

Cancer Survivorship Care in Australia

Position Statement

Critical Components of Cancer Survivorship Care



Preamble

There have been important failings of post-treatment care of cancer survivors recognised internationally since the early 2000's. Oncology services are finding it increasingly difficult to provide high quality follow-up care to all survivors as numbers grow and resources do not match this growth. It is also clear that the cancer survivor experience varies greatly between individuals, for some it is life as normal, while for others the disease and its treatments impact on their ability to function in daily life. The recognition that there is a need for post-cancer care to be done better promoted the COSA Survivorship Group to develop this position statement and model of care to support survivors, healthcare providers, health care administrators, government, and non-government organisations to consider how to deliver better care to survivors without negatively impacting cancer recurrence and survival outcomes.

Objective

The objective of this project was to develop a position statement for COSA and its members and stakeholder groups defining the critical components of cancer survivorship care. The guiding questions for the project are:

- What are the critical components of survivorship care in Australia?
- What defines quality survivorship and how can it be survivor-centred?
- How can we deliver a minimum standard of survivorship care in Australia?

A further objective was to develop an action plan to would support staged implementation of Cancer Survivorship Care across a range of Australian healthcare settings.

Definition of Survivorship

"An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience".²

<http://cancercontrol.cancer.gov/ocs/definitions.html>

Adapted from the National Coalition for Cancer Survivorship

Many alternatives have been suggested, including "thrivers" and "someone who has had cancer".¹ Currently, there is no consensus beyond the term cancer survivor. Consequently, we will use the term cancer survivor.

We acknowledge that the broad definition of cancer survivorship includes the full gamut of patient experiences and the concept of cancer as a chronic illness, as well as those of caregivers, families and friends of a person diagnosed with cancer. There is a need to reflect

this position in policy, practice and research. However completion of adjuvant treatment or definitive primary treatment is to be the starting point for COSA survivorship work, a position that is in line with the international survivorship focus and the seminal USA Institutes of Medicine Report. This should not be a barrier to using the model to support wellness in people living long term with incurable cancer.

Why is a Survivorship model of care needed?

Historically, the emphasis of follow-up care of cancer survivors has focused on monitoring for cancer recurrence and second primary cancers, with little attention given to the late effects of cancer and its treatment, other chronic illnesses, or modifiable risk factors. However, it is well recognised that the number of people surviving for long periods after a cancer diagnosis have increased. Not only are the numbers increasing, so is the proportion of the population affected. Cancer survivors experience increased rates of comorbid, chronic health conditions, their healthcare needs are complex but likely amenable to change.

Current models of care for cancer survivors are not survivor-centred, coordinated, or accessible. Nor do they effectively manage and minimise the burden of disease and treatment related side effects in the post-treatment phase. Internationally there has been a substantial move toward development of better models of cancer survivorship care to optimise survival times and quality of life. The evidence base for care in the survivorship setting is limited. To deliver healthcare effectively to those most in need we need a system with greater emphasis on integration across sectors, addressing the health needs of survivors to ensure that the level of care and intervention accessed meets their needs and potential health risks.

Any model of care must address the differing needs of three distinct stakeholders: individuals, health professionals, and the system. Care for the individual must meet their post-cancer care needs, for the health professionals it must be feasible, and for the system it should result in greater efficiency.

The Institutes of Medicine define the essential components of survivorship care as including:

1. Prevention of recurrent and new cancers, and of other late effects;
2. Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
3. Intervention for consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and
4. Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met.

There is no doubt that care that addresses these four factors will vastly improve the post-cancer experience. However, it continues to place emphasis post-cancer treatment on the medical care and deficits rather than optimising outcomes. Consequently, COSA recommends consideration of modifiable factors associated with better cancer and quality

of life outcomes amongst cancer survivors as critical to defining a wellness plan, particularly one that emphasises improved quality of life.

COSA Model for Wellness in Cancer Survivorship

In 2006 the World Health Organisation (WHO) added a definition of wellness to its glossary of terms. The decision reflects an increasing emphasis on health and well-being rather than only the absence of disease or illness. As the long-term and/or late effects of living with cancer and its treatment have become increasingly recognised, so the concept of wellness in cancer survivorship has emerged as an aspirational goal for survivors and the healthcare professionals involved in their care.

