



**TACTICS**

Targeted Approaches To Improve Cancer Services  
for Aboriginal and Torres Strait Islander Australians

# Roundtable Cancer Survivorship for Aboriginal and Torres Strait Islander people

17<sup>th</sup> March 2021

Online Roundtable co-hosted by

Menzies School of Health Research and Clinical Oncology Society of Australia



Clinical  
Oncology  
Society of  
Australia

## Acknowledgements

We acknowledge the Traditional Owners of country throughout Australia and recognise their continuing connection to land, waters and culture. We pay our respects to Elders past, present and emerging.

We also acknowledge and give thanks to every delegate at the Roundtable, particularly the Aboriginal and Torres Strait Islander people affected by cancer. We couldn't have had this conversation without each of you. Thank you for sharing your stories that will help shape the future of cancer survivorship for Aboriginal and Torres Strait Islander people.

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This Roundtable report was prepared by Dr Bronwyn Morris, Dr Daniel Lindsay, Dr Abbey Diaz, Dr Bena Brown, Prof Joan Cunningham, Prof Michael Jefford, Prof Bogda Koczwara, and Prof Gail Garvey.

## Contents

Acknowledgements .....	2
1. Introduction .....	4
2. Delegates.....	4
3. Roundtable Agenda.....	4
4. Presentations .....	5
Mapping the Landscape: Cancer Survivorship in Australia – Prof Michael Jefford.....	5
Cancer Survivorship for Aboriginal and Torres Strait Islander people – Prof Gail Garvey .....	5
COSA Survivorship Model – Prof Bogda Koczwara.....	6
5. Group Discussions .....	6
5.1. What does cancer survivorship mean for Aboriginal and Torres Strait Islander people?.....	6
5.2. What would a model for Aboriginal and Torres Strait Islander cancer survivorship look like? .	7
5.3. If there were two things in the area of cancer survivorship that you would like to see done tomorrow – what would they be? .....	7
6. Summary and Moving Forward .....	8
7. Appendices.....	10
Appendix 7.1: References .....	11
Appendix 7.2: List of Organisations represented at the Roundtable .....	12
Appendix 7.3: Roundtable Agenda.....	13
Appendix 7.4: Materials sent to Delegates prior to Roundtable.....	14

## 1. Introduction

Across Australia and the world more broadly, cancer diagnosis rates are increasing, and advances in screening, detection and treatment are contributing to higher numbers of people living with cancer<sup>1,2</sup>. With the rising number of cancer survivors, as well as the now well-documented negative health outcomes this population experience, understanding how people can live well with cancer post-diagnosis is becoming increasingly important. Although the definition of survivorship remains contentious, in its broadest sense, cancer survivorship begins from the moment of diagnosis and continues for the remainder of life.<sup>3</sup>

Various models outlining how individuals living with cancer can achieve optimal wellbeing and quality of life when living with a cancer diagnosis exist, including the Clinical Oncology Society of Australia's Model of Survivorship Care<sup>5</sup>. Unfortunately, existing models do not consider factors which may influence the experiences of Aboriginal and Torres Strait Islander people living with cancer, including cultural and spiritual beliefs and the importance of family and community support.<sup>7-9</sup>

Partnering with the Clinical Oncology Society of Australia (COSA), Menzies School of Health Research (Menzies) hosted this Roundtable with an aim to discuss what cancer survivorship care means to Aboriginal and Torres Strait Islander people. The Roundtable was supported by the Menzies' TACTICS (Targeted Approaches to Improve Cancer Services for Aboriginal and Torres Strait Islander people) Centre for Research Excellence, which provides national and international leadership in research, knowledge translation, training and capacity building to improve cancer outcomes for Indigenous Australians across the cancer continuum.

The Roundtable gave us an opportunity to explore current Australian survivorship models of care and their relevance to Aboriginal and Torres Strait Islander people, and to identify priorities in moving forward to improve cancer survivorship care for Aboriginal and Torres Strait Islander people living with cancer.

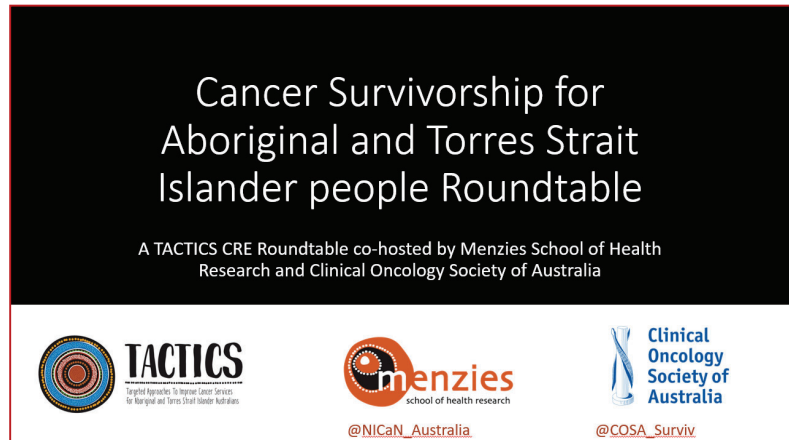
## 2. Delegates

In order to consider cancer survivorship care for Aboriginal and Torres Strait Islander people, we invited Aboriginal and Torres Strait Islander people affected by cancer and key people working in research, policy and clinical practice to take part in the Roundtable. Delegates included 42 people from across Australia, representing a diverse range of organisations and professional groups (see Appendix 7.2). The involvement of Aboriginal and Torres Strait Islander people affected by cancer in the Roundtable was integral to ensuring their perspectives were central to the discussions.

## 3. Roundtable Agenda

The Roundtable took place on 17 March 2021. It immediately preceded COSA's Cancer Survivorship Conference 2021, which was held 18-19th March, with a theme of *Life after cancer – redefined, reimagined and rebuilt*.

The Roundtable program (see Appendix 7.3) commenced with a Welcome to Country from Turrbal Elder Songwoman Maroochy. The Roundtable was facilitated by Professor Jacinta Elston (Monash University) and Professor Gail Garvey (Menzies School of Health Research).



Turrbal Elder Songwoman  
Maroochy

## 4. Presentations

Presentations were given by Professor Michael Jefford (Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre), Professor Gail Garvey (Menzies School of Health Research), and Professor Bogda Koczwara (Flinders Medical Centre and Flinders University).

### Mapping the Landscape: Cancer Survivorship in Australia – Prof Michael Jefford

Prof Jefford, Chair of COSA's Cancer Survivorship Group, presented an overview of the important work being done by this group as guided by their [2019-2021 Strategic Plan](#). The Cancer Survivorship group, the largest COSA interest group, provides a forum for health professionals involved in cancer survivorship care through their e-News, Twitter, and suite of resources and free online education. The group's Research Fellows are currently mapping current survivorship research in Australia, defining the research priorities, and working towards implementation of Patient-Reported Outcomes (PROs) into routine clinical care. This group works in partnership with government and non-government agencies to develop advocacy platforms to ensure survivors have access to the services they need.

