SA Cancer Service

Statewide Survivorship Framework

The Framework

Government of South Australia
SA Health

Acknowledgements

The South Australian Statewide Survivorship Framework has been developed through collaborative partnerships, led by the South Australian Cancer Service with key stakeholders including consumers, representatives from across government and non-government organisations, researchers and other health professionals who attended the various forums and working groups, contributing to the compilation of this Framework.

Particular acknowledgement to the members of the Survivorship Steering Group who provided ongoing support, expertise and oversight during the development and pilot implementation of the Framework and the Champion Teams and their willingness to be involved with piloting the key components of the Framework (refer to Appendix 1. for full listing).

The development of the South Australian Survivorship Framework was supported and funded by the National Cancer Expert Reference Group (NCERG) as an initiative of the National Cancer Work Plan.

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Definitions

Survivor

This Framework considers an individual is a cancer survivor “from the time of diagnosis, through the balance of his or her life” [8]

Survivorship

Survivorship is considered to likewise commence from the point of diagnosis recognising the many people who “live with cancer” for years following diagnosis and can remain well with support to address their needs as they arise. It encompasses the “physical, psychosocial and economic sequelae of cancer diagnosis and its treatment” [7, 8]

Executive Summary

Framework Objectives

The South Australian Survivorship Framework has been developed to address four key objectives including:

1. Identify and address cancer survivor needs
2. Enable well-coordinated, best-practice care for cancer survivors
3. Monitor and continuously improve care for cancer survivors
4. Engage, inform and collaborate with key stakeholders

The Framework

The Framework includes:

1. **Survivor (patient)-centred care**, with the survivor featured at the centre of survivorship care which is tailored to their individual requirements, situation and comorbidities
2. **Overarching and implementation principles**
3. **Three key components** identified as the minimum standard of care cancer survivors will receive including a documented cancer treatment summary, needs assessment and survivorship care plan.
4. **Implementation tools and considerations** including workforce requirements, tools for implementation and data to drive survivorship care delivery
5. **Evaluation and monitoring** including key performance indicators and health economic measures to monitor, evaluate and continually improve survivorship care services in SA
6. **Context specific considerations and factors** that may impact on implementation including the unique needs of different population groups

Key components of the Framework

Three key components have been identified for delivery at a minimum for best-practice survivorship care in South Australia, including:

1. Cancer Treatment Summary
2. Needs Assessment
3. Survivorship Care Plan

Each component is designed to be developed, reviewed and updated in partnership between the cancer survivor and service providers. Tools and templates have been developed to support the implementation of each component.

Minimum standard of survivorship care:

All cancer survivors receive a cancer treatment summary and individualised survivorship care plan (informed by a needs assessment) following *completion of definitive treatment or adjuvant therapy.*

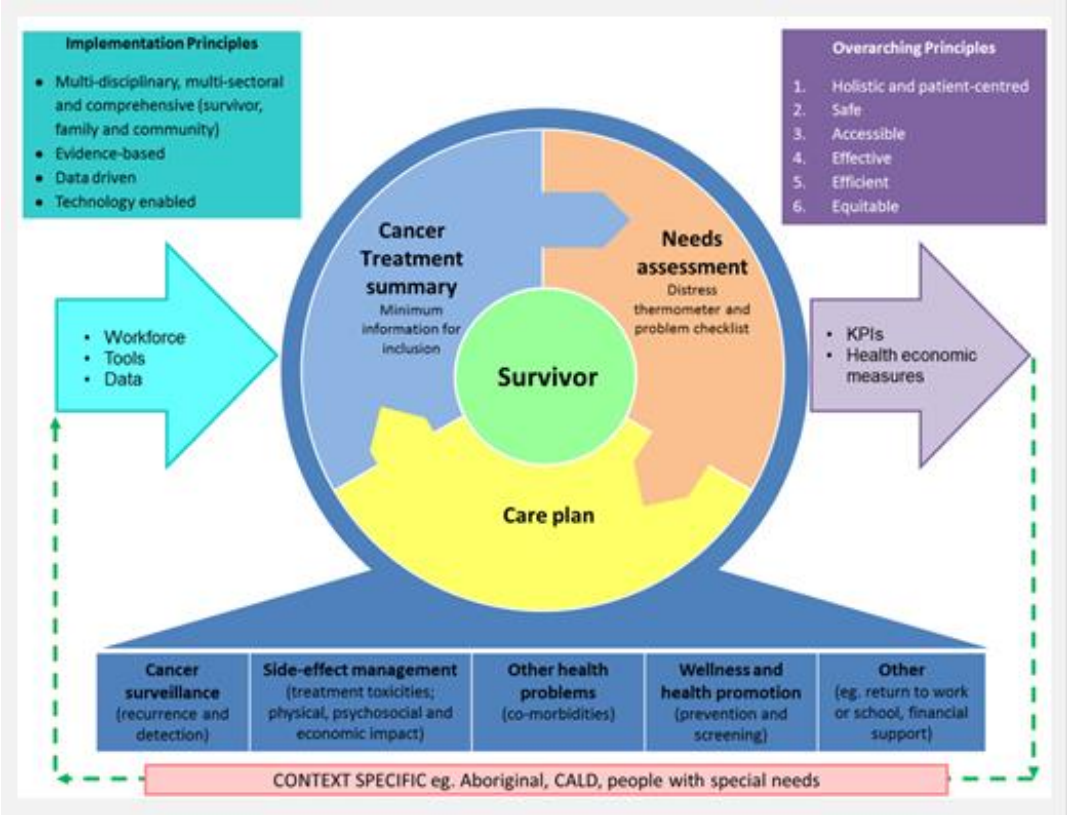
Recommended standard of survivorship care:

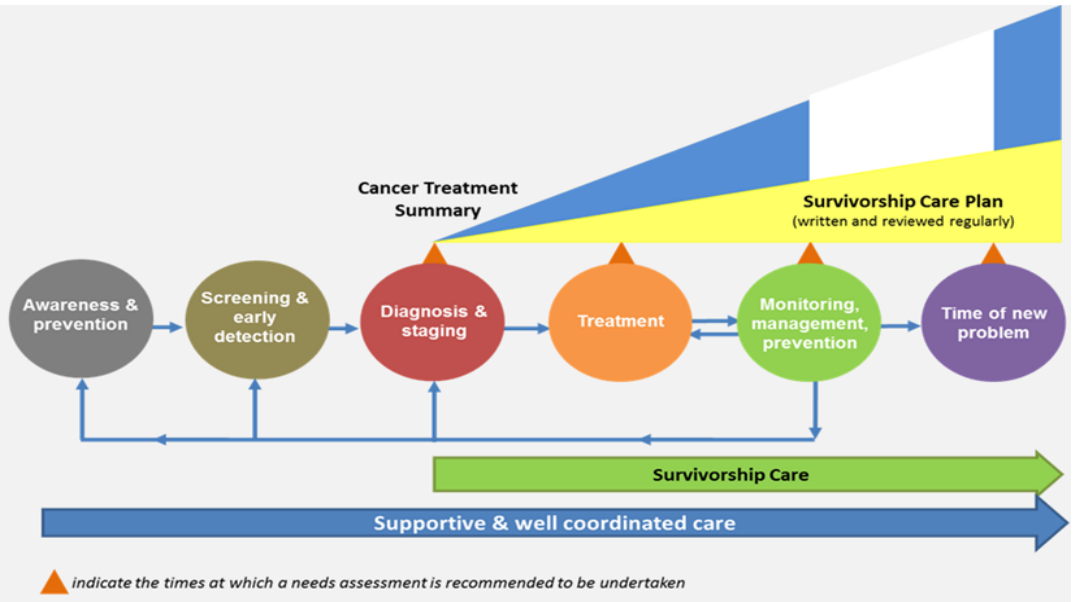
The development of a cancer treatment summary and survivorship care plan should be commenced from the point of diagnosis and regularly updated (including needs assessment) throughout treatment and beyond for *all cancer survivors.*

Framework implementation & evaluation

A conceptual and staged implementation process is recommended to support services in adopting the Framework, developed following pilot implementation of the Framework across four medical oncology service providers in SA. An initial key performance indicator (KPI) for monitoring has been established *"the number of cancer survivors with a Survivorship Care Plan developed and documented".*
Following health economic review of the theoretical Framework and implementation pilots, it's recommended that the *"number of cancer survivors with reported unmet needs"* is considered as an additional KPI into the future. Process and outcome measures have also been identified to assist in

the continual review and improvement of the implementation of the Framework and associated services.





