

Clinical Oncology Society of Australia Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer





COSA's Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer

Contents			
Introduction	3	(\$	
Roadmap	5 – 9		
Glossary and list of abbreviations	10		
Acknowledgments	10		

Version 1.0, March 2024

Suggested citation

Chan RJ, Varlow M, Bass M, Goldsbury DE, Gordon LG, Hobbs K, Hunt L, Karikios DJ, Khaw J, Knowles R, Lindsay D, McLoone J, Nguyen T, Piper A, Thamm C, Whittaker K, Woodall S on behalf of the COSA Financial Toxicity Working Group. *Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer*. Clinical Oncology Society of Australia. March 2024.

Please direct any enquiries or comments on this publication to: Marie Malica, Chief Executive Officer Clinical Oncology Society of Australia GPO Box 4708 Sydney NSW 2001 Tel: (02) 8256 4100 cosa@cancer.org.au

© Clinical Oncology Society of Australia.

Introduction

COSA's Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer

The Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer (the Roadmap) outlines actions to identify and reduce the financial burden from the cancer experience. It outlines recommended national-level actions required to prevent, alleviate and manage financial toxicity in Australia.

Financial toxicity is "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."¹

While financial toxicity can affect anyone, including individuals diagnosed with cancer, their carers, and family members, it disproportionately affects socioeconomically disadvantaged populations, exacerbating healthcare access inequities.^{2,3} Australians directly fund 14 per cent of total healthcare expenditure, yet nearly a quarter of people with a chronic condition, including cancer, report not receiving recommended care due to the associated costs.^{4,5}

The Roadmap aims to bring together individuals and organisations interested in identifying and implementing initiatives and systemic changes within the cancer care ecosystem, that reduce, and ultimately eliminate financial stress from access to optimal treatment and care. Living in a country with universal healthcare and a publicly funded income support system, Australians should not face financial disadvantage or receive inferior healthcare due to cancer-related financial impacts.

The Roadmap aligns with the strategic focus of the Australian Cancer Plan which is to reduce inequities and address specific issues for priority populations.⁷

The Clinical Oncology Society of Australia (COSA) Financial Toxicity Working Group has been instrumental in driving the development of the Roadmap. Stakeholders from across the cancer care community, as well as providers of health, social and financial services, have contributed to its development. The need for a comprehensive and collaborative approach to reducing financial toxicity in cancer care was a key outcome of the National Think Tank on Financial Toxicity in Cancer Care¹ hosted by the COSA Financial Toxicity Working Group on 26 May 2023. Subsequently, a draft Roadmap was presented to delegates at the COSA Annual Scientific Meeting in November 2023.

COSA's Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer

Implementation of the Roadmap requires collaborative efforts across the cancer sector, with actions outlined for short, medium, and long term progress tracking, achievable within a five-year timeframe. The Roadmap aims to promote efforts from within and beyond the cancer sector to most effectively address financial toxicity over time. The COSA Financial Toxicity Working Group will review the sector's progress in implementing Roadmap actions, recognising achievements and identifying additional opportunities to mitigate financial toxicity for people affected by cancer.

¹ Clinical Oncology Society of Australia Financial Toxicity Working Group. 2022. Financial Toxicity in Cancer Care. <u>www.cosa.org.au/media/q3ohepgs/financial-toxicity-in-cancer-care-7.pdf</u>

² Paul C, Boyes A, Searles A, Carey M, Turon H. The impact of loss of income and medicine costs on the financial burden for cancer patients in Australia. The Journal of community and supportive oncology. 2016;14(7):307-13.

³ Callander EJ, Fox H, Lindsay D. Out-of-pocket healthcare expenditure in Australia: Trends, inequalities and the impact on household living standards in a high-income country with a universal health care system. Health Economics Review. 2019;9(1):10.

⁴ Australian Institute of Health and Welfare. Health expenditure. Canberra: AIHW; 2023. <u>www.aihw.gov.au/reports/health-welfare-expenditure/health-expenditure</u>

⁵ Cummins J, Crabbe A, Samuell D, Visser D. The cost of care whitepaper. Sydney (AU); 2021. www.zurich.com.au/content/dam/au-documents/files/advisers/cost-of-care-whitepaper.pdf

⁶ Cancer Council Australia, 2023. Universal health coverage to address the financial costs of cancer. www.cancer.org.au/about-us/policy-and-advocacy/national-cancer-care-policy/financial-cost-of-cancer/universal-healthcoverage-address-financial-costs-cancer

⁷ Cancer Australia. 2023. The Australian Cancer Plan. <u>www.australiancancerplan.gov.au/</u>

Collective advocacy for financial support for all people affected by cancer

COSA's Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer



Consistent, coordinated advocacy involving all stakeholders would create a collaborative and united voice for meaningful systemic policy and supportive care change. Advocating for initiatives focused on prevention and early intervention in financial toxicity is crucial, with impacts on the healthcare system and beyond.

1.1 Advocate for initiatives that reduce financial toxicity in cancer care.

Ensure organisations responsible for funding and delivering health, social, and financial services understand their roles and the impact of their initiatives on Australians affected by cancer.