Visit their website [www.cosa.org.au/groups/survivorship/about/](http://www.cosa.org.au/groups/survivorship/about/) for more information.

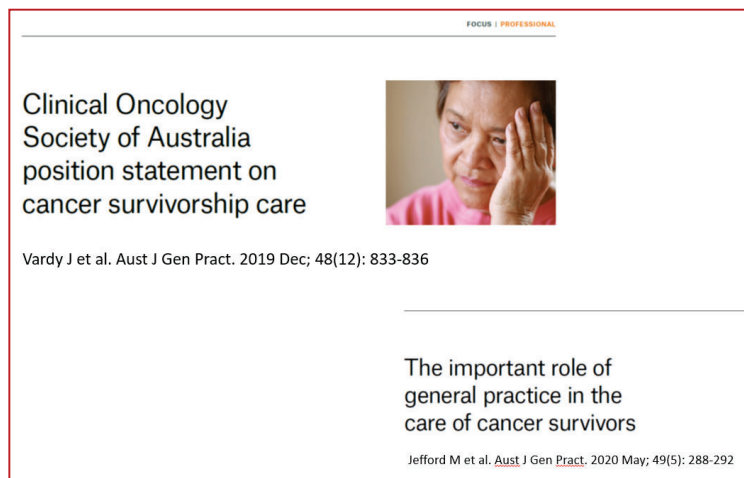


Figure 1. COSA position statement on cancer survivorship care <sup>5</sup>

### Cancer Survivorship for Aboriginal and Torres Strait Islander people – Prof Gail Garvey

Prof Garvey discussed that while there is growing interest in cancer survivorship research, especially in the post-cancer treatment phase, very little work has been done to date with Aboriginal and Torres Strait Islander people. Prof Garvey presented the findings of a small number of papers that exist to date <sup>7-9, 15</sup>, with highlights including:

- The importance of connection with self, family, community<sup>8</sup> for positive survivorship experiences
- Needing more practical approaches to improve support (e.g., community advocates, peer support programs, Indigenous health care staff in primary and tertiary care)<sup>9</sup>
- Care coordination is important.
- Unmet needs still remain high for Aboriginal and Torres Strait Islander people and we need to ensure that our Aboriginal and Torres Strait Islander patients receive culturally appropriate care<sup>15</sup>
- Understanding the importance of Aboriginal and Torres Strait Islander peoples' cultural and family connections and how this can contribute to a culturally safe model of cancer survivorship care.

Prof Garvey also presented unpublished work from the development of the National Aboriginal and Torres Strait Islander Cancer Framework (Menzies and Cancer Australia) <sup>16</sup>, which highlighted the issues that impact cancer survivorship for Aboriginal and Torres Strait Islander people as:

- Barriers to accessing services, including not knowing what services exist
- Lack of appropriate and high-quality services across the cancer continuum (particularly in rural and remote areas)
- Social determinants of health (poverty, education, housing, racism)
- Lack of cultural connection and understating of cultural and spiritual healing
- Being left alone to cope with little support
- The need for Indigenous-specific resources.

## COSA Survivorship Model – Prof Bogda Koczwar

Prof Koczwar prefaced her presentation by stating that she frames survivorship as an approach to care, rather than a reflection of individuals' experiences and identity in the time after their cancer diagnosis.

Prof Koczwar presented multiple models of survivorship, beginning with the COSA Survivorship model<sup>5</sup> (Figure 2). Developed in 2016, this detailed model provided a linear progression of the needs of a patient across the cancer continuum, with greater emphasis on the period after treatment ends.

In other models presented by Prof Koczwar additional elements of cancer survivorship care were identified, such as:

- Survivorship outcomes (e.g., quality of life, hospitalisations, costs, mortality)<sup>17</sup>
- Survivorship for people with metastatic cancer (and the need for more research focused on living with metastatic disease)<sup>18</sup>
- Care delivery for chronic illness extends beyond the patient and health service; it also involves factors such as policy, social determinants of health, health literacy and cultural norms<sup>19, 20</sup>
- A model of care for chronic illness, such as cancer, needs to acknowledge the interaction between patient, community, health care service, and health care partners<sup>20</sup>
- A new model of survivorship for prostate cancer has been developed that puts the person with cancer at the centre of decision making<sup>21</sup>

Delegates were asked to consider what elements they felt were important for cancer survivorship for Aboriginal and Torres Strait Islander people, and what elements they felt may still be missing from these models.

## 5. Group Discussions

The presentations were complimented by a series of small breakout group discussions on three topics:

1. **What does cancer survivorship mean to Aboriginal and Torres Strait Islander people?**
2. **What would a model for Aboriginal and Torres Strait Islander cancer survivorship look like?**
3. **If there were two things in the area of cancer survivorship that you would like to see done tomorrow – what would they be?**

The voices and experiences of Aboriginal and Torres Strait Islander delegates, especially those with an experience of cancer either as a patient or a carer/family member, were prioritised throughout the Roundtable, particularly during the small breakout group discussions. Rich discussion was recorded in each group, and below is a snapshot of some of the highlights for each topic.

### 5.1. What does cancer survivorship mean for Aboriginal and Torres Strait Islander people?

To emphasise the lived experience, we spoke with a group of Aboriginal and Torres Strait Islander people who currently have, or have had, cancer prior to the Roundtable to ask them *“what does cancer survivorship mean to you?”* The key outcomes from these discussions highlighted the **practical barriers to optimal cancer survivorship, which included a lack of access to services, good food, accommodation and transport, in addition to the financial burden experienced.** Survivorship during the diagnosis and treatment experience was hindered by **health services that were not culturally appropriate and a lack of understanding about cancer and treatment.** These Aboriginal and Torres Strait Islander people affected by cancer also discussed what was important to them for cancer survivorship and this included: **strength and self-determination, clear self-care plans, peer support, and the importance of family.**

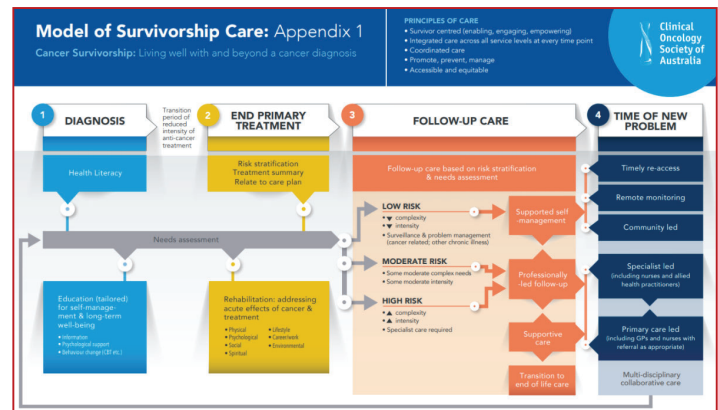


Figure 2. COSA Model of Survivorship Care<sup>5</sup>

During the small breakout groups, highlights of discussions included:

