillian Mackay	COSA
Marie Malica	COSA
Gemma McErlean	COSA Survivorship Research Fellow
Jordana McLoone *	UNSW Sydney/Sydney Children's Hospital
Anne Mellon	Cancer Nurses Society of Australia (CNSA)
Mark Middleton	Icon Cancer Care
Sam Mills	Breast Cancer Network Australia (BCNA)
Naveena Nekkalapudi	Breast Cancer Network Australia Financial Impacts working group
Tri Nguyen *	Cancer Council Australia
Amanda Piper *	Cancer Council Victoria
Md Mijanur Rahman	COSA Survivorship Research Fellow
Nicola Richards	MSD
Aldo Rolfo	GenesisCare

Attendee	Affiliation
Christopher Steer	Border Medical Oncology & Private Cancer Physicians of Australia
Carla Thamm *	Flinders University SA / COSA Survivorship Research Fellow
Megan Varlow *	Cancer Council Australia
Rebecca Venchiarutti	COSA Survivorship Research Fellow
Kate Whittaker *	Cancer Council Australia
Angela Wicks	Canteen Australia
Sue Woodall	LiveWorkCancer

*COSA Financial Toxicity working group member

APPENDIX III: THINK TANK AGENDA

Date: 26 May 2023
Venue: ParkRoyal, Darling Harbour, Sydney
Time: 9.30am–4.30pm

Time	Session	Speaker
9.15–9.30am	**Arrivals, tea and coffee**	
9:30–9:45am	**Welcome and introductions**	Ray Chan Alison Evans
9.45–11.10am	**Financial toxicity in cancer care: defining the issues** Presentations and discussion	Sue Woodall Ray Chan Louisa Gordon Alison Evans
11.10–11.30am	**Morning tea**	
11.30am–12.50pm	**Strategies to address financial toxicity in cancer care** Pre-workshop survey insights Small group discussion on strategies, priorities and roles	 Alison Evans Small group discussions
12.50–1.30pm	**Lunch**	
1.30–2.20pm	**Defining the Roadmap** Presentation and reflections on strategies	Small group leads All group discussion
2.20–2.45pm	**Reviewing the Roadmap** Discussion of interdependencies	All group discussion
2.45–3.30pm	**Making change happen** Presentation and reflections on short- and longer-term priorities and roles	Small group leads All group discussion
3.30–3.45pm	**Afternoon tea**	
3.45–4.20pm	**Validating priorities** Individual reflections on priorities and commitment to action	Individual reflection and all group discussion
4.20pm	**Thanks and next steps**	Ray Chan, Dion Forstner
4.30pm	**Close**	

APPENDIX IV: PRE-WORKSHOP SURVEY RESPONDENTS

Total number of respondents: 37

Role / work setting of respondents (substantive role) (n=37)

Setting	Number	Percentage
Government	1	3%
Patient Advocacy Organisation	6	16%
Public Health Provider	4	11%
Private Health Provider	6	16%
Insurance industry	2	5%
University/Research Institute	13	35%
Other Not-for-Profit not included above	3	8%
Other (please specify)	2	5%

Other:

- Industry
- Self-directed work to support employees/employers during and after cancer: the aim to provide enduring work participation

Location of respondents (n=36)

Location	Number	Percentage
New South Wales	21	58%
Queensland	1	3%
South Australia	1	3%
Victoria	4	11%
Western Australia	2	6%
USA	4	11%
Canada	2	6%
Europe	1	3%

Role title (n=31)

- Assistant Director, Australian Cancer Plan Taskforce, Cancer Australia
- Assistant Professor of Nursing
- Assistant Professor of Oncology
- Associate Professor (Cancer Survivorship)
- Consumer advocate
- Consumer representative
- Consumer representative
- Director Cancer Control Policy
- Director, Patricia Ritchie Centre for Cancer Care and Research, Mater Hospital North Sydney
- Executive Manager
- Founder, LiveWorkCancer
- Gynecologic oncologist and Head of the Affordability Working Group, Memorial Sloan Kettering Cancer Center

- Gynae-oncology Clinical nurse consultant
- Manager, Hardship Strategy & Services
- Medical Oncologist
- Medical Oncologist
- Medical Oncologist
- National Coordinator, Disaster Recovery, Financial Counselling Australia
- NHMRC Emerging Leadership Fellow
- Nurse Researcher
- Oncologist
- Oncology Clinical Nurse Specialist
- Post-doctoral researcher, paediatric psycho-oncology
- Professor
- Professor, School of Business, McMaster University
- Program Director (Clinical Exercise Physiology)
- Public Affairs
- Radiation oncologist
- Rehabilitation Consultant
- Senior Policy Officer
- Social worker
- Specialist GP/Primary Care Physician and Research Fellow
- Statistician