Submission to the Australian Cancer Plan Consultation from the

COSA Survivorship Group, Policy Working Group

March 2022

The Clinical Oncology Society of Australia (COSA) is the peak national body representing health professionals from all disciplines whose work involves the care of cancer patients. This submission is made on behalf of the COSA Survivorship Group, Policy Working Group to inform the Australian Cancer Plan regarding cancer survivorship policy considerations.

1. What would you like to see the Australian Cancer Plan achieve?

Think ahead to the next 10 years. What do you want the Australian Cancer Plan to achieve? Think big – what transformational change(s) should we be aiming to influence?

We recommend realistic, achievable projects and actionable strategies for Cancer Australia; small ideas implemented across the system can make transformational change for a large number of Australian cancer survivors.

The COSA Survivorship Policy Group suggest ten priority actions with possible actions within the ten-year period, below. The COSA Survivorship Policy group have expertise in post treatment cancer care with authority and connections nationally and internationally. We are eager to help expand upon, develop or investigate any of these with Cancer Australia and others.

1. **Establish a monitoring / evaluation framework to accompany the ACP, which describes responsibility and accountability.**
    - Years 1- 2: Establish a plan for the framework, implementation strategies and associated timeframes, set key performance indicators.
    - Years 3- 5: Pilot some measures at jurisdiction or national level.
    - Years 6- 10: A fully functioning monitoring and evaluation framework for the ACP.

How can we help? As an example, the COSA Survivorship Policy Group can help review the implementation plans that sit alongside existing jurisdictional cancer plans.

2. **Establish appropriate funding mechanisms to enable implementation of evidence-based supportive care interventions**, especially those with proven benefit that are not routinely funded or implemented, for example exercise physiology, psychology and other allied health interventions, multidisciplinary rehabilitation, and pre-habilitation programs.

Empowering patients pre-treatment and establishing good self-management practices may support this to occur throughout and post initial cancer treatment. There may be opportunities in the future with prehab to better engage primary care providers (GP + local allied health/community health) and start earlier conversations re: expectations for care delivery, as a roadmap to better survivorship care post initial treatment. The funding mechanisms for these evidence-based interventions needs to incorporate the likely referrer, often a primary care provider, who has a central oversight role amongst the various multidisciplinary professionals.

We can learn from the UK experience, for example the MacMillian Principles and guidance for prehabilitation within the management and support of people with cancer (2020) https://www.macmillan.org.uk/healthcare-professionals/news-and-resources/guides/principles-and-guidance-for-prehabilitation

- Years 1-2: Establish a plan for the funding mechanism.
- Years 3-5: Enacting plans to implement funding.
- Years 6- 10: Having a fully functional mechanism to allow survivors to access evidence based supportive care interventions.

How can we help? The COSA Survivorship Policy Group are experts in multidisciplinary care working within existing funding models and can help inform this process.

3. **Develop and streamline navigation and information support for all cancer survivors.** Survivors need direction to information and resources to support them post-treatment. Survivors may need multiple services; they need services to be: (i) available, and (ii) accessible, affordable.

   - Years 1- 2: Establish an evidence-based model with stakeholder input.
   - Years 3-5: Pilot the navigation system with stakeholder feedback.
   - Years 6-10: Having a fully functioning system streamlining navigation and information support that utilises cross-sector expertise and takes the pressure off acute services.

How can we help? The COSA Survivorship Policy Group can assist in connecting Cancer Australia with key stakeholders, and suggesting appropriate services and information resources.

4. **Establish agreed standards for quality cancer survivorship care for health services – this should form an excellence framework or a national accreditation system.** We can learn from existing Australian jurisdictions' cancer plans and quality frameworks, as well as the US experience.

   - Years 1-2: Establish a plan and reviewing the content of existing jurisdictions' cancer plans and quality survivorship frameworks to consider what could be adapted nationally, and what learnings already exist in implementation.
   - Years 3- 5: Enacting plans / piloting implementation at jurisdiction or national level.
   - Years 6- 10: Having a fully functional mechanism to with funding to measure quality survivorship care against agreed standards.