- A holistic view of health and wellbeing, that also extends beyond just the person diagnosed with cancer
- Living well – not just surviving
- Self-management and clarity around care plans
- Individualised care and figuring the best ways to assess what is needed by the individual
- Language matters – the term “survivor” does not necessarily represent the experience
- Support and reducing burdens (e.g., financial)

## 5.2. What would a model for Aboriginal and Torres Strait Islander cancer survivorship look like?

To emphasise the voices of Aboriginal and Torres Strait Islander people affected by cancer, Prof Garvey presented unpublished data from the development of the National Aboriginal and Torres Strait Islander Cancer Framework<sup>16</sup>. Framework consultations with Aboriginal and Torres Strait Islander people revealed several factors to be considered for a survivorship model, including:

- Awareness of the worry that comes with survivorship
  - Cultural beliefs and practices can support people through this worry and should be factored into models of survivorship
- Healthy behaviours and lifestyle, and education around cancer recurrence
- The period after treatment completion is an important time to provide support
- “Cancer survivorship is a white fella term” – models need language that is inclusive
- Programs and initiatives that promote survivorship and people living well after cancer are needed.

During the small breakout groups, several critical elements of survivorship care were identified by the delegates and it was felt that an optimal model of care for Aboriginal and Torres Strait Islander people affected by cancer would include:

- The patient in the centre – this was considered integral, yet was missing from most of the existing models
- The whole cancer pathway needs, with an emphasis on “living well” (regardless of whether this is with or without cancer)
  - The pathway is not linear
- Preventive care, including of cancer recurrence, metastases, and other chronic conditions, after a cancer diagnosis
- Self-determination – which delegates thought could be achieved through a patient and family advocate
- Cultural, family, and spiritual aspects
- Additionally, delegates stated that the model needs to be presented in an easier way to be understood. Specifically, less text and more pictures and graphics were thought to be important for patient materials

## 5.3. If there were two things in the area of cancer survivorship that you would like to see done tomorrow – what would they be?

Delegates were asked to consider what their priorities would be to improve cancer survivorship for Aboriginal and Torres Strait Islander people. Highlights of the small breakout group discussions included:

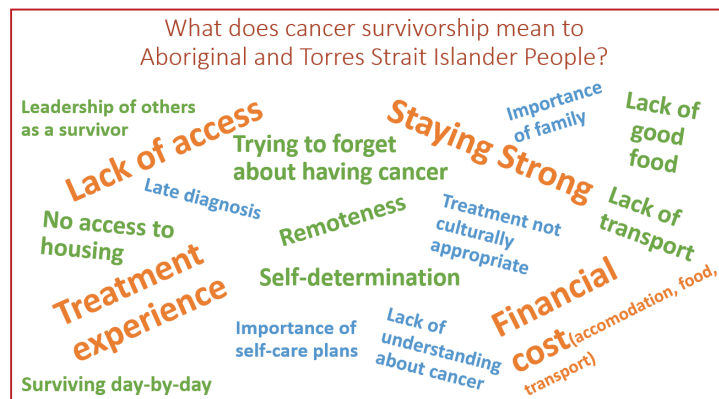
- Cancer workforce shake-up including:
  - Hospital setting – multidisciplinary coordination including Aboriginal Liaison Officers being in the room when treatment decisions are being made
  - Navigator within the health system to ensure the cancer survivor is aware of services
  - Aboriginal and Torres Strait Islander healthcare workers who are specialised in cancer, including across cancer types (and childhood cancers)
  - Community setting – navigators/advocates, peer support groups
  - Cultural training and awareness for all workforce across the cancer continuum

- Funding and infrastructure to support coordination of cancer care across all areas/sectors. Particularly when it comes to survivorship after active treatment ends – it’s essential that the tertiary sector engages with the primary healthcare sector
- Develop government funded programs e.g., transport, make access to allied health services more affordable (e.g., telehealth)
- Survivorship needs to focus on quality survivorship, with patient-centred models of care
  - This is especially important to providing support for patients returning to their community (e.g., support from health sector, volunteers, advocates)
- Involvement of Aboriginal and Torres Strait Islander people to ensure community engagement and ownership of what survivorship looks like
  - Importance of sharing stories to improve the survivorship experience and improve care
- Peer support from Aboriginal and Torres Strait Islander people with cancer (e.g., Survivor buddy, support groups)
  - Sharing positive stories of cancer survivorship
- Detailed cancer care plans including health behaviours, diet, regular check-ups etc
- Create a central source of medical records (e.g., a better version of My Health) so that healthcare services (not just cancer services) are aware of patient records
  - This will help to coordinate follow-ups and check-ups etc
- Development of culturally appropriate resources about living well with and beyond cancer and ensuring widespread distribution
- Acknowledging the critical role of family in survivorship
- Include meaningful strategies in cancer plans (including appropriate investment and infrastructure) regarding cancer wellness management for Aboriginal and Torres Strait Islander people

## 6. Summary and Moving Forward

This Roundtable was the beginning of an important discussion about cancer survivorship and care for Aboriginal and Torres Strait Islander people, and existing survivorship models and their relevance to Aboriginal and Torres Strait Islander people, and identifying some areas to move forward.

The Roundtable discussions emphasised the importance of promoting cancer survivorship stories from Aboriginal and Torres Strait Islander people. These experiences highlight that not only can Aboriginal and Torres Strait Islander people survive cancer, but that Aboriginal and Torres Strait Islander people can live well with, and beyond, cancer.



Survivorship for Aboriginal and Torres Strait Islander people impacts on the patient, carers, family and broader community. Current survivorship models are not appropriate for or reflect the experiences of Aboriginal and Torres Strait Islander people. Holistic survivorship models are needed that promote self-determination and that incorporate Aboriginal and Torres Strait Islander culture, highlight the importance of family in the cancer journey and have a larger focus on the later stages of the cancer journey.

There are many challenges to improving cancer survivorship for Aboriginal and Torres Strait Islander people and fundamental systemic changes include a shake-up of the cancer healthcare workforce and providing high quality practical and cultural support for Aboriginal and Torres Strait Islander patients and their families.

Moving forward, we know that we can’t do this alone. We need to work together to engage all the key stakeholders if we are to make a difference. Future work and continued discussions must be grounded in the voices and experiences of Aboriginal and Torres Strait Islander people. A key component in this would



be investing in, and supporting, Aboriginal and Torres Strait Islander people affected by cancer to demonstrate that cancer can be beaten.