Development

Cancer Survivor
Clinician(s) or Specialist(s) within treating service

1 Cancer Treatment Summary

- Brief and concise
- Written summary
- Includes details relating to diagnosis, treatment, complications, managing specialist(s) team and dates

2 Needs Assessment

- Brief, easily administered and holistic
- Captures physical, social, emotional, occupational, educational, lifestyle and spiritual needs
- Informs development of care plan

3 Survivorship Care Plan

- Needs based (consumer prioritised)
- Action focussed
- Living document
- Addresses cancer surveillance, late-effects and toxicities, co-morbidities, general health and wellness

Dissemination

Cancer survivor (consider the use of My Health Records to upload and share)
General Practitioner
Specialist(s)
others where appropriate

Review & further development

Cancer Survivor (include family and carer)
General Practitioner/ Practice Nurse
Specialist(s)
Allied Health Professional
Other government and non-government organisations (eg. Counselling Services; Financial advisors)

Part A: Framework Purpose

Use of the Framework

Who the Framework is for

The Framework provides a reference for health care and other service providers to work in partnership with cancer survivors to document the treatment and care needs of survivors from diagnosis, and to enable these needs to be met.

The Framework provides an outline of the minimum level of care South Australian cancer survivors will receive regardless of:

- Tumour type
- Age
- Geographical location
- Ethnicity
- Socioeconomic status
- Co-morbidities
- Service or setting (eg. public or private)

The Framework may also be of interest to researchers, particularly those interested in examining the care of cancer survivors, health economics and models of cancer care.

When to use the Framework

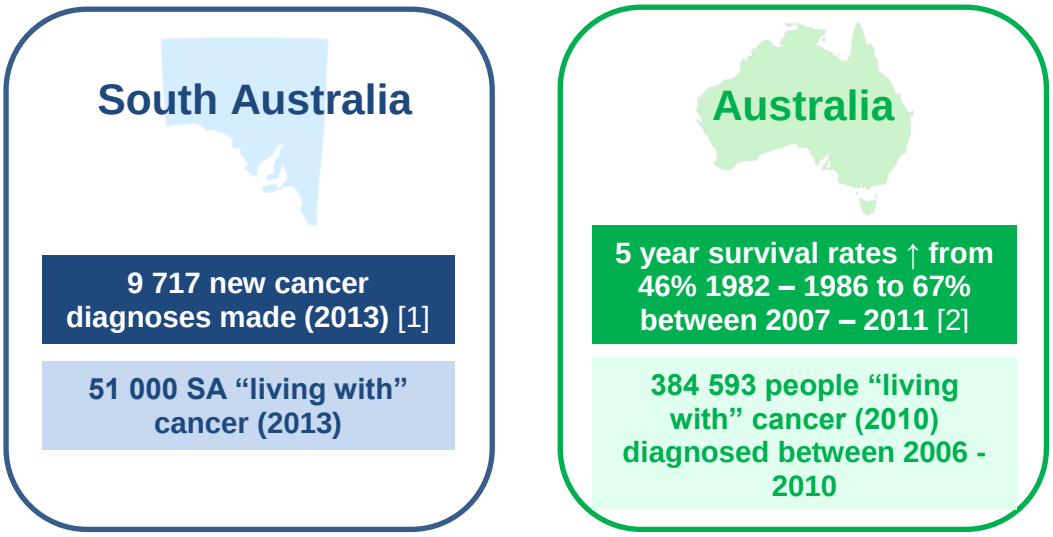
All elements of this Framework can be utilised in developing and reviewing the provision of survivorship care services and should be considered with the implementation of the Optimal Cancer Care Pathways [9].

Recommended time points to implement the Survivorship Model are described later in this document.

South Australia's approach to survivorship care

Background

Cancer survival continues to increase with improvements in early detection, diagnosis, technology and treatment modalities [10]. With increasing survival rates in conjunction with the projected increase in new cancer diagnoses in both South Australia and nationally, a greater emphasis and review of survivorship care is required. This includes broadening the scope of what is meant by good survivorship care into something that recognises that for many people, cancer is a complex, chronic disease that they may live with for years [11].



Traditionally survivorship care has been provided by cancer specialists and focussed predominantly on monitoring for disease surveillance and recurrence. It is becoming increasingly recognised that survivors have other significant post-treatment care needs that aren't well addressed (or are exacerbated at this point in time) consistently across the system, impacting on their quality of life and health outcomes [12-14]. Supporting and empowering survivors to understand the treatment received, follow-up requirements and potential late-effects is important, for self-management as well as engaging with others including family, friends, employers and health professionals[14].

The following table provides an overview of the key components of quality, consumer-centred survivorship care that typically involves assessment and/or screening of individual risks and needs.

Table 1. Key considerations and areas of need for best-practice survivorship care

Key considerations	Purpose	Examples
Cancer surveillance, monitoring and follow-up care	Detection of recurrence and/ or secondary cancers	• Colonoscopy (Bowel Ca) • Mammography (Breast Ca) • Thyroid Stimulating Hormone testing (Head & Neck Ca)
Immediate, ongoing or delayed late-effects of treatment toxicities and original disease	Prevention (including secondary and tertiary prevention), screening, early intervention and management.	• Osteoporosis • Peripheral neuropathy • Cardiomyopathy • Fertility impairment
Physical, psychosocial and economic impact of cancer and its treatment [5, 15]	Identify and support the management of existing or future concerns (eg. ability to return to activities of daily living)	• Anxiety and depression • Body image concerns • Return to work/school/study
Co-morbidities or other health problems	Prevention and management of future or existing co-morbidities	• Obesity/metabolic disorders • Diabetes • Cardiovascular Disease

		• Asthma
Health promotion and wellness [16]	Promote risk reduction for health problems that commonly present with increasing age	• Participation in national cancer screening programs • Dietary and physical activity practices • Minimising exposure to harmful substances (tobacco) or environments (sun) • Immunisations

Considerable variations in the provision of survivorship care exist across institutions in South Australia. As capacity and resourcing within cancer specialist services are already stretched and demand likely to continue to increase, it is an unrealistic expectation for these services to meet all survivor needs. With a diverse range of providers beyond the specialist setting including other government (health and non-health related), non-government organisations, primary health care and other support and advocacy groups, opportunities exist to collaborate and reorientate survivorship care. As SA Health is currently transforming services to ensure consumers receive consistent, equitable and efficient delivery of care, it's timely to address the needs of cancer survivors and review how this can best be provided and integrated with other services such as primary health care and community services [17].

Whilst work is underway in this area across Australia and internationally, South Australia is aiming to take a unique, statewide, population-based approach to survivorship care.

The Development of the Framework

The development of the Framework was funded by the National Cancer Expert Reference Group (NCERG) as an area of national interest and component of the National Cancer Work Plan.

The Framework has been developed in recognition of the diverse needs of cancer survivors and the impact on quality of life and health outcomes that arise when these needs remain unmet. This includes and extends beyond the traditional approach to survivorship care, whereby the primary focus has been on surveillance delivered by specialists within the acute cancer setting to also include the identification and addressing of:

- Immediate, ongoing and late-effects of cancer, its treatment and toxicities
- Physical, psychosocial and economic impact
- Co-morbidities (including the prevention and/or management of) and other health conditions
- Health promotion and general wellness (including participation in screening programs)

South Australian Cancer Service (SACS) in collaboration and consultation with key stakeholders throughout South Australia (SA) led the development of and pilot implementation of the Framework and key components. Stakeholder engagement varied including:

- Consumers,
- Government (including health) and non-government organisations,
- Health care providers (public and private; across paediatric and adult settings) and
- Researchers.

Consultation included exploration of current practice, identification of barriers and enablers to survivorship care, undertaking implementation pilots and theoretical health economic analysis. With a diverse range of providers outside the specialist cancer setting including other government (health and non-health related), non-government organisations, primary health care and other support and advocacy groups, this Framework recognises the opportunities that exist to further collaborate and reorientate survivorship care across South Australia.

The Framework provides guidance relating to considerations for implementation within specific population groups, settings and other complexities. It considers highlighted needs and barriers that have been identified within SA including transitioning between services and settings:

- Acute ↔ Primary Health Care (Community)
- Metropolitan ↔ Rural
- Paediatric and adolescents and young adults (AYA) ↔ Adult services
- Public ↔ Private

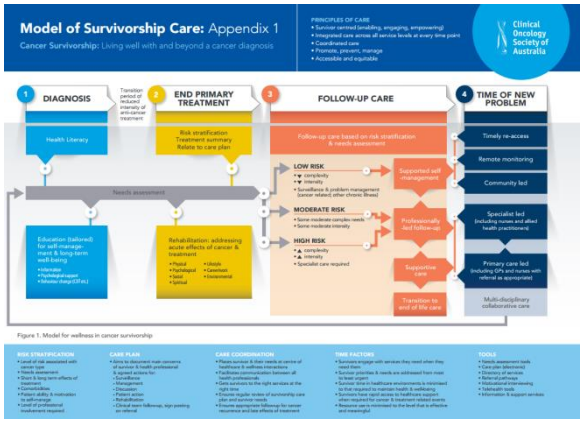
Implementation pilots of the minimum standards of survivorship care further informed the Framework development and refinement of tools, templates and process to implementation.