Actions:

Short term

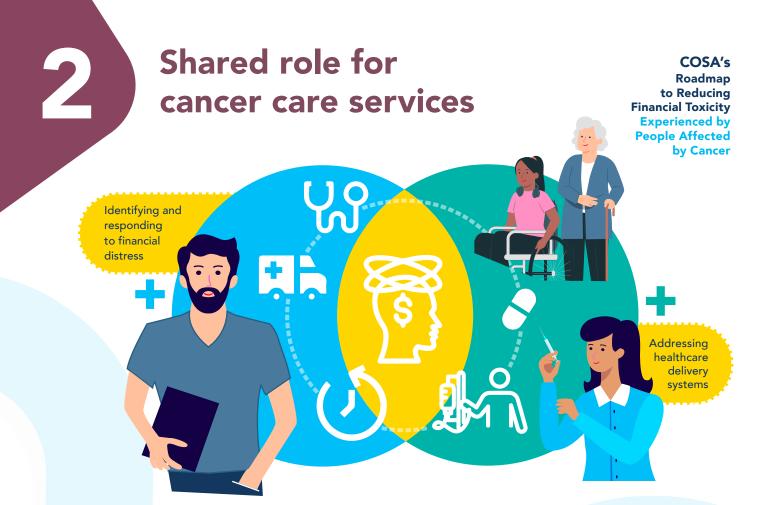
1.1a. Map the roles and responsibilities of federal, state and territory governments, health services and non-government organisations in addressing financial toxicity.

1.1b. Identify current exemplars and advocacy efforts for addressing and reducing the impact of financial toxicity and assess their influence on federal government, jurisdictions, health services and non-government organisations.

1.1c. Lead cross sector advocacy on health and social policy issues for people affected by cancer, including improving access to appropriate, government funded income support and access to financial counsellors.

Medium to long term

1.1d. Implement the identified exemplars to reduce financial toxicity across relevant jurisdictions and service levels including specialist cancer centres and networks.



People affected by cancer often require treatment and support from different healthcare professionals, providing multiple opportunities to identify a person's care needs across their care pathway. Creating routine opportunities to identify financial toxicity, or the risk of financial toxicity, and implementing actions to reduce the financial impact of their cancer care early, can enable each person affected by cancer to access optimal cancer care without fear of the financial impact.

2.1 Identifying and responding to financial distress.

Understanding a person's risk of financial toxicity or the sources of their financial distress early and connecting them to relevant financial information and support services can reduce the impact of financial distress. There are various ways to identify a person's support needs, one of which is the use of screening tools validated in the cancer context, for example those specific to financial toxicity (e.g <u>COST-FACIT</u>), and those that include questions relevant to financial health. This enables people to take the level of action relevant to their circumstances, ensuring interventions are individualised and appropriate.

Actions:

Short term

2.1a. Reach consensus agreement on the use of financial distress and financial toxicity risk screening tools in Australian cancer care services.

2.1b. Develop effective educational strategies for healthcare providers to identify and manage financial distress in their patients.

Medium to long term

2.1c. Implement early/proactive identification of and response to financial distress.

2.1d. Development of supports to assist health care providers' provision of financial education, management of financial distress, and appropriate referral to financial counselling and services.

2.2 Addressing healthcare delivery systems.

The funding and delivery of healthcare in Australia impact the efficiency of care and the financial burden on people affected by cancer. Factors such as the availability of cancer care services in the public or private system (or both), the range of treatment options, and geographic location influence the outof-pocket costs incurred by people. Innovative healthcare models that prioritise both clinical effectiveness and cost reduction, are beneficial for people affected by cancer and the overall healthcare system. Efforts to enhance value-based healthcare approaches including maximising telehealth, providing treatment closer to home, and promoting nurse practitioner led care are essential.

Actions:

Short term

2.2a. Map current and innovative healthcare delivery and reimbursement models to identify opportunities to improve the delivery of cost-effective cancer care.

2.2b. Consult on the implementation requirements for innovative healthcare delivery and reimbursement models to be introduced to reduce costs and the risks of financial toxicity.

2.2c. Develop a system-wide implementation plan to build on current and innovative healthcare delivery and reimbursement models to reduce costs including current exemplars and the risks of financial toxicity.

Medium to long term

2.2d. Incorporate system-wide implementation plans in all cancer plans including the Australian Cancer Plan and all jurisdictional cancer plans.

Ensure access to information and support that enables informed decision making

COSA's Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer

i

Access to financial navigation

Provision of information on financial support services

Information about the risk of financial toxicity and knowing where to access practical support to reduce the impact of financial toxicity can empower individuals to make decisions appropriate for their situation. While there are common factors influencing the risk of financial toxicity, enabling timely access to information that can be contextualised to the individual circumstances and preferences is important.

3.1 Provision of information on financial support services.

Understanding the financial support service options available is the first step to accessing the relevant support and/or informing decisions to reduce financial toxicity. It can be challenging for people to know and understand their financial circumstances and sources of financial assistance to which they are entitled. Financial support services, including financial counselling, financial assistance or financial hardship programs can directly ease financial burden and provide information that support people to make decisions relevant to them.