How can we help? The COSA Survivorship Policy Group have national and international connections in this space. Members have been heavily involved in development of jurisdictional cancer plans and survivorship quality frameworks:

   - The SA Cancer Service Statewide Survivorship Framework, https://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/About+us/Publications+and+Resources/Plans/South+Australian+Survivorship+Framework

- In 2021, Victoria released the Victorian Quality Cancer Survivorship Care Framework, https://www.petermac.org/sites/default/files/media-uploads/PM0061_ACSC_Quality_Cancer_Survivorship_Care_Framework_v9_WEB.pdf which has national applicability.
- In 2021, the Australian Cancer Survivorship Centre reviewed which Australian state and territory cancer plans include survivorship-related objectives and propose quality survivorship outcomes and measures. In brief: 12 policy documents were identified from 7 of Australia's 8 jurisdictions. There was variability in the number of survivorship-related objectives (4-37 per jurisdiction) and the number of survivorship-related outcomes (0-22 per jurisdiction, total of 27). All 12 cancer plans highlighted outcome assessment, with quality of life, other patient reported outcomes, and five-year survival rates being most common. There was little detail regarding how to measure proposed outcomes. More detail on this work and the specific survivorship-related objectives and outcome measures can be provided.

5. **Implementation of national survivorship outcome measure/s that account for minority populations**.
   Use of Patient Reported Outcome Measures (PROMs) to guide clinical care more routinely. How do we provide quality care if we don't understand issues? A PROM is a tool to help self-management support and patient centred care. We recognise that patients have a right to position themselves within care according to what is important to them, therefore we need to ask patients what is important to them. A useful way forward is to use PROMs to systematically address patient needs; using brief tools at point of care to inform the clinical encounter. We note that many PROMs are used to assess service performance rather than to deliver patient centred care. We should be very clear what we mean by PROMs. Patient Reported Experience Measures (PREMS) can be used to understand the patient experience within a service.

   - Years 1-2: Establish which survivorship measure/s can be implemented nationally and how these will be measured.
   - Years 3-5: Pilot the measure/s at jurisdiction or national level including benchmarking.
   - Years 6-10: A fully functional reporting mechanism for national survivorship outcomes.

How can we help? Currently, no one jurisdiction is doing this well, so we can create a national approach, the COSA Survivorship Policy Group can help capitalise on this opportunity. COSA members are survivorship and PROMS experts.

6. **Implementation of different models of survivorship care and personalised stratified pathways of care.**
   Survivors are stratified to shared-care, nurse-led models, primary care professional-led models, allied health-led models, supported self-management etc. to demonstrate significant reduction on time spent with specialists in hospital systems, and ensure people receive care that meets their needs, close to home. Survivorship care plans are a useful communication tool. The utilisation of telehealth is supported.

Primary care can oversee/lead shared or self-managed care and provide for ongoing support and surveillance, lifestyle optimisation, care of other health issues etc. Recognition of this important role along with appropriate primary care funding/policies/planning is crucial in order to support stratified and personalised models of survivorship care into the future; with expected improved health outcomes, improved PROMS and cost saving.

Learnings from the UK experience: the UK has seen a major shift in the model of post-treatment care. From 2008 to 2014, the National Health Service (NHS) tested personalised stratified follow-up care pathways for survivors of breast, prostate and colorectal cancer. The pilots found that 50 -80% of these patients treated with curative intent could safely self-manage and have their needs met. In England there are targets that 66% of breast and 50% of colorectal and prostate cancer patients should be in supported self-management programs by 2022. Data suggests that personalised stratified pathways could improve outcomes with more efficient use of oncology time, reduced hospital visits and potential reduction in overall costs. Two key enablers of the re-designed pathways of care are remote monitoring and care coordination.

- Years 1- 2: Plan targets for: percentage of patients to be stratified to different models of care, percentage reduction in specialist, hospital based follow up cancers.
- Yeas 3-5: Establish guidance on risk stratification for the three most common cancer types and pilot personalised pathways of care; begin pilots.
- Years 6- 10: Fully functioning personalised stratified pathways of care for the three most common cancer types, with plans to expand to other cancers.

How can we help? The COSA Survivorship Policy Group are multidisciplinary health professionals, with expertise in reforming models of care, we also have connections in the UK who have led this work.