A number of key state and national documents including guidelines, principles, models of care and plans have been utilised to inform the Framework in conjunction with work and research that has or is currently underway in survivorship care. These include:

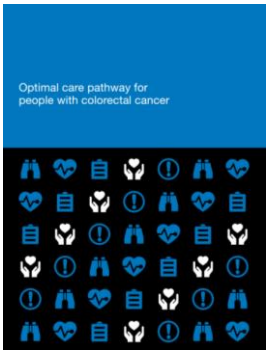
1. Clinical Oncology Society of Australia (COSA) Model of Survivorship Care for Wellness [5]
2. National Optimal Cancer Care Pathways [9]
3. The Chronic Care Model [18]
4. SA Transforming Health [17]
5. South Australian Statewide and Aboriginal Cancer Control Plans [19]

1. COSA Model of Survivorship Care for Wellness [5]

The Framework reflects South Australia's approach to the adaptation and integration of the COSA Model of Survivorship Care for Wellness into practice with consideration to the local context. The minimum standards of survivorship care outlined in the Framework align with critical components identified within the COSA Model, supporting the transition from illness to wellness.



2. National Optimal Care Pathways (OCPs) [9]

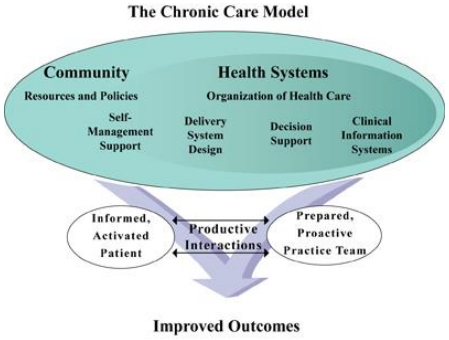


The OCPs describe the optimal cancer care for 15 different tumour streams, supporting survivor experiences by mapping the whole pathway and promoting quality care.

Key components and respective standards identified within the Framework align with *Step 5 – Care after initial treatment and recovery* of the OCP. As SA commences adoption of the colorectal and oesophagogastric optimal care pathways in 2017, the Framework will be incorporated within these.

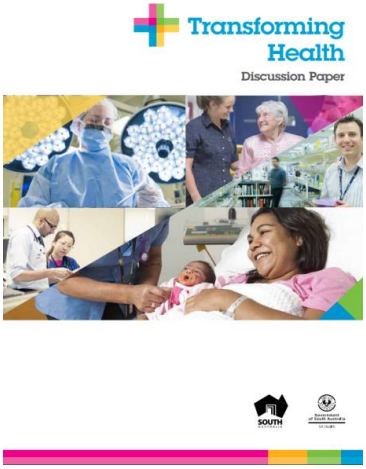
3. The Chronic Care Model [18]

The Chronic Care Model highlights the key elements of a health care system that enable the delivery of high quality, chronic disease care. Recognising that many cancer survivors are "living with cancer" as a chronic and complex condition, the Framework has been developed to align with this Model



4. SA Transforming Health [17]

SA Health reform, ensuring all South Australians receive the *best care, first time, every time*



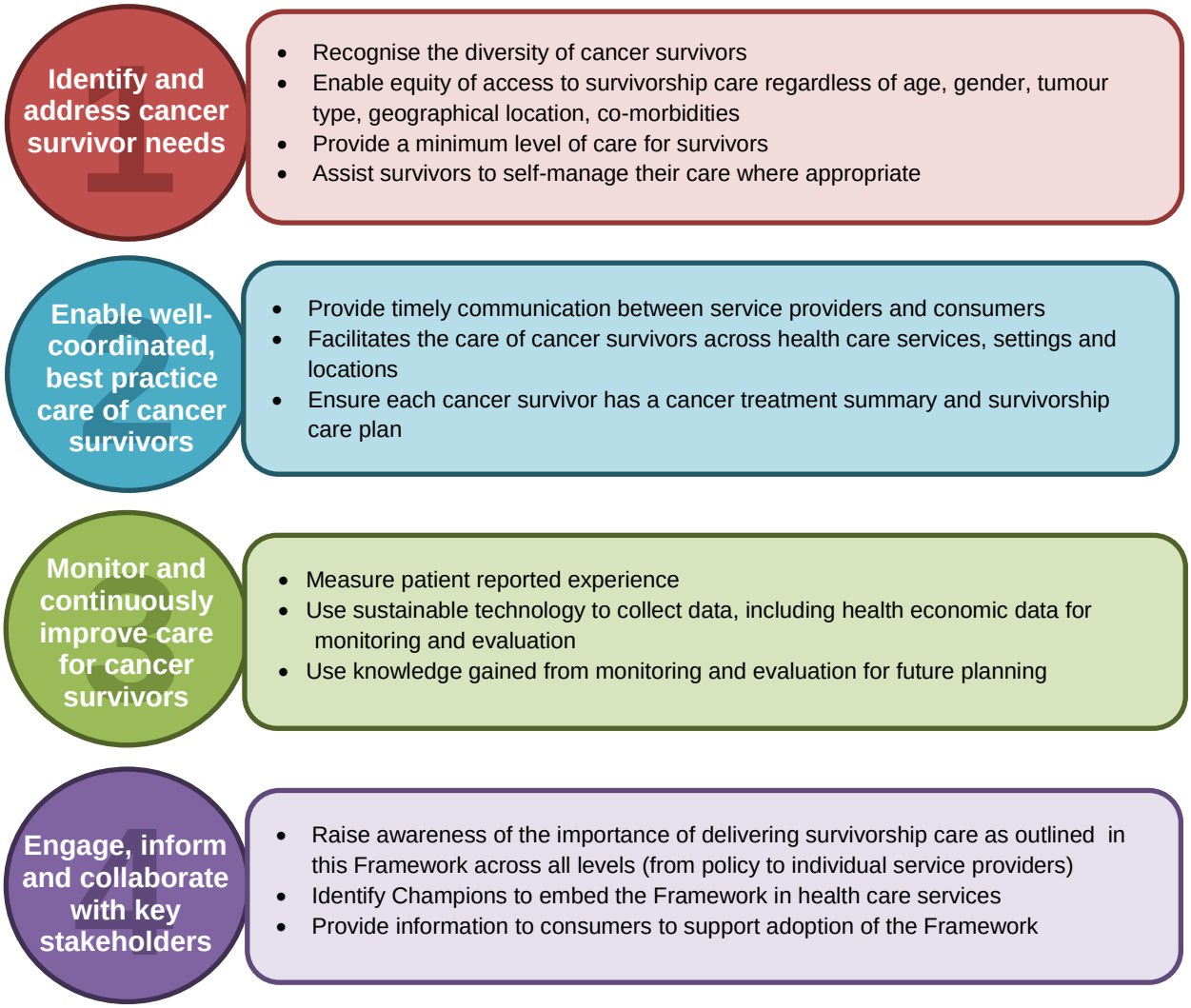
5. SA Statewide and Aboriginal Cancer Control Plans [19]

The Framework has been shaped by ideas and needs identified within previous statewide cancer control plans. Implementation of the Framework has been incorporated in the 2016 – 2021 editions as a key priority for the state over the next 5 years.

Objectives

This Framework aims to guide and support the implementation of key components of best-practice survivorship care (as outlined in Table 1) for service providers in South Australia, assisting in meeting the needs of cancer survivors. It provides strategies, processes and practical tools to enable adoption and adaptation of three key components (including treatment summary, needs assessment and care plan) within practice, supporting change management, communication, data collection, monitoring and continuous improvement. This Framework also highlights priorities and future directions to continue to support implementation and deliver high quality, equitable survivorship care services across SA that is acceptable to both survivors and health care providers.