Definition of Wellness

Since 1948 WHO has defined health as *“a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”*² Policy and guidance documents have previously emphasised the term “well-being”, more recently wellness has been defined as *“the optimal state of health of individuals and groups. There are two focal concerns: the realization of the fullest potential of an individual physically, psychologically, socially, spiritually and economically, and the fulfilment of one’s role expectations in the family, community, place of worship, workplace and other settings.”*³

Some models of wellness have existed since the 1970’s, usually in the context of complementary, alternative, and integrative medicine.⁴ The National Wellness Institute has developed the Six Dimensions of Wellness Model,⁵ which incorporates the following dimensions of wellness:

- Physical
- Social
- Intellectual
- Spiritual
- Emotional
- Occupational

Other models focus on the following five dimensions as contributing to wellness:

- Physical
- Social
- Spiritual
- Lifestyle
- Mental

The terms wellness and well-being are commonly used interchangeably. However, as wellness models evolve and become better supported by evidence, it is likely that well-being will be considered a component of wellness.

The common underlying factor is that wellness focuses holistically on the person and ability to live the life they desire, rather than focusing on disease, its prevention or amelioration. It is a patient-centred concept in which people are actively increasing their awareness and making choices which can lead to a more integrated and robust existence.

Recovery-oriented practice

Recovery is a concept related to wellness, emerging during the 1970s and 1980s as part of

the consumer health movement. It is a concept recognised in mental health policy and services internationally. The concepts of clinical and personal recovery are commonly used: Clinical recovery, defined by mental health professionals, refers to the reduction or cessation of symptoms, a restoration of function. While personal recovery, defined by the individual, refers to ongoing holistic process of personal growth, healing, and self-determination. There are clear parallels between the concept of recovery and wellness as they related to cancer survivorship. Recovery is one of the principles underpinning the COSA model of survivorship care, encompassing the concepts of self-determination, self-management, personal growth, empowerment, and choice.

Recovery-oriented practice

Recovery-oriented practice aims to support people in building and maintaining meaning and satisfaction in their lives and identity regardless of their ongoing experience of symptoms of their cancer and its treatment. This is a more holistic approach to recovery and well-being that builds on individual strengths, reflecting a shift from the biomedical view of illness.

As the principles of self-determination and individualised care are key to recovery-oriented practice, the concepts of hope, inclusion, community participation, goal setting, and self-management are emphasised. To successfully build these concepts at a personal level service provision promotes coaching or partnership relationships between individuals and their healthcare providers. Thus, the individual with lived experience are experts on their own lives, with healthcare professionals expert on available healthcare and lifestyle interventions.

The journey for any cancer survivor is individual, unlikely to be linear, but can promote recovery to wellness.

The COSA model for wellness in cancer survivorship is shown in Figure 1.

DRAFT

Cancer Survivorship

A process for living well with and beyond a cancer diagnosis

Principles:

How we do it

- Survivor centred (enabling, engaging, empowering)
- Integrated care across all service levels at every time point
- Coordinated care