Actions:

Short term

3.1a. Identify the sources of information about financial support services available for people affected by cancer in Australia.

3.1b. Develop a comprehensive dissemination strategy, including education, of financial support and resources available to people affected by cancer.

Medium to long term

3.1c. Enhance and expand existing information offerings where current information does not meet identified needs.

3.1d. Improve access to and embed the provision of financial support services information into standard healthcare practice.

3.2 Access to financial navigation.

Navigation connects people to individualised support to ensure people can access the information, resources, and services they need to understand their care and costs, and their options, empowering them to make decisions to reduce the financial burden of cancer. There are multiple interventions addressing different needs, provided by various organisations or functions across the health and social support systems.

Actions:

Short term

3.2a. Identify existing financial navigation, the providers and funders of such support and programs, including government and non-government organisations.

3.2b. Develop and test the effectiveness and implementation of financial navigation.

Medium to long term

3.2c. Incorporate financial navigation support into system-wide navigation and supportive care initiatives.

Create supportive work environments and financial protections through reform

COSA's Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer



The capacity of an individual with cancer and/or their family to work often changes immediately following a cancer diagnosis and can leave detrimental and longlasting effects on financial security. Policy and programs to mitigate the detrimental impacts of cancer on employment and income can provide people with greater financial security and create inclusive and supportive work environments.

4.1 Job/employment and income security reform.

Creating secure and supportive employment environments is crucial for people diagnosed with cancer, or people caring for someone with cancer. This helps reduce financial stress and uncertainty about ongoing employment or the ability to return to work when ready. Disparities in access to secure employment and financial security can lead to financial distress and discouragement from working, prompting individuals to seek government-funded income support. Promoting greater equity and accessibility to employment and income security can enhance financial independence and personal satisfaction.

Actions:

Short term

4.1a. Conduct an options analysis to identify and agree on feasible and beneficial options to enhance job and income security and mitigate the risk of financial toxicity.

4.1b. Advocate for improved employer practices and return to work supports for those who are able and interested in returning to work.

Medium to long term

4.1c. Develop and implement an advocacy plan to establish the desired approaches to support job and income security.

Foster a collaborative research community and translation into practice

COSA's Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer

Research into solutions to reduce financial toxicity

Directing research into developing initiatives to reduce financial toxicity in cancer and how systems can support equitable access to optimal cancer care without fear of financial toxicity can guide nongovernment organisations and governments to make decisions that best support people. Strengthened through fostering collaborative and coordinated efforts, resources and expertise can be utilised efficiently and effectively to identify optimal policy and program solutions.

5.1 Research into solutions to reduce financial toxicity.

Research into the experience of financial toxicity of Australians with cancer has highlighted many influencing factors and contributors to the issue. Planning research activities which prioritise gaps in knowledge and support practical solutions to the financial burden experienced by people with cancer in Australia can inform changes to the healthcare system to improve equitable access to optimal cancer care and reduce costs.

Actions:

Short term

5.1a. Form a research consortium to collaborate on research on financial toxicity and support actions within the Roadmap.

5.1b. Research consortium to identify and prioritise key gaps in knowledge to inform local and national health policy to understand the long-term impact of financial toxicity on outcomes that matter to people affected by cancer.

5.1c. Research consortium to identify resource efficiencies and redundancies in the health system that will reduce overall costs (e.g. de-escalation trials, annual medication reviews, strategies that reduce treatment toxicity, treatment closer to home).

Medium to long term

5.1d. Conduct implementation research (including economic evaluations) to activate and evaluate strategies for reducing the level and impact of financial toxicity.



COSA's Roadmap to Reducing Financial Toxicity Experienced by People Affected by Cancer

Glossary and list of abbreviations

Cancer care:

Encompasses pathways to diagnosis, treatment, clinical trials, supportive care, survivorship, and palliative care.

COSA:

Clinical Oncology Society of Australia.

Equity:

The principle of fairness and impartiality, ensuring that all individuals have equal access to healthcare services and resources, regardless of their socioeconomic status or other factors.

Financial counselling:

Services provided to individuals to help them understand and manage their financial situation, including budgeting, debt management, and accessing financial assistance programs.

Financial distress:

The subjective experience of financial toxicity.

Financial toxicity:

The negative impact of cancer-related costs on patients, including direct out-of-pocket expenses and indirect costs, leading to physical and psychological harm.

Healthcare system:

The network of organisations, institutions, and individuals involved in providing healthcare services, including government agencies, private and public health service providers, and nongovernment organisations.

Social security system:

A government program that provides financial assistance to individuals or families facing financial hardship, often including benefits such as income support and financial counselling.

Acknowledgments

COSA Financial Toxicity Working Group

Raymond Chan (Co-Chair)	Lee Hunt	Tri Nguyen
Megan Varlow (Co-Chair)	Deme Karikios	Amanda Piper
Michelle Bass	June Khaw	Carla Thamm
David Goldsbury	Reegan Knowles	Kate Whittaker
Louisa Gordon	Daniel Lindsay	Susan Woodall
Kim Hobbs	Jordana McLoone	