This Framework aims to support the care of cancer survivors by setting and achieving clear objectives outlined below:



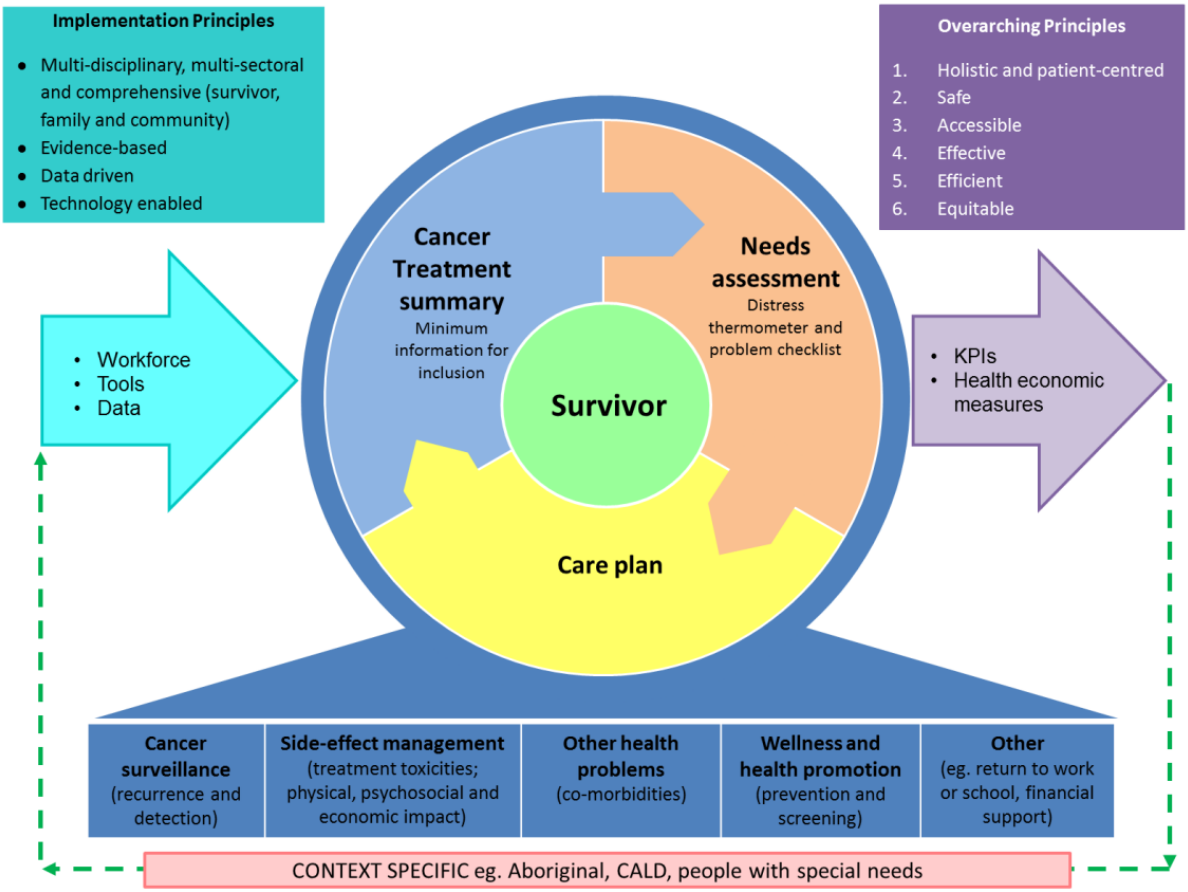
Part B: The South Australian Survivorship Framework

Framework Overview

The Framework includes:

1. **Survivor (patient)-centred care**, featured at the centre of survivorship care which is tailored to their individual requirements, situation and comorbidities
2. **Overarching and implementation principles**
3. **Three key components** identified as the minimum standard of care cancer survivors will receive including a documented cancer treatment summary, needs assessment and survivorship care plan.
4. **Implementation tools and considerations** including workforce requirements, tools for implementation and data to drive survivorship care delivery
5. **Evaluation and monitoring** including key performance indicators and health economic measures to monitor, evaluate and continually improve survivorship care services in SA
6. **Context specific considerations and factors** that may impact on implementation including the unique needs of different population groups

Diagram 1. The South Australian Survivorship Framework Overview



Survivor-centred care

Cancer survivors are featured at the centre of the Survivorship Framework, recognising the diverse needs, health and life experiences for individuals that can impact on overall wellbeing and quality of life. Placing the emphasis on survivor-centred care, the Framework aims to:

- Facilitate the transition of cancer survivors from a model of illness to wellness
- Ensure cancer survivors understand the treatment received, manage existing short and long-term effects as well as have an awareness of possible late-effects
- Equip and empower cancer survivors to identify their needs, engage with service providers (within and beyond the health care system) and access information to have these needs met
- Identify and develop self-management strategies where appropriate to support in achieving wellness and improving overall health outcomes and quality of life including prevention of further chronic conditions through lifestyle modification [5]

Framework Principles

The Framework has a number of overarching and implementation principles that have been defined below (refer to Diagram 2.). The overarching principles were adapted from South Australia Transforming Health. Stakeholder engagement and best-practice guidelines were utilised to determine principles for implementation.

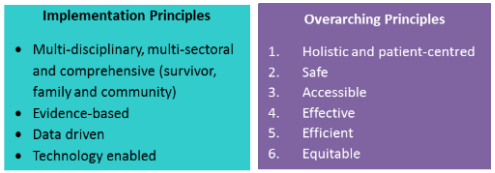
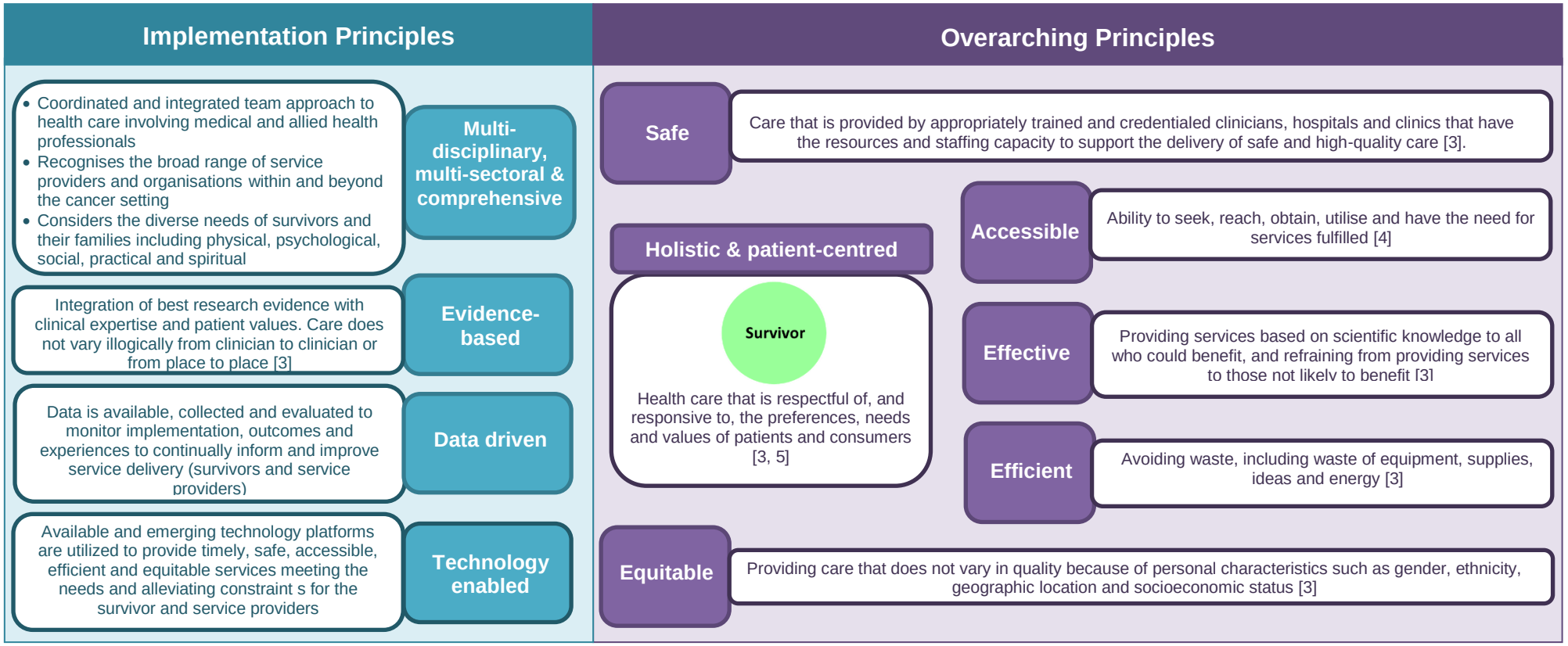