Following on from this Roundtable, the team at Menzies School of Health Research, will continue to progress these discussions with Roundtable delegates and other key stakeholders, with the goal of improving cancer survivorship for Aboriginal and Torres Strait Islander people.

## 7. Appendices

Appendix 7.1: References for Introduction

Appendix 7.2: List of Organisations represented at the Roundtable

Appendix 7.3: Roundtable Agenda

Appendix 7.4: Materials sent to Delegates prior to Roundtable

7.4.1: COSA Position Statement on cancer survivorship care

7.4.2: COSA Model of Survivorship Care

7.4.3: Cancer Australia Principles of Cancer Survivorship

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*Appendix 7.2: List of Organisations represented at the Roundtable*

**In addition to ensuring that Aboriginal and Torres Strait Islander people directly affected by cancer (n=12) were included in the Roundtable, delegates also included people from the following organisations:**

Australian Cancer Survivorship Centre
Cancer Australia
Cancer Council Australia
Cancer Council Queensland
Cancer Institute NSW
COSA
Flinders University
GENESISCARE
Gippsland Regional Integrated Cancer Service
Menzies School of Health Research
Monash University
Mount Isa Aboriginal Community Controlled Health Services trading as Gidgee Healing
NT Radiation Oncology
Peter MacCallum Cancer Centre
Queensland University of Technology
SAHMRI
University of Adelaide
University of NSW
University of South Australia
University of Sydney

## Appendix 7.3: Roundtable Agenda

# ROUNDTABLE AGENDA

Cancer Survivorship for Aboriginal and Torres Strait Islander People



# TACTICS

Targeted Approaches To Improve Cancer Services  
for Aboriginal and Torres Strait Islander Australians

WEDNESDAY 17 MARCH 2021 | 9am – 12pm (AEDT)

Welcome to Country

Housekeeping and introduction to the Roundtable

*Co-facilitators: Professor Jacinta Elston and Professor Gail Garvey*

 **Our purpose and anticipated outcomes from the Roundtable**

*Presented by Professor Jacinta Elston, Monash University*

 **Mapping the landscape: Cancer Survivorship in Australia**

*Presented by Professor Michael Jefford, Australian Cancer Survivorship Centre, Peter Mac*

 **Cancer Survivorship for Aboriginal and Torres Strait Islander people**

*Presented by Professor Gail Garvey, Menzies School of Health Research*

 **Breakout Groups**

*What does cancer survivorship mean for Aboriginal and Torres Strait Islander people?*


 **Feedback from Breakout Groups**

 **COSA Survivorship Model**

*Presented by Professor Bogda Koczwara, Flinders Medical Centre and Flinders University*

 **Breakout Groups**

*What would a model for Aboriginal and Torres Strait Islander cancer survivorship look like?*

 **Feedback from Breakout Groups**

 **Breakout Groups**

*If there were two things in the area of cancer survivorship that you would like to see done tomorrow – what would they be?*

 **Feedback from Breakout Groups**

Summary, Wrap up, and Where to from here?

*Appendix 7.4: Materials sent to Delegates prior to Roundtable*

# Clinical Oncology Society of Australia position statement on cancer survivorship care



**Janette L Vardy**, Raymond J Chan, Bogda Koczwara, Karolina Lisy, Richard J Cohn, David Joske, Haryana M Dhillon, Michael Jefford

## Background

Cancer survivors often experience long-term negative consequences of their cancer and cancer treatment. With increasing numbers of survivors and duration of survival, a sustainable model of care is required to better meet the needs of cancer survivors.

## Objective

The aim of this article is to outline the Clinical Oncology Society of Australia Model of Survivorship Care, summarising the critical components of cancer survivorship care.

## Discussion

Recommendations include: a systematic, multidisciplinary care approach that optimises self-management and enhances coordinated and integrated survivor-centred care from diagnosis; stratified care pathways based on survivors' needs, capacity to self-manage and anticipated treatment sequelae; a focus of care on wellness, healthy lifestyle, symptom management and prevention of life-altering and life-threatening late effects in addition to cancer surveillance; development of a treatment summary and care plan; and equitable, timely access to services, while minimising unnecessary use of healthcare services.

**WITH ADVANCES IN CANCER SCREENING,** detection and treatment, the number of people surviving cancer is increasing rapidly. In 2018, an estimated 140,000 new cases of cancer were diagnosed in Australia, with 1.1 million people having a personal history of cancer. This is expected to increase to 1.9 million by 2040.<sup>1</sup> In its broadest definition, a person is a cancer survivor from diagnosis for the remainder of their life.<sup>2</sup>

Cancer survivors often experience long-term negative consequences of their cancer and cancer treatment, in addition to the risk of a cancer recurrence or a second primary cancer. Cancer survivors have an increased risk of cardiovascular disease, type 2 diabetes, metabolic syndrome and osteoporosis.<sup>2-6</sup> Many have long-term residual symptoms, with more than half of early-stage survivors reporting five or more symptoms of at least moderate severity 12 months after diagnosis,<sup>7</sup> and fatigue, loss of strength, pain, sleep disturbance and weight changes up to five years after diagnosis.<sup>8,9</sup> Cognitive impairment, fatigue and other symptoms can affect independent functional ability and return to work, decreasing financial security.<sup>10,11</sup> Other common physical long-term treatment effects include sexual dysfunction, infertility and chemotherapy-induced peripheral neuropathy.<sup>12</sup> Late-term effects include second malignancies, and impaired cardiac and pulmonary function.<sup>12</sup>

Fear of cancer recurrence occurs in approximately 70% of survivors, with approximately 50% reporting fear of at least moderate severity,<sup>13</sup> high levels of uncertainty about the future,<sup>8</sup> and unmet needs focused on fear of relapse.<sup>14</sup> Changes in social roles, support networks and family and intimate relationships often occur, creating added distress.<sup>15</sup>

To address these unique needs of cancer survivors, there have been a number of recommendations for delivery of survivorship care. The seminal report *From cancer patient to cancer survivor: Lost in transition* defined essential components of survivorship care.<sup>16</sup> These included prevention of recurrent and new cancers and late effects of treatment; surveillance for cancer spread, recurrence, second cancers, and physical and psychosocial late effects; interventions for the consequences of cancer and its treatment; and coordination between the specialist cancer care team and primary care providers to ensure survivors' health needs are met.