7. Survivors receive care close to home, including telehealth

Care close to home, and greater reimbursed care provided by primary care and allied health providers provides more coordinated and holistic care, may provide mechanisms to enhance transitions of care, and support shared care, and can reduce the amount of oncologist-led follow up care, allowing specialists to focus on the management of patients with new cancer diagnoses.

Telehealth can form an important component of survivorship care. Telehealth facilitates improved care for cancer survivors by addressing some of the current challenges with care, including: minimising or eliminating the financial impact of travelling to appointments (travel, parking, accommodation) particularly for regional and rural patients); reducing the impact that face-to-face appointments have on work and family commitments; improving access to care provided by nurse practitioners, midwives, allied health and primary care, which more fully meets the needs of cancer survivors, and supports return to previous functioning.

Care close to home and telehealth also provide benefits at a health system level, which align with the recommended Australian model of cancer survivorship care, as outlined in the COSA Model of Survivorship Care and COSA Cancer Survivorship Position Statement.

- Years 1- 2: Establish a national approach and principles.

- Years 3- 5: Pilot and trial the approach in jurisdictions.
- Years 6- 10: A fully functioning national approach to providing care close to home, supporting the use of telehealth as indicated.

How can we help? The COSA Survivorship Policy Group are experts who contributed to the models and position statements described above. We are well placed to help contribute to a national approach consistent with these models.

8. **Establish national agreement on cancer prevalence data and burden of disease.** We need more than just incidence and mortality data. Routine collection of a mix of burden of disease and healthcare outcomes / monitoring performance, for example long term treatment side effects, co-morbid disease, prevalence data, premature death (non-cancer causes versus cancer causes), disability, disability on productivity, cost of healthcare delivery etc.

We should integrate cancer survivorship care with metrics that are applied to non-cancer care – for example cardiac rehabilitation, dialysis, mental health services.

- Years 1- 2: Establish a plan, set agreed data points.
- Years 3- 5: Pilot some measures at jurisdiction or national level
- Years 6- 10: A fully functioning national cancer prevalence data system, including burden of disease and healthcare outcomes.

How can we help? The COSA Survivorship Policy Group are cancer care experts who can contribute to determining the data that matters, and how to capture this.

9. **Establish Survivorship Centres of Excellence or accreditations for Supportive Care Centres of Excellence. Similar to the US National Cancer Institute (NCI) designated Cancer Centers.**

We can learn from the US experience. The US Commission on Cancer Guidelines (American College of Surgeons, 2021, Standard 4.8) is used to accredit cancer services across America:

i) A suite of services offered either in-house or by referral to meet the needs of attending cancer survivors
ii) Access to physicians, nurses and allied health professionals, coordinated to deliver person-centred care
iii) Oversight by a governance group
iv) Policies and procedures defining the survivorship program requirements.

In Australia, rural centres of excellence exist (such as those in Townsville and Albury-Wodonga), however some rural centres are stand-alone and need close integration with metro centres for service delivery, so patients may be confident they receive equitable care.

- Years 1- 2: Establish an evidence-based model with consumer input for Survivorship Centres of Excellence, including accreditation measures and determining how to integrate these centres with primary care.
- Years 3- 5: Pilot 1-2 Survivorship Centres of Excellence with accreditation measures.
- Years 6-10: Establish a nationwide network of Survivorship Centres of Excellence, with accreditation measures.

How can we help? The COSA Survivorship Policy Group represent regional and metropolitan perspectives, lead survivorship centres and have connections to the US who have implemented this model.

10. **Cancer survivors have equity in access to best possible outcomes and supports**, regardless of their cancer type, cancer stage, cultural background, geography or age. This includes minority groups of survivors; those with low prevalence cancers, paediatric, adolescent and young adult, geriatric survivors. Aboriginal and Torres Strait Islander survivors, those who are culturally and linguistically diverse, gender and sexually diverse, those with advanced / metastatic disease, those who live regionally.

    - Years 1-2: Establish measures to determine equitable outcomes of care that is designed to include minority groups.
    - Years 3-5: Enact plans to collect this data, nationally, with benchmarking.
    - Years 6- 10: A fully functioning national system that measures equitable outcomes of care across a broad range of cancer types and groups.