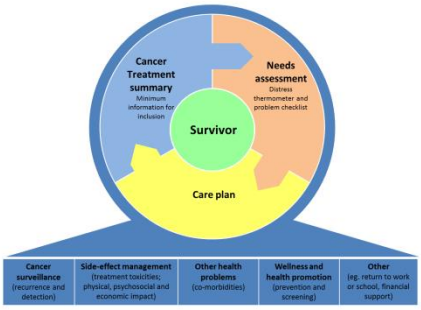
Diagram 2. Definitions of Framework principle



Key Components of the Framework

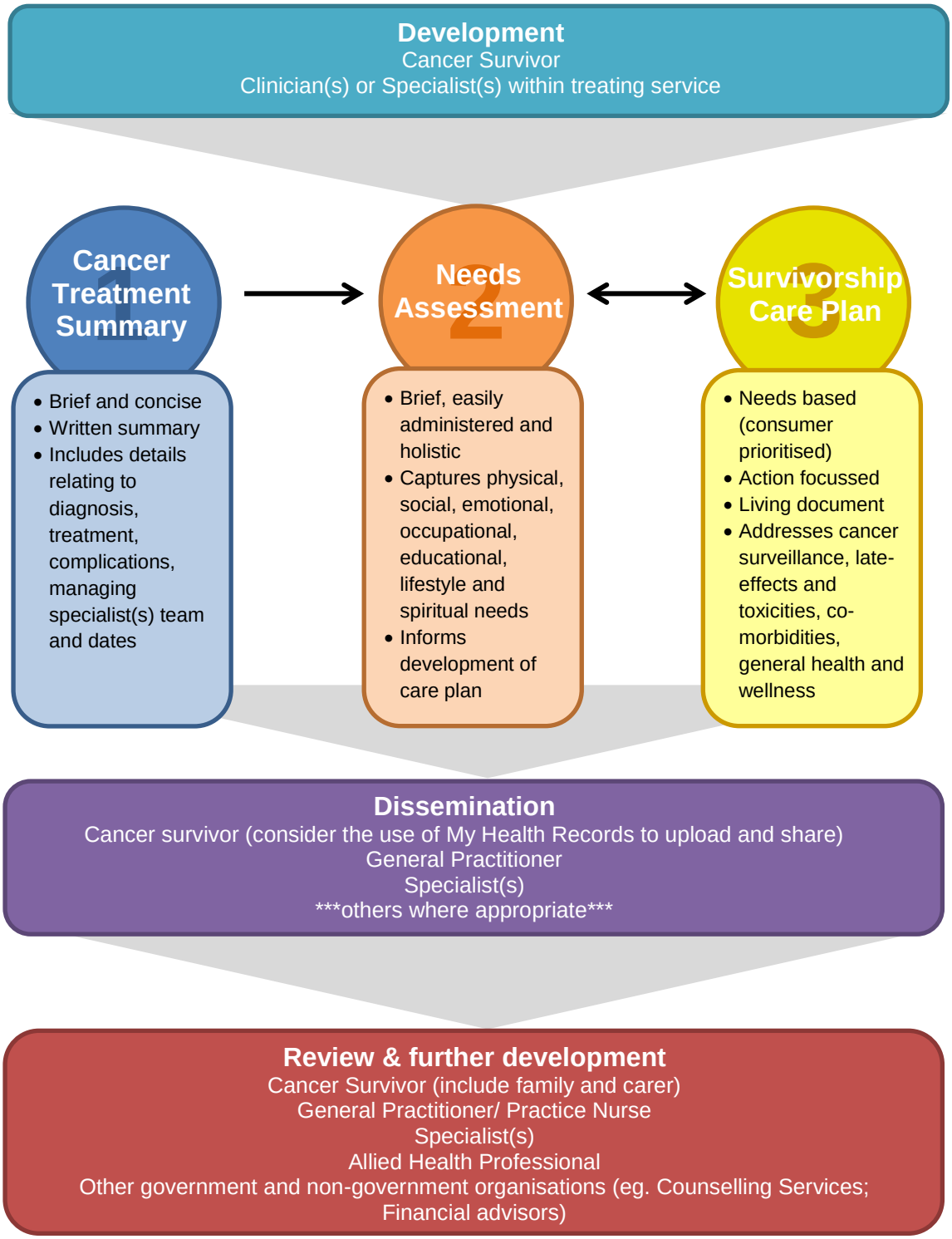
The three key components provide a baseline of the minimum best-practice survivorship care included within the Framework (refer to Diagram 3. below). They are intended to support the best outcomes for cancer survivors by working with them to document an evolving:

1. Cancer Treatment Summary (CTS)
2. Needs Assessment (NA)
3. Survivorship Care Plan (SCP)



The approach to and content of each component is outlined in Diagram 3 below, including how the CTS and SCP will be disseminated, reviewed and further developed (with suggestions on who may be involved at each step).

Diagram 3. Key components of survivorship care and process for implementation



Development

The initial development of the cancer treatment summary and survivorship care plan is designed to be in partnership between the cancer survivor and a clinician(s) or specialist(s) within the treating service(s).

The needs assessment is aimed to support in identifying priority needs determined by the cancer survivor and facilitate conversations led by the cancer survivor with the clinician/specialist to develop goals and strategies to address these within the survivorship care plan.

Survivorship care plans have been designed to clearly articulate the roles and actions to be taken in supporting cancer survivors to achieve the goals outlined including self-management strategies and required follow-up, monitoring or referrals from the GP, Specialists or other service providers involved in current and future care.

Consideration: as the process for the development of the CTS and SCP is quite different in approach (wellness focussed) compared with the prescriptive, medical model of treatment, earlier conversations and information about the purpose of survivorship care and core components with cancer survivors is beneficial to support this transition

Dissemination

A copy of the developed cancer treatment summary and survivorship care plan should be disseminated to the cancer survivor (if not at the time of the appointment) and their GP identified for ongoing care. Copies should also be provided to relevant medical specialists or other service providers with a key role in the cancer survivor's ongoing care as early as possible following their completion. *Consideration:* encourage cancer survivors to utilise the My Health Records platform to upload and share their CTS and SCP with service providers as needed.

Review and further development

The SCP particularly, is designed to be a living document and continually updated by all providers involved in care (based on cancer survivors preferences) and reviewed as cancer survivors needs change.

Opportunities may exist to translate aspects of the SCP onto a GP Chronic Disease Management Plan.

Further scoping is required to determine additional needs and information of GPs to be involved with the provision of survivorship care

Implementation tools and considerations

Tools and templates

Tools and templates have been developed to support implementation of the key components within practice and are available within the Survivorship Framework Companion Document – ***Implementation Tools***. This includes:

1. ***Cancer Treatment Summary***

- Blank Template
- MOCK Example

2. ***Needs Assessment***

- Modified NCCN Distress Thermometer and Problem Checklist

3. ***Survivorship Care Plan***

- Blank Template
- MOCK Example
- Key phrases and goal setting examples
- Resources & referrals directory

4. ***OACIS Instructions*** **(access CTS and SCP OACIS templates)**

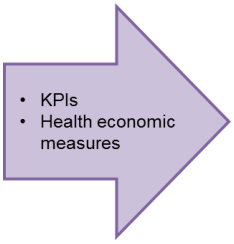
The cancer treatment summary and survivorship care plan templates have been uploaded onto OACIS for services with access to utilise. Refer to the Survivorship Framework Companion Document – ***Resources*** for instructions on utilising and accessing these.

The tools have been developed to meet the minimum standards and content defined following stakeholder consultation. It may be necessary to adapt or source alternative tools (eg. needs assessment) to ensure consideration to specific and unique needs of different population groups can be identified and addressed. This is explored further in the section *Population-based considerations.*

Workforce

South Australia piloted the implementation of the key components by Nurse Practitioners (NP)/ NP Candidates Champions within the Medical Oncology setting, recognising the diverse range of skills and knowledge they have to deliver. Opportunities exist however to look at other roles and skillsets (members from the multi-disciplinary team) within services to develop, update and review cancer treatment summaries and survivorship care plans.

A checklist has been developed to identify workforce skillset and capacity in delivering these key components (refer to the Survivorship Framework Companion Document – ***Resources*** for details). Examples of different models of providing survivorship care are highlighted in Part C of this Framework



Framework Monitoring and Evaluation

Key Performance Indicators

Key performance indicators (KPIs) and associated data sets have been developed to continually monitor and build the evidence of the outcomes of the Framework. The following factors were considered in the development of the Framework KPIs including:

- Sustainability and ongoing monitoring
- Existing strategic documents within SA and associated KPIs that are relevant
- Meaningful and actionable data produced

One KPI has been developed initially and reviewed via pilot implementation of the key components of the Framework:

1. **The number of cancer survivors with a Survivorship Care Plan developed and documented** (KPI currently exists within the *SA Cancer Services "Safety and Quality Framework 2015 – 2017*)

   Purpose: establish a starting point of what's currently happening across individual services and SA overall that will then enable comparison with the reach and scope with the roll-out of the Framework statewide.