In 2017, Cancer Australia released a national framework to guide policy development and health system responses to cancer survivorship, focusing on improving the health and wellbeing of people living with and beyond cancer.<sup>17</sup> National 'optimal care pathways' define recommendations for care across the cancer trajectory, including in the post-treatment follow-up (survivorship) phase, calling for 'screening and assessment of medical and psychosocial

late effects' and 'interventions to deal with the consequences of cancer and cancer treatments'.<sup>18</sup>

Despite these calls for action, care of cancer survivors in Australia continues to focus on cancer surveillance in the specialist setting without sufficiently addressing the concerns or needs of cancer survivors.<sup>19</sup> With increasing awareness that cancer is a chronic disease for many people, a shift in emphasis is required to a more structured and multidisciplinary approach for prevention and treatment of symptoms, long-term complications and comorbidities to improve survivors' health and wellbeing. To address this, the Clinical Oncology Society of Australia (COSA) Survivorship Group developed a Model of Survivorship Care outlining the critical components of cancer survivorship care with the aim of improving the care of Australians beyond cancer diagnosis and treatment.<sup>20</sup>

## Methods

A multidisciplinary working group of experts from cancer, allied health, primary care and community-based organisations was convened to develop the model using a literature review and consensus processes where evidence was

### Box 1. Clinical Oncology Society of Australia position on a model of care for early-stage cancer survivors after completion of primary treatment

1. Healthcare teams should implement a systematic approach to enhance coordinated and integrated survivor-centred care.
2. Stratified pathways of care are required.
3. Survivorship care should support wellness, healthy lifestyle and primary and secondary prevention while preventing and managing treatment-related symptoms, late-term effects and comorbidities, in addition to cancer surveillance.
4. At transition to follow-up care, healthcare teams should develop a treatment summary and survivorship care plan.
5. Survivors require equitable access to services in a timely manner, while minimising unnecessary use of healthcare services and resources.

lacking. An iterative development process was undertaken including survey and feedback of COSA members and groups, professional organisations and national consumer advocacy groups.

## Recommendations

The model is outlined in Figure 1. Box 1 summarises the key recommendations.

**1. Cancer healthcare teams should adopt a multidisciplinary, systematic approach to deliver coordinated and integrated survivor-centred care for all individuals from the time of diagnosis in partnership with primary care providers. Care teams should support self-management with integration between primary care, community support, non-government organisations and the specialist cancer care services.**

Care should be integrated, with recognition that primary care may be best placed to provide preventive care and manage comorbidities, health risk factors (eg smoking, obesity, inactivity) and aspects of cancer follow-up.<sup>21</sup> Most cancer survivors have comorbid illnesses<sup>22,23</sup> and existing regular reviews with their general practitioners (GPs).<sup>24</sup> Integrated care requires clear and timely communication between all healthcare professionals involved in a patient's care. It is critical that professional roles are defined so that all aspects of needed care are provided without duplication.

**2. Stratified pathways of care should be based on the needs and risk factors of the individual, treatment sequelae, existing comorbidities and capacity to self-manage (including assessment of health literacy). Risk of late effects is informed by treatment received. Needs require regular review and update to ensure relevance, with tailored education and rehabilitation as appropriate.**

The COSA model recognises that post-treatment outcomes are informed by events during the diagnostic and treatment phases. Survivorship care should be tailored to the individual's issues, needs

and concerns (via a needs assessment such as patient-reported outcome or experience measures) and guided by their risk of developing late and long-term effects, recurrence or a new cancer.<sup>12,25</sup> Care requirements will also be affected by comorbidities, social circumstances, health literacy and a person's ability and desire to self-manage. Patients who wish to be involved in their own post-treatment cancer care should be provided with the information and support needed to self-manage, as is commonly done for other chronic disease management models (eg diabetes, asthma).<sup>21,26</sup>

**3. In addition to cancer surveillance and management of symptoms and late-term effects, survivorship care should support wellness, healthy lifestyle and primary and secondary prevention.**

Until recently, post-treatment cancer care focused on surveillance for cancer recurrence and/or new primary cancers.<sup>2</sup> While surveillance remains important, lifestyle factors of survivors increase their risk of developing comorbid illnesses. Many struggle to meet Australian diet and physical activity recommendations.<sup>7,27</sup> Survivorship care that supports healthy lifestyle behaviours is essential to reduce comorbid disease and maximise recovery and wellness. Referral to allied health professionals and evidence-based programs to assist cancer survivors to be physically active and eat well is critical in achieving these outcomes, as few patients achieve these goals without assistance. Practitioners should refer survivors to local services using chronic disease management GP plans, private health insurance and/or community-based low-cost programs to engage patients in effective behaviour change. Lifestyle behaviour change programs offer the best available options for long-term prevention, minimisation and management of symptoms and late effects of cancer and its treatments.

**4. At transition to follow-up care, healthcare teams should develop a treatment summary and survivorship care plan as key tools to facilitate comprehensive care planning and communication between healthcare**



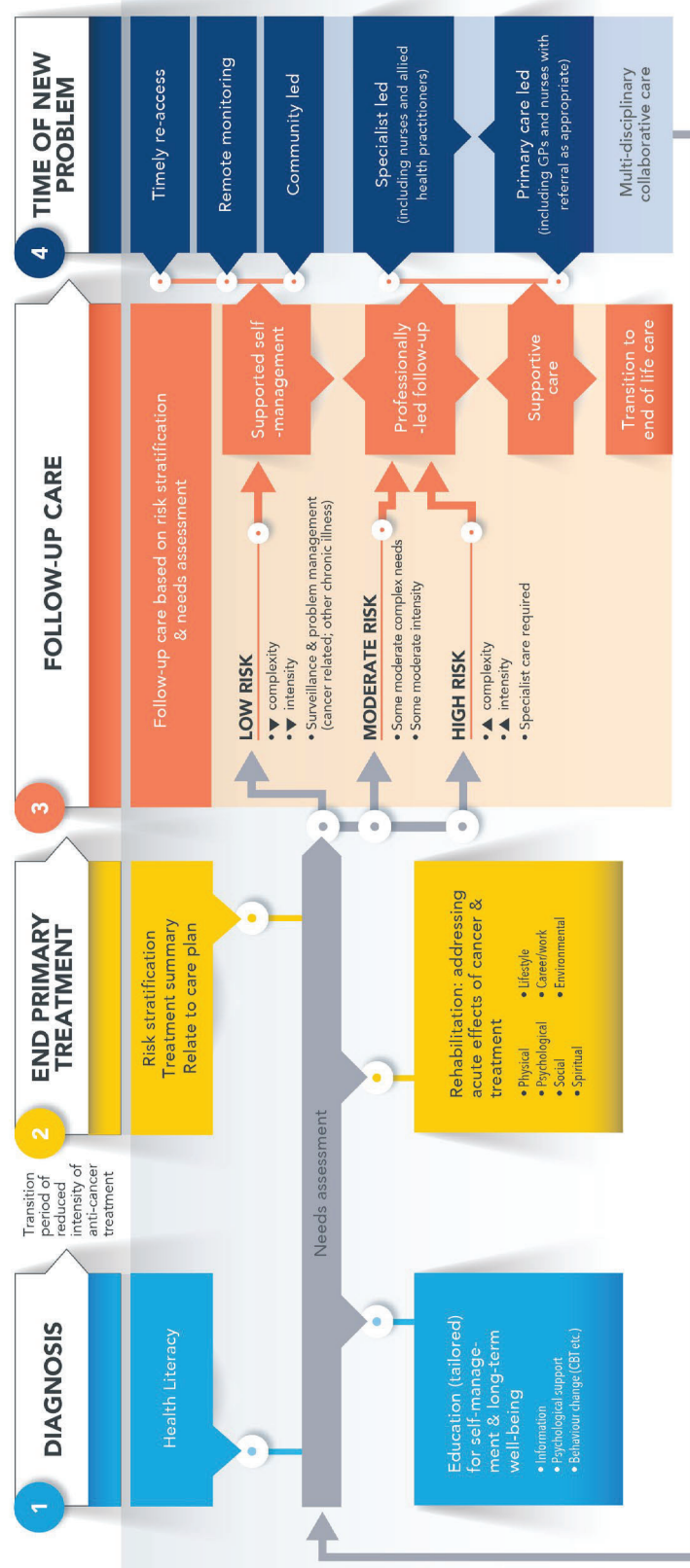
providers. The survivorship care plan requires regular review and update to document main concerns and agreed actions.