How can we help? The COSA Survivorship group include those who specialise across cancer types and groups, leading research in this space. They are experts in the determination of equitable care, and have national and international connections, including experts in countries leading in some of these areas.

2. *What are the opportunities with the greatest potential to realise your vision?*

Think about what you would like the Australian Cancer Plan to achieve. What priorities need national action? In what areas could national action drive or accelerate progress?

The COSA Survivorship Policy Group suggest ten priority actions with possible actions within the ten-year period, in question one. Of those ten, the opportunities with the greatest potential may include:

- Establish agreed standards for quality cancer survivorship care for health services – this should form an excellence framework or a national accreditation system.
- Implementation of national survivorship outcome measure/s that account for minority populations.
- Implementation of different models of survivorship care and personalised stratified pathways of care.
- Survivors receive care close to home, including telehealth
- Establish national agreement on cancer prevalence data and burden of disease.
- Establish Survivorship Centres of Excellence or accreditations for Supportive Care Centres of Excellence. Similar to the US National Cancer Institute (NCI) designated Cancer Centers.

3. *What examples and learnings can we build on as we develop the Australian Cancer Plan?*

Think about great examples of work within or outside the cancer sector in Australia and internationally. How can we learn from these examples and build on them to improve cancer outcomes and experience for all Australians?

The COSA Survivorship Policy group have expertise in post treatment cancer care with authority and connections nationally and internationally. They are eager to help expand upon, scope or investigate any identified survivorship priorities with Cancer Australia and others.

We can also provide resources on specific topics. Some suggested, relevant resources include:

- Issues, needs of Australian cancer survivors:
  - https://pubmed.ncbi.nlm.nih.gov/18648984/
  - https://pubmed.ncbi.nlm.nih.gov/28434095/
  - https://pubmed.ncbi.nlm.nih.gov/31215167/

- Learnings from models of care in Australia:
  - https://pubmed.ncbi.nlm.nih.gov/26245952/
  - Victorian Cancer Survivorship Program (VCSP) phase 1 (2011- 2014) report, https://www.health.vic.gov.au/sites/default/files/migrated/files/collections/research-and-reports/s/supporting-cancer-survivors-in-victoria---final-report---pdf.pdf
  - Victorian Cancer Survivorship Program Evaluation and Outcomes Framework (2016), https://www.health.vic.gov.au/sites/default/files/migrated/files/collections/research-and-reports/s/supporting-cancer-survivors-in-victoria---final-report---pdf.pdf
  - Victorian Cancer Survivorship Program (VCSP) phase 2 (2016-2019) report, https://www.petermac.org/sites/default/files/media-uploads/VCSPII_EvaluationFinalReport.pdf

- Existing guidance regarding models of care:
  - COSA model, https://pubmed.ncbi.nlm.nih.gov/31774985/
  - Review of evidence around models of care, https://pubmed.ncbi.nlm.nih.gov/34786652/
  - Recommendations around shared care included within https://pubmed.ncbi.nlm.nih.gov/32947973/ (this paper is also relevant, https://pubmed.ncbi.nlm.nih.gov/32803729/)

- Multidisciplinary oncology rehabilitation (Allied health led follow up)
  - MacMillan Cancer rehab pathways 2020, https://www.macmillan.org.uk/assets/macmillan-cancer-rehabilitation-pathways.pdf
  - https://www.jisprm.org/article.asp?issn=2349-7904;year=2021;volume=4;issue=3;spage=146;epage=155;aulast=Song

- Guidance around needs assessment, https://pubmed.ncbi.nlm.nih.gov/28921739/
- Australian cancer survivorship quality framework, https://pubmed.ncbi.nlm.nih.gov/34064957/
- Australian survivorship research priorities, https://pubmed.ncbi.nlm.nih.gov/35031828/
- Clinical Oncology Society of Australia, https://www.cosa.org.au/
- Australian Cancer Survivorship Centre, https://www.petermac.org/cancersurvivorship
- Nationally relevant, free online survivorship care plan generator for survivors and health professionals, available for six common cancer types, mycareplan.org.au, https://www.mycareplan.org.au