   This KPI will be measured at an individual site and statewide, population based level to determine if the minimum standard of the Framework is being met and reflect the level of implementation. Ideally it should be expressed as the proportion of SCP developed in comparison to the total number of cancer survivors completing treatment or adjuvant therapy over a specified period of time. The KPI will vary across services and would anticipate being low initially and increase pending the phase of implementation and roll-out.

Outcome and performance measures utilised within the implementation pilots are included in *Part C of the Framework* as possible strategies for services to consider into the future.

It is recommended that the following KPI is considered and further strategies developed to measure with the implementation of the Framework:

2. **The number of cancer survivors with reported unmet need**

Purpose: As the Framework has been developed to better meet the diverse needs of cancer survivors, understanding the impact on implementation of the Framework is important. Capturing data in relation to reported unmet needs of cancer survivors can support in identifying and informing:

- Specific needs that require further exploration and discussion when developing and updating SCP
- Gaps in service delivery and/or the awareness of available services within SA to refer cancer survivors to, to meet their needs
- Alternative models and approaches to survivorship care (eg. survivorship/follow-up clinics being provided in a community centre by a skilled nurse practitioner or specialist rather than the acute sector)
- Costs associated with unmet needs not being addressed for both cancer survivor and service providers (short and long-term; primary health care and acute services)

This KPI has come from the recommendation following the Health Economic analysis of the theoretical Framework[20].

Health Economic Measures

Following the health economic (HE) analysis of the Theoretical SA Survivorship Framework (including literature review), the following HE measures need to be considered and monitored into the future including:

1. Cost of current models of survivorship care prior to implementation of the Framework over a finite period of time
    - Consumer (time, leave from work/study, scans/tests, parking)
    - Service providers within the acute cancer setting (time involved with preparation, delivery and follow-up)
    - Primary Health Care providers

2. Cost of survivorship care with the implementation of the Framework over a finite period of time
    - Consumer
    - Service providers (including consideration to resource usage with the downstream effect of the Survivorship Care Framework)

3. Value-added to care with the introduction of the Framework, specifically the provision of the key components from perspective of the consumer and service provider including General Practitioner &/ Specialists

Survivorship care data

Limited data is currently available in relation to the:

- Number of cancer survivors completing treatment or adjuvant therapy in SA (site specific and statewide). This is particularly difficult with limited systems in place to identify cancer survivors completing treatment or adjuvant therapy
- Number of cancers survivors who currently receive a cancer treatment summary and survivorship care plan already in SA
- Cost associated with the provision of current survivorship care services with consideration to all areas including cancer surveillance, effects of treatment and cancer (short, long-term and late including physical, psychosocial and economic) as well as co-morbidities, both to cancer survivors and service(s).
- Potential cost if survivorship care is not well provided and needs are unmet (consumer and service providers)
- Value and acceptability of the current provision of survivorship care services in SA by cancer survivors

These challenges are not necessarily unique to South Australia as evident in the Health Economic Analysis conducted on the theoretical SA Survivorship Framework[20]. Therefore it is critical for systems to collect and analyse this data to further inform the future provision of survivorship care services in SA as well as nationally and internationally.

Context specific considerations

CONTEXT SPECIFIC eg. Aboriginal, CALD, people with special needs

The Framework recognises the importance of the unique needs and considerations for different population groups in order to provide a minimum and consistent level of survivorship care for all cancer survivors including:

1. Paediatrics
2. Aboriginal peoples
3. Culturally and Linguistically Diverse (CALD)
4. Elderly (Geriatrics)

Paediatrics

- Small patient numbers
- Age appropriateness and developmental stage care
- Significant education issues
- Transition to adult services will be required at some stage
- Family focus transitioning to patient focus
- "engagement" with other health services
- Duration of survivorship much longer than the adult population

Currently there is no paediatric specific needs assessment tool available. Opportunities may be available to adapt current work and tools being developed interstate. This will be a key point of focus with the implementation of the Framework in the future.

Aboriginal Australians

The following points are features of person centred care for Aboriginal peoples and has been adapted from the South Australian Aboriginal Cancer Control Plan 2016 – 2021[19]. It's imperative that the provision of survivorship care for Aboriginal people is delivered in a culturally appropriate and respectful manner.

1. *Aboriginal peoples have a holistic view of health and wellbeing*
   - Health and wellbeing encompasses all aspects of physical, emotional, social, spiritual and cultural wellbeing and a specific kinship with family.
   - There is a belief that wellbeing is determined socially, rather than biologically or pathologically.
2. *Structured and busy specialist clinical services may not cater well for the cultural needs of Aboriginal peoples*
   - This can contribute to a broader sense of disillusionment, indifference and apathy.
   - Adherence to unfamiliar treatments that have unpleasant side effects may be poor, especially when there are competing pressures to meet community responsibilities.
   - Without cultural and allied support, patients can become lost in unfamiliar health service environments they do not understand and where their needs are poorly understood.
3. *Many Aboriginal people experience discomfort with health professionals of the opposite gender*
   - Traditionally, there are divisions in the roles of 'men's and women's business', including differences from western values in relation to reproduction and sexuality. For example, it is often not appropriate for Aboriginal men to discuss any part of their body in the presence of a woman.
4. *Family and community involvement in health decision making is of paramount importance in Aboriginal cultures*

- Aboriginal cultures place a high importance on kin, with holistic, family-based care being valued over segregated care.
- Aboriginal health is more a collective consideration about family and community, therefore individualistic decision making rarely occurs within Aboriginal society.

5. *Many Aboriginal people have a strong connection to country (traditional homelands), and value being on country or close by, particularly when ill*
   - Aboriginal peoples have strong links to country and this connection can be strong regardless of whether or not they are living a culturally-traditional lifestyle or live in remote, regional or metropolitan areas.
   - Some patients may be reluctant to leave their community for treatment, even though this care may only be available in a metropolitan setting [19].

Tools and templates developed as a part of the Survivorship Framework have been designed to be adapted to meet the needs of various population groups. It may be necessary to source an alternative needs assessment tool to ensure cultural appropriateness and acceptability. A modified version of the Supportive Care Needs Assessment Tool (SCNAT) has been developed for Indigenous Australians (SCNAT-IP). Clinical implementation studies are being conducted to evaluate the feasibility and acceptability of the tool for Indigenous Australians with cancer [21]. Opportunities to trial implementation of the tool in SA will be a focus for the next phase of the Framework to assist in identifying and addressing needs of Aboriginal Australians in a culturally appropriate and acceptable manner.

Culturally and Linguistically Diverse (CALD)

The following provides a list of commonalities across CALD communities within Australia, in relation to their needs and provision of culturally appropriate and sensitive services:

- Personalised, high quality, written information that supports ownership over health status
- Services able to be provided by or in collaboration with someone from their own culture, providing greater comfort, support and familiarity (rather than feeling separated and isolated when not)
- Male care giving roles aren't always recognised within CALD communities, thus support to male carers in a relaxed environment may be beneficial. Support and information for carers in general may be quite different
- Utilisation of interpreters and need for psychological and spiritual support
- Family can play an important role in discussions with health professionals and cancer survivor [22]

Elderly (Geriatrics)

- Often managing other complex health co-morbidities (including reduced cardiovascular performance and respiratory capacity, hearing and vision impairments, reduced physical and cognitive function, loss of independence and limited social support) that can exacerbate the physical health problems associated with cancer and its treatment and ability to undertake activities of daily living
- Multiple specialists involved in their healthcare, both for treatment and follow-up for cancer and other co-morbidities
- Consideration to caregivers essential and their capacity to support, particularly when caregivers are older and have their own health conditions and needs requiring addressing
- Polypharmacy
- Consider shared-care approaches to survivorship care for elderly cancer survivors including oncologist and/or geriatrician and general practitioner [23, 24]

Standard of Survivorship Care in South Australia

Minimum standard of survivorship care:

All cancer survivors receive a cancer treatment summary and individualised survivorship care plan following completion of definitive treatment or adjuvant therapy.