Transition from intense, acute specialist care to survivorship care can be facilitated by preparing the survivor with timely communication and provision of a treatment summary and survivorship care plan.<sup>2,18,20</sup> This should include a treatment summary, outlining the cancer diagnosis and treatments, and a plan for follow-up, including strategies to remain well. Survivorship care plans should be completed by a member of the specialist cancer care team with input from the survivor and those involved in providing survivorship care. The care plans should clearly define the role of members in the care team, be regularly reviewed with the GP and other relevant health professionals, be updated as required and be communicated to all parties when changes are made to facilitate communication.

According to a recent systematic review, survivors who received a treatment summary and survivorship care plan reported a greater preference for shared care, were more likely to identify the GP’s responsibility in follow-up care, and had more cancer-related contact with their GP and increased implementation of survivorship care recommendations when compared with those who did not receive a treatment summary and survivorship care plan.<sup>28</sup>

**5. Survivors require equitable access to services in a timely manner, while minimising unnecessary use of healthcare services and resources.**

The burden of unmet need and disability after cancer diagnosis varies according to cancer type and treatment, place of residence and socioeconomic status, with patients from rural and remote Australia and lower socioeconomic status reporting more comorbidity, worse health outcomes and less access to cancer care and support.<sup>29</sup> To ensure care is efficacious and equitable, effective survivorship care needs to be accessible



**Figure 1.** Model of Survivorship Care  
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through novel models of care delivery such as telemedicine and digital technology interventions as well as primary care-led services. An integrated approach that takes advantage of shared care arrangements between cancer services and primary care is likely to be more cost effective.<sup>30</sup>

## Conclusions

An improved model of survivorship care is expected to result in better outcomes for survivors. These outcome measures may include improved duration of survival, reduced risk of cancer recurrence, decreased risk of late effects, better quality of life and improved functional and wellbeing outcomes. At present, the evidence basis remains incomplete, and successful implementation will require research, education, coordination and advocacy. The COSA Survivorship Model of Care provides a template for change, guiding the key steps for implementation into the future.

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Competing interests: MJ reports personal fees in the form of a travel grant from Roche, outside the

submitted work. HD reports honoraria paid to her institution from MSD, outside the submitted work. Funding: None.

Provenance and peer review: Not commissioned, externally peer reviewed.

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# Model of Survivorship Care: Appendix 1

Cancer Survivorship: Living well with and beyond a cancer diagnosis

## PRINCIPLES OF CARE

- Survivor centred (enabling, engaging, emp...
- Integrated care across all service levels at
- Coordinated care
- Promote, prevent, manage
- Accessible and equitable