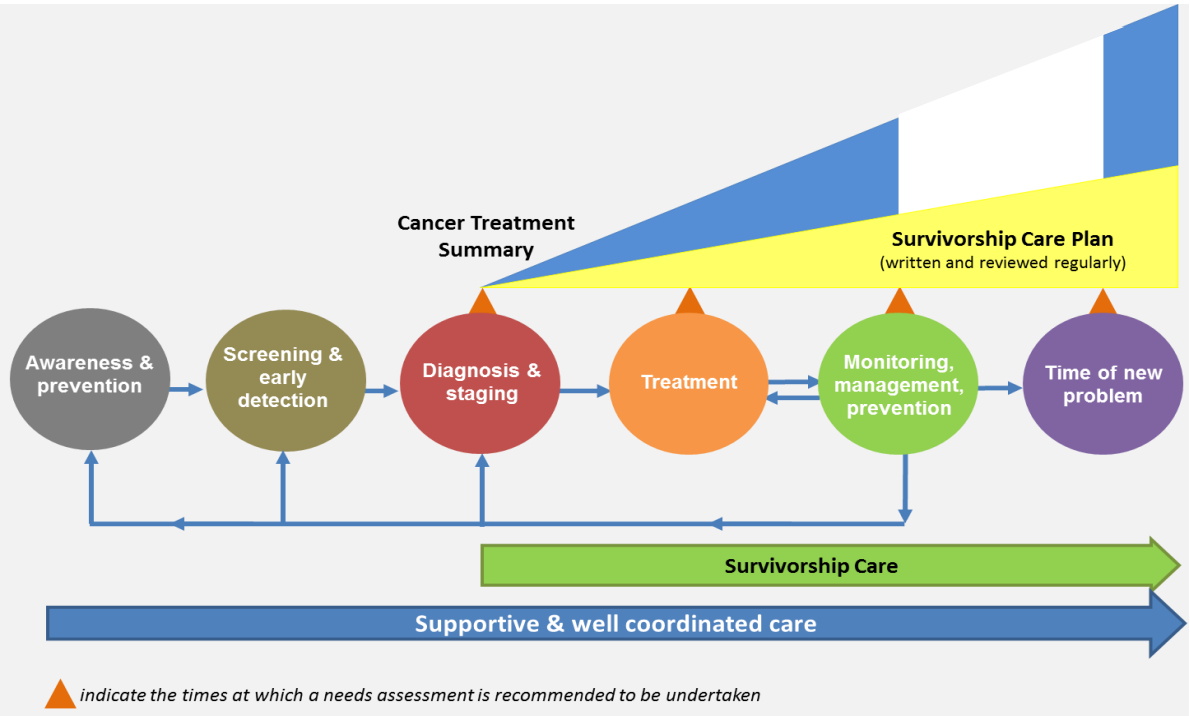
Transition from the acute cancer setting to the community that is well coordinated, organised and resourced to meet cancer survivor needs

Recommended standard of survivorship care:

There are many people who are "living with" cancer in SA as a chronic condition. As such, cancer treatment summaries and survivorship care plans should be updated with regular needs assessments and commenced from point of diagnosis and developed throughout treatment and beyond for all cancer survivors.

The diagram below (Diagram 4) indicates time points in which the key components are recommended to be developed, reviewed and updated (adapted from the SA Cancer Care Continuum diagrams in the SA Statewide and Aboriginal Cancer Control Plans 2016 – 2021 and COSA Model of Wellness [5, 19]). The orange arrows indicate points in time for the completion of a needs assessment to further inform the survivorship care plan. Designed to be a living document, cancer survivors are encouraged to share their survivorship care plan with their GP, specialist(s) and other providers, families and carers to continually support the management of any ongoing or emerging needs as well as acknowledge the achievements and goals met.

Diagram 4. Key time points for implementation, development and review of the three core components of the Framework

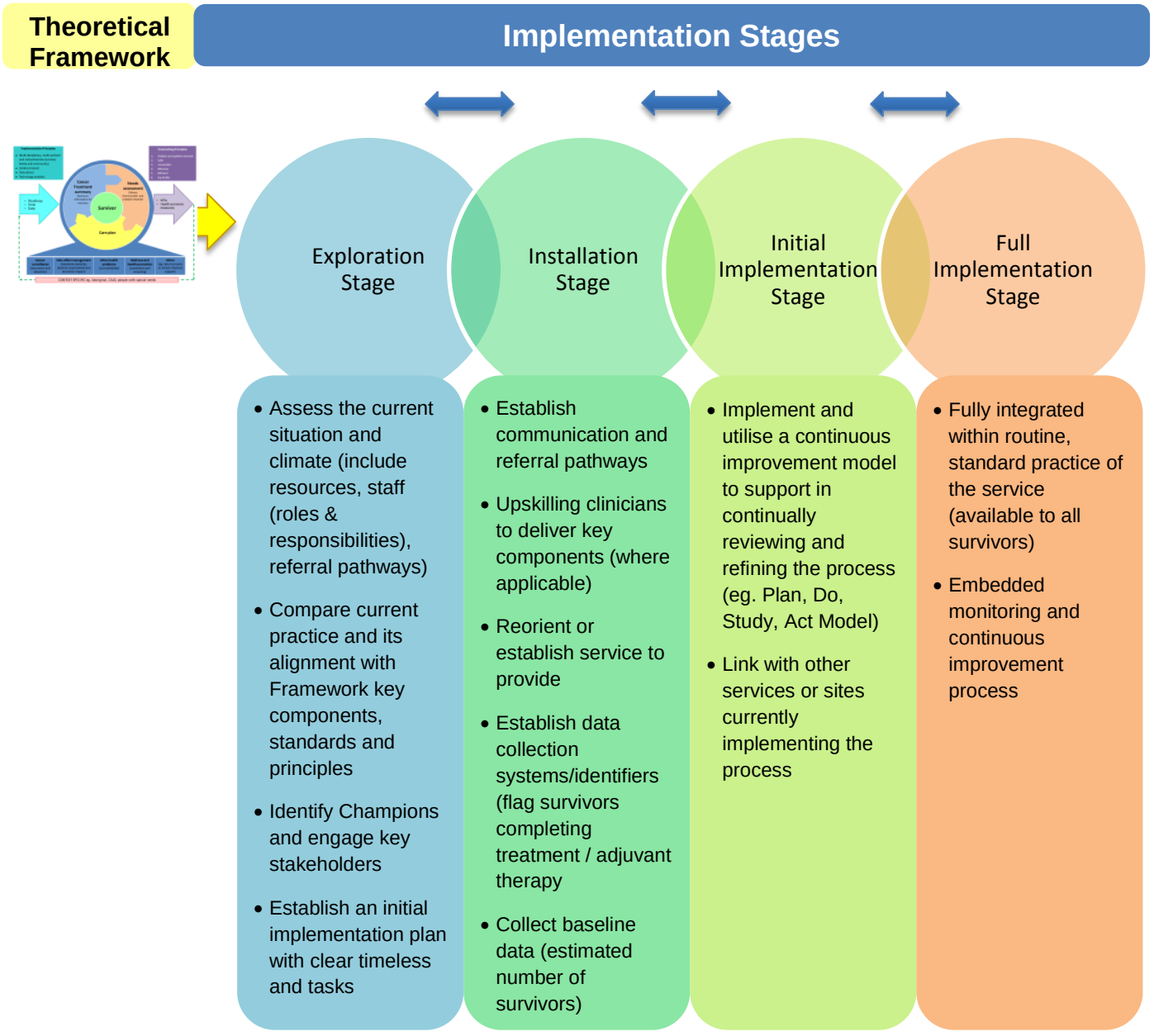


Part C: Framework Implementation

Conceptual Implementation Stages

For effective and successful service and system change, taking a stage-appropriate approach to implementation and required activities is essential [25]. The following diagram (Diagram 5) has been adapted from the *Frank Porter Graham Child Development Institute – Overview of the Stages of Implementation* and is designed to be utilised as a statewide approach to implementation of the Framework as well as by individual sites and services to implement [25]. Implementation strategies including resources and tools have been developed to support sites and services to adopt the Framework and key components utilising the staged approach to implementation (refer to the *SA Survivorship Framework Resources* Document).