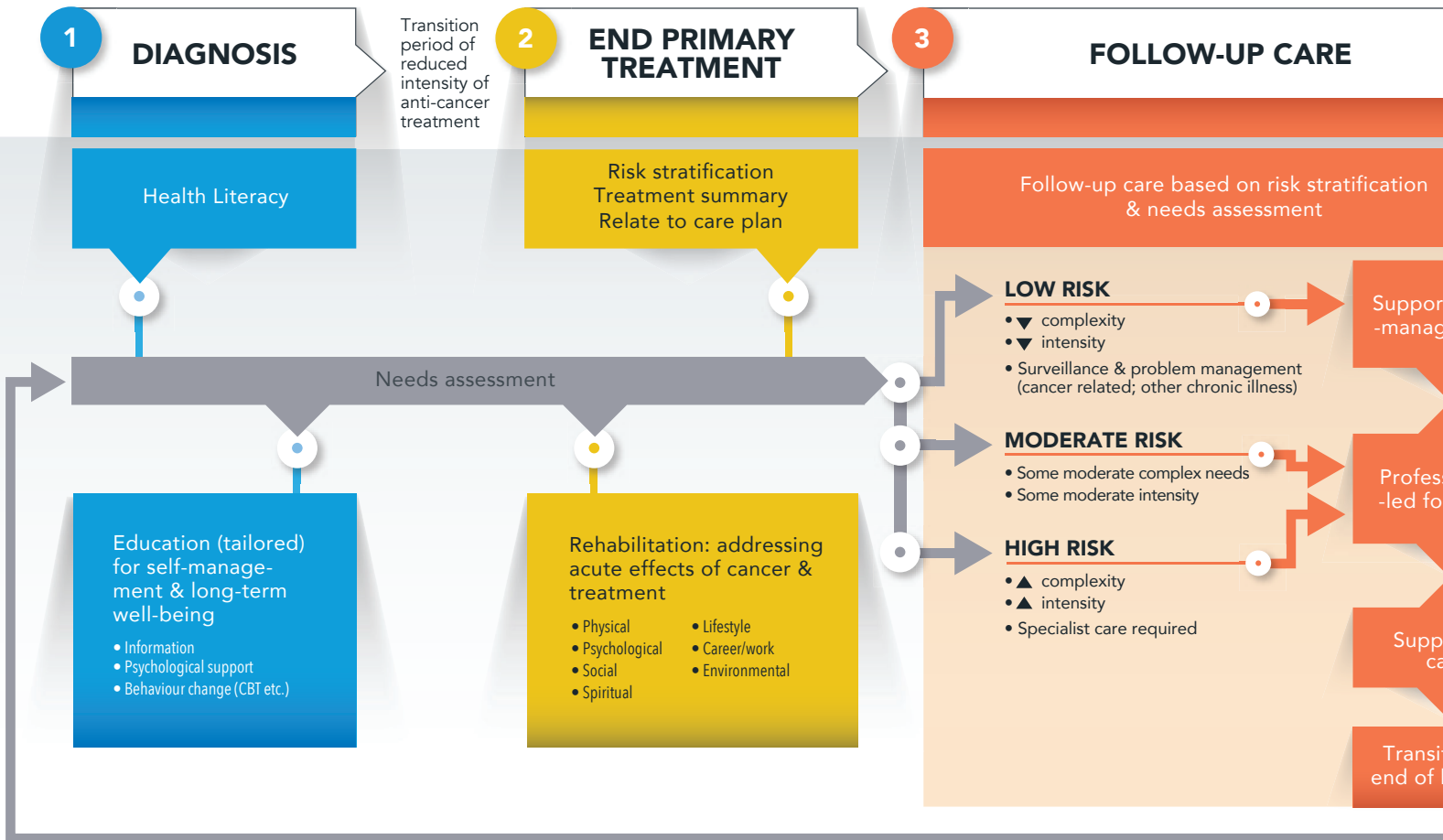


Figure 1. Model for wellness in cancer survivorship

### RISK STRATIFICATION

- Level of risk associated with cancer type
- Needs assessment
- Short & long term effects of treatment
- Comorbidities
- Patient ability & motivation to self-manage
- Level of professional involvement required

### CARE PLAN

- Aims to document main concerns of survivor & health professional & agreed actions for:
  - Surveillance
  - Management
  - Discussion
  - Patient action
  - Rehabilitation
- Clinical team follow-up, sign posting on referral

### CARE COORDINATION

- Places survivor & their needs at centre of healthcare & wellness interactions
- Facilitates communication between all health professionals
- Gets survivors to the right services at the right time
- Ensures regular review of survivorship care plan and survivor needs
- Ensures appropriate follow-up for cancer recurrence and late effects of treatment

### TIME FACTORS

- Survivors engage with services they need
- Survivor priorities & needs are addressed to least urgent
- Survivor time in healthcare environments to that required to maintain health & well-being
- Survivors have rapid access to healthcare when required for cancer & treatment related needs
- Resource use is minimised to the level that is safe and meaningful

# Model of Survivorship Care: Appendix 1

Cancer Survivorship: Living well with and beyond a cancer diagnosis

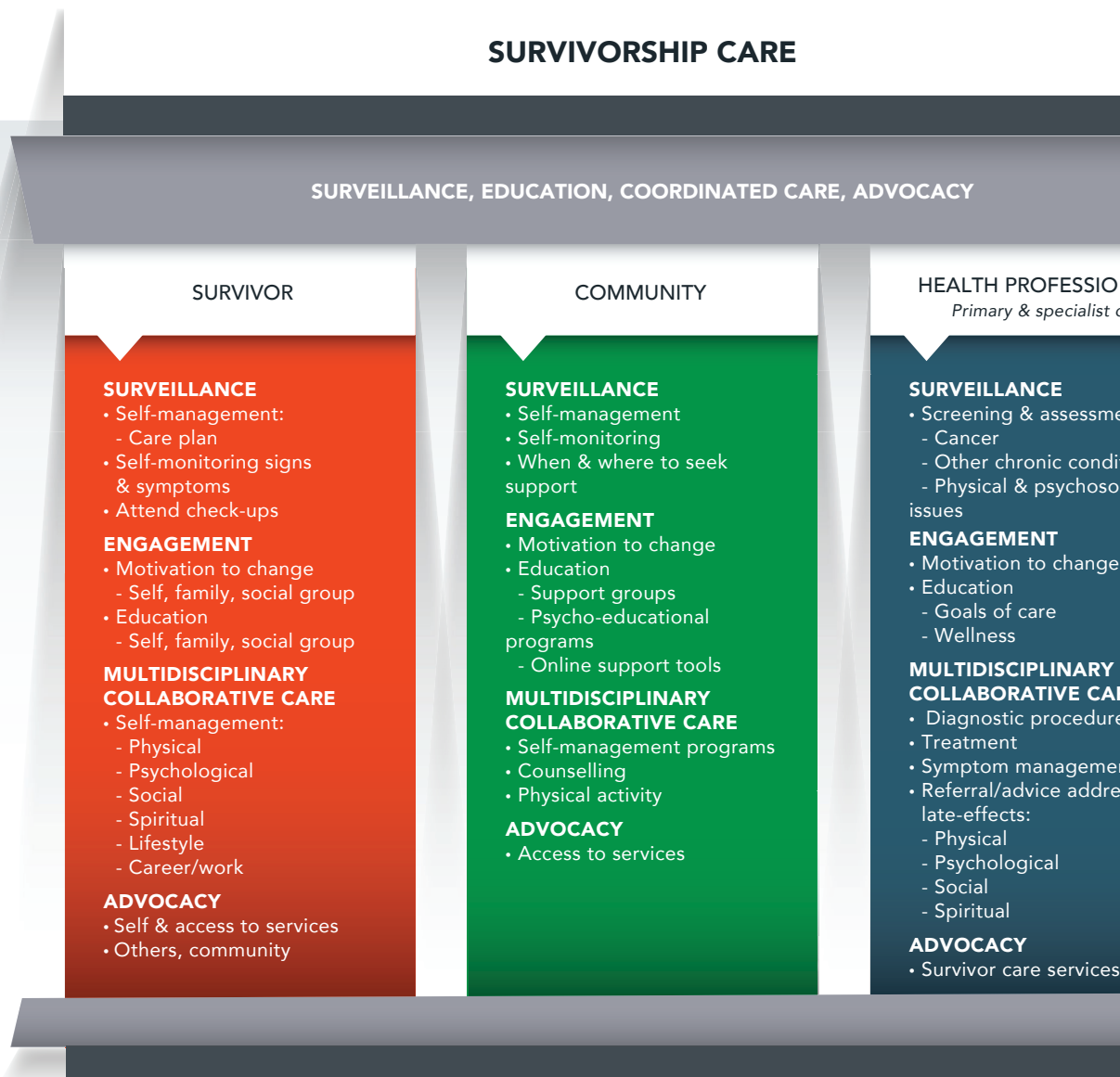


Figure 2. Three pillars of survivorship care

## Principles of Cancer Survivorship

### Purpose

Cancer Australia's *Principles of Cancer Survivorship* (the Principles) provide a national framework to guide policy, planning and health system responses to cancer survivorship, focusing on the health and wellbeing of people living with and beyond cancer.

The Principles are intended for government, policy makers, health system decision makers, cancer organisations and consumer organisations.

### Context

An estimated 1.1 million people living in Australia have had a diagnosis of cancer.<sup>1</sup> Australians experience among the highest cancer survival rates in the world, and improvements in diagnostic methods, earlier detection and advances in treatment are contributing to more Australians surviving cancer than ever before. As survival for cancer overall continues to improve, an increasing proportion of the population will require ongoing treatments, support and long-term follow-up care.

With a 38% projected increase in cancer diagnosis between 2015 – 2025,<sup>2</sup> and an increasing number of people living longer with cancer and other chronic diseases, there is an ongoing need to address the long-term health and wellbeing of people affected by cancer.

Survivorship provides a focus on the health and wellbeing of a person living with and beyond cancer. Family members and caregivers are also part of the survivorship experience.

Cancer Australia's Principles of Cancer Survivorship have been developed to guide national approaches to reduce the impact of cancer and improve the health and wellbeing of people affected by cancer across the cancer care continuum (Figure 1).

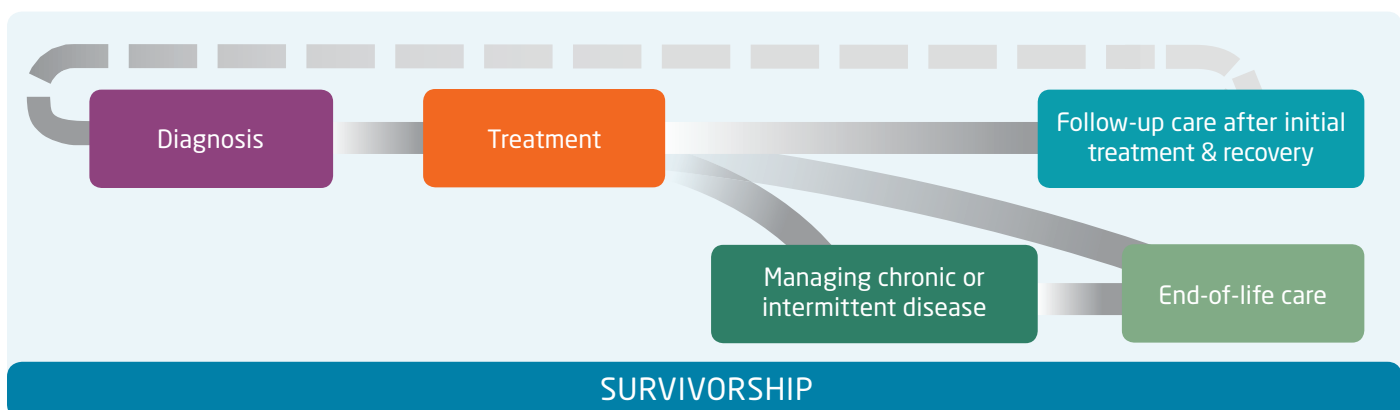
### The Principles of Cancer Survivorship

The Principles of Cancer Survivorship provide a national framework to guide policy, planning and health system responses to cancer survivorship, focusing on the health and wellbeing of people living with and beyond cancer.

The Principles are supported by intended outcomes and underpinned by elements to achieve personalised care, opportunities for self-management, an emphasis on recognising and incorporating patient experiences, and a focus on the ongoing management, recovery, health and wellbeing during and after cancer treatment.

- ▶ PRINCIPLE 1 CONSUMER INVOLVEMENT IN PERSON-CENTRED CARE
- ▶ PRINCIPLE 2 SUPPORT FOR LIVING WELL
- ▶ PRINCIPLE 3 EVIDENCE-BASED CARE PATHWAYS
- ▶ PRINCIPLE 4 COORDINATED AND INTEGRATED CARE
- ▶ PRINCIPLE 5 DATA-DRIVEN IMPROVEMENTS AND INVESTMENT IN RESEARCH

FIGURE 1 CANCER CARE CONTINUUM \*



# Principles of Cancer Survivorship



## Principle 1: Consumer involvement in person-centred care

### Outcome

People affected by cancer are enabled to be involved in shared decision-making and supported to self-manage according to their preferences.<sup>3,4</sup>

Informed and engaged consumers lead to better health outcomes and improved safety.<sup>5,6</sup>

### Elements

- ▶ People affected by cancer are provided with timely evidence-based information tailored to their individual circumstances and needs, and supported to participate in shared decision-making according to their preferences.
- ▶ People affected by cancer are empowered and supported to self-manage according to their preferences, with identified pathways for timely access to specialist providers as required.
- ▶ Care is person-centred with consideration and respect given to consumer preferences and beliefs.

## Principle 2: Support for living well

### Outcome

The supportive care needs\* of people affected by cancer are assessed and they receive appropriate referrals to promote optimal health and quality of life outcomes.<sup>7</sup>

People affected by cancer are supported to make informed lifestyle choices to promote wellness, manage treatment related side effects and co-morbidities, and reduce risk of second and recurrent cancers.<sup>8</sup>

\*Includes physical, psychological, social (including educational, financial and occupational issues), cultural, information and spiritual needs.

### Elements

- ▶ The supportive care needs of people affected by cancer are systematically assessed at key points across the continuum of care with appropriate interventions and referral as required to promote optimal quality of life.
- ▶ People affected by cancer receive information on healthy lifestyles and are actively encouraged and supported in making lifestyle choices to promote optimal health and to prevent disease and distress.

## Principle 3: Evidence-based care pathways

### Outcome

People affected by cancer receive consistent, safe, high-quality evidence-based cancer care in line with Optimal Cancer Care Pathways,<sup>7</sup> according to their individual circumstances and needs.

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### Elements

- ▶ People affected by cancer receive timely evidence-based care in line with Optimal Cancer Care Pathways, including personalised care planning across the continuum of care.
- ▶ A multidisciplinary team considers all relevant treatment and supportive care options and develops recommended individual treatment plans which are adjusted over time to address changing patient needs.
- ▶ Stratified pathways for follow-up are based on tumour characteristics, treatments applied and individual circumstances, with identified pathways for timely access to specialist providers as required.

## Principle 4: Coordinated and integrated care

### Outcome

People affected by cancer receive holistic patient-centred care which is coordinated and integrated across treatment modalities, providers and health settings, including public and private sectors; and specialist, primary, community based and not-for-profit services.

Care is delivered in a logical, connected and timely manner for optimal continuity and to meet the individual needs of people affected by cancer.

### Elements

- ▶ Care is integrated and coordinated between health and other service providers to enable seamless holistic patient-centred care for people affected by cancer.
- ▶ Clear and timely communication processes are adopted between providers and with consumers.

## Principle 5: Data-driven improvements and investment in research

### Outcome

National collection and reporting of key cancer data, including consumer experience and outcome data, provides an indicator for high quality care, influences health service improvements and informs investment in research.

Published research in cancer survivorship enriches the evidence base and informs improvements to enhance the care and outcomes of people affected by cancer.

### Elements

- ▶ Consumer and carer experience, treatment and outcome data are routinely captured and consistently reported for accountability and to improve quality of care.
- ▶ Research in cancer survivorship is translated to inform practice, innovation and improvement in cancer care.

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