Diagram 5. Conceptual implementation stages of the Framework



Process and Outcome Measures for Consideration

The following process and outcome measures have been developed as a guide to determining whether the KPIs of the Framework are being met as well as the level of and effectiveness of implementation. These measures have been developed through capturing within pilot implementation projects and feedback from Champions and cancer survivors as well as health economic recommendations following analysis of the theoretical Framework. Recommendations for future consideration and exploration (that have not been captured in the work to date) are noted in grey. Strategies for collection should be considered at both a service and also population level

Table 2. Recommended process and outcome measures with Framework implementation

Process	
Service/ Clinician	Time to create the SCP (efficiency) Difficulties or issues encountered when completing Resources or additional support required
Cancer Survivor	Value added to care (discussion and identification of needs) Relevance of the SCP to them and their health concerns/needs
Outcome	
Service/ Clinician	**Reach:** Demographics of consumers who have received a SCP (access and equity) Total number of SCP developed compared with total number of cancer survivors completing treatment or adjuvant therapy **Needs:** Key concerns or problems identified within the SCP **Quality:** Quality of the SCP developed
	Economics: Cost of current model of survivorship care delivery (including downstream and long-term) to both the service and consumer Cost of survivorship care with the implementation of the Survivorship Framework (including downstream and long-term) to both the service and consumer
Cancer Survivor	Timeliness of receiving the SCP following completion of treatment or adjuvant therapy What actions were taken How often the SCP has been reviewed and updated Adherence to the SCP Confidence to self-manage (where appropriate)
General Practitioner	Willingness to be involved with the delivery of survivorship care Relevance of the SCP to their needs and ability to be involved with providing effective survivorship care and reconnecting with cancer services as required (including understanding of the purpose of the SCP) Time required to work through and review the SCP Difficulties or issues encountered on utilising Access to resources or referrals

Models of Survivorship Care

Innovative models of survivorship care are continually being developed and piloted. During the development of the Framework a nurse-led (Nurse Practitioner (NP)/NP Candidate) survivorship clinic was piloted to implement the key components and appeared to be feasible to deliver pending the context and circumstances in which implemented.

The following provides a brief overview of potential models that may be adapted when implementing the Framework and key components into practice. The most appropriate model for adoption should consider:

- Risk relating to complexity (of survivors needs, treatment, possible recurrence and other chronic conditions), intensity of monitoring and surveillance required
- Preferences, primarily of cancer survivors as well as providers and their willingness to engage with survivorship care
- Settings and contextual barriers and enablers evident for implementation
- Cost effectiveness for both cancer survivor and service providers

With increasing demands on cancer care services and specialists, exploration of different models for delivering survivorship care is important, providing opportunities to increase capacity within these services and allow for rapid re-entry into the system where required as well as a holistic approach to meeting the diverse needs of cancer survivors.

Shared Care

Survivorship follow-up is shared across two or more health professionals this may include:

1. Specialist oncologist & GP
2. Oncologist and cancer nurse (eg. NP/NPC)
3. Specialists from across disciplines (eg. surgeon, medical oncologist, radiation oncologist)

Appointments may be alternated between health professionals

Specialist Led

Management of survivorship care continued to be provided by the treating specialist, usually within the acute cancer setting

Nurse Led

Survivorship care is provided by an advanced practice nurse (eg. Nurse Practitioner). Benefits of such model include:

- Greater liaison and number of referrals with other support services
- More capacity to respond to and address individual needs
- Provide tailored, individualised care and information including management of existing conditions and support for health behaviour change [5, 6]

GP/Primary Health Care Provider Driven

Involves the transition and discharge of cancer survivor's health care management from the acute cancer service to their GP. A once off comprehensive consultation may occur with a member from the acute cancer setting to establish a detailed follow-up plan shared with the cancer survivor and their GP. Contact details are provided to re-connect with specialist services if required.

Part D: South Australian Examples & Experiences

Implementation Pilots

Champions Perspectives

Pilot implementation of the key components of the Survivorship Framework occurred over a three month period across four sites, Championed by a Nurse Practitioner (NP)/ NP Candidate and Medical Oncologist. Fortnightly debrief sessions via phone and videoconference were conducted to support implementation and further refine processes as well as the tools. Below are a number of examples and reflections of the experience for Champions implementing.

Tools and Templates

- Change in format of templates, particularly the Treatment Summary, much easier to prepare than previous (x2 sites implementing similar process already)
- Time to deliver improved with familiarity with the tools and templates.
- Having a common outline/template is useful

Consumer engagement in process (Champion perspective)

- Appointment considered to be a "round up" to their care with consumers feeling they still have a connection with service/system
- Consumers were quite interested in having the conversations
- Survivorship appointment provided the opportunity to refresh consumers with information, particularly in relation to implications or late-effects that they may have heard/been told previously however not necessarily remembered
- Important that the purpose of the survivorship appointment is explained to survivors prior and allow them to prepare for this. Valuable when Medical Specialist instigates these conversations
- Consumers willing to engage with NP/NPC for the appointment, irrespective of the level of involvement in their care during treatment

Implementation support

Opportunity to work and debrief together as a group was considered valuable to discuss challenges, enablers and strategies others were using to implement, particularly in relation to:

- **Building confidence**, particularly in developing SCP
- **Establishing and refining** processes
- **Learning from each other's experiences** (level of survivorship care provided prior varied)

Process of implementation

- Best supported and taken up when Specialists are willing to refer, understand the benefits of and encourage survivors to attend a survivorship appointment
- Preparing survivors for the conversation – setting goals based on their needs and priorities is useful as it is a very different approach to care from being advised of plan of treatment to transitioning to a model of wellness and self-management

Time of Survivorship appointment

Currently there are no definitive guidelines within the literature indicating the most appropriate time to provide cancer survivors with a cancer treatment summary and care plan. Determining consumer's readiness (particularly emotionally) to engage may be an important factor to consider in relation to timing of developing a care plan [5, 7].

The general consensus from Champion Teams, indicated the provision of the survivorship appointment may be best 3 – 6 months following completion of treatment or adjuvant therapy, providing time for acute treatment toxicities to subside and enable focus on wellbeing.

Cancer Survivor Experiences

Following pilot implementation of key components of the Survivorship Framework, surveys were sent to seek feedback from cancer survivors on the overall experience of the appointment as well as the usefulness and value of receiving a written cancer treatment summary and survivorship care plan. Quotes below reflect some of the initial feedback received. Of the surveys completed at the time of developing this document, 70% of cancer survivors reported having shared their survivorship care plans with their GP.

Cancer Treatment Summary

"All my questions concerning my recovery have been answered. I am pleased with the results"

"Sometimes it is hard to remember just what is said at the time but it helps to re-read the copy to answer any questions you or your family have"

"Get bombarded with so much information, it was good to have a concise written summary"

"Good to have things set out clearly as a personal reference"

"It makes it easier to explain…it made me more confident about what happened to me"

Survivorship Care Plan

"Have used the healthy living after cancer program"

"It is an encouragement to keep your hopes for your future health and ongoing wellness into the future"

General

"I found talking to X very beneficial and comforting. Especially to know X (or the team) are available to me at any time"

"Even after all the treatments and follow-up there is always the doubt that the cancer will come back – somewhere, sometime and that is something that you need constant reassurance about at a later date. In the beginning, it's all about your treatments but after all that, you need the reassurance".

Appendix 1. Key contributors to the SA Survivorship Framework

South Australian Survivorship Framework Steering Group

Chair	Co-chair
Professor Bogda Koczwara Senior Staff Specialist in Medical Oncology Flinders Centre for Innovation in Cancer	**Ms Tracey Doherty** A/Service Director SA Cancer Service

Members	
Ms Chantelle Hislop Senior Project Officer SA Cancer Service	**Dr Kate Cameron** Nursing Director Women's and Children's Health Network
Professor Marion Eckert Director, Rosemary Bryant AO Research Centre University of South Australia	**Ms Julie Marker** Consumer and Chairperson Cancer Voices SA
Ms Chris Christensen Consumer & Deputy Chairperson Cancer Voices SA	**Ms Karen van Gorp** Consumer, Melanoma Patients SA Facilitator and Cancer Voices SA representative
Mr Michael Fitzgerald Nurse Practitioner Candidate (Oncology) Southern Adelaide Health Network	**Ms Nicole Loft** Nurse Practitioner (Haematology) Central Adelaide Local Health Network
Dr Dagmara Poprawski Medical Oncologist Country Health SA Local Health Network	**Ms Kate Turpin** Nurse Practitioner (Oncology/Haematology) Women's and Children's Health Network
Dr Michael Osborn Lead Clinician, Consultant Haemtologist Oncologist Youth Cancer Service SA/NT	**Ms Janet Stajic** Senior Project Officer – Aboriginal Cancer Control SA Cancer Service
Clinical A/Professor Taryn Bessen Senior Staff Radiologist Central Adelaide Local Health Network	**Dr Nadia Corsini** Senior Research Officer Cancer Council SA

Survivorship Pilot Champion Teams

Mr Michael Fitzgerald Nurse Practitioner Candidate (Oncology) Southern Adelaide Health Network	**Professor Bogda Koczwara** Senior Staff Specialist in Medical Oncology Flinders Centre for Innovation in Cancer
Ms Julie Campbell Nurse Practitioner Candidate (Oncology) Country Health SA Local Health Network	**Dr Dagmara Poprawski** Medical Oncologist Country Health SA Local Health Network
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