What we do

- Promote well-being
- Prevent illness
- Manage symptoms and issues

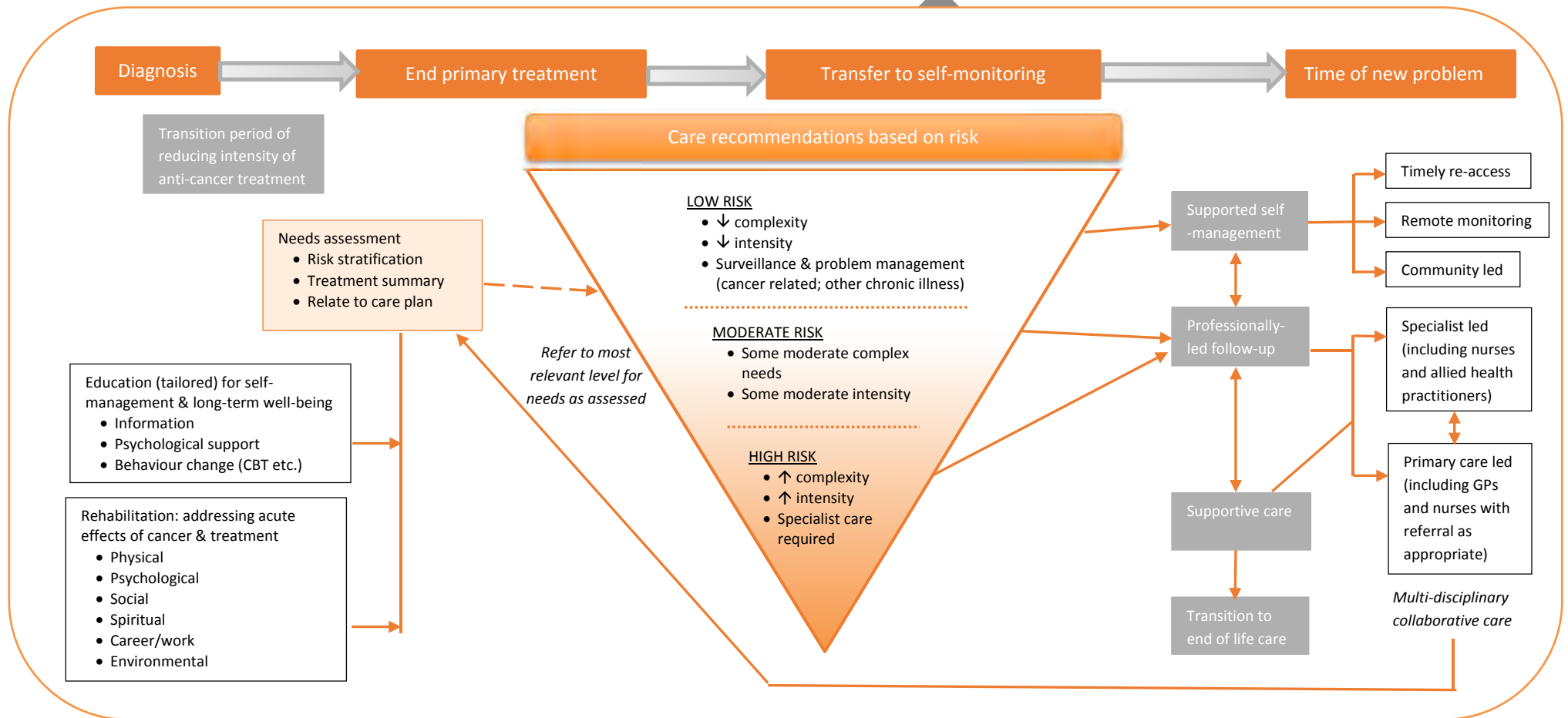


Figure 1. Model for wellness in cancer survivorship

RISK STRATIFICATION

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

CARE PLAN

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

TOOLS

- Care plan (electronic)
- Directory of services
- Referral pathways
- Motivational interviewing
- Telehealth tools

CARE COORDINATION

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

TIME FACTORS

- Survivors engage with healthcare and lifestyle services they need when they need it
- Survivor priorities & needs are addressed from most to least urgent
- Survivors keep time spent in health care environments to the minimum required to maintain their health & well being
- Survivors have rapid access to healthcare support if & when it is required for cancer & treatment related events
- Survivor & health care resources are not spent on unnecessary tests, treatments, & health encounters



HEALTH PROFESSIONALS *Primary & specialist care*

- Surveillance
- Screening & assessment for:
 - Cancer
 - Other chronic conditions
 - Physical & psychosocial issues
- Engagement
- Motivation to change
 - Education
 - Goals of care
 - Wellness
- Multidisciplinary Collaborative Care
- Diagnostic procedures
 - Treatment
 - Symptom management
 - Referral/advice addressing late-effects:
 - Physical
 - Psychological
 - Social
 - Spiritual
- Advocacy
- Survivor care services

COMMUNITY

- Surveillance
- Self-management
 - When & where to seek support
 - Self-monitoring
- Engagement
- Motivation to change
 - Education
 - Support Groups
 - Psycho-educational programs
- Multidisciplinary Collaborative Care
- Self-management programs
 - Counselling
 - Physical activity
- Advocacy
- Access to services

SURVIVOR

- Surveillance
- Self-management:
 - Care plan
 - Self-monitoring signs & symptoms
 - Attend check-ups
- Engagement
- Motivation to change
 - Self, family, social group
 - Education
 - Self, family, social group
- Multidisciplinary Collaborative Care
- Self-management:
 - Physical
 - Psychological
 - Social
 - Spiritual
 - Lifestyle
 - Career/work
- Advocacy
- Self & access to services
 - Others, community

Figure 2. Integration of care for cancer survivors

Fundamental principles underpinning all aspects of this model for wellness in cancer survivorship are how we do things (survivor centred, integrated care across all service levels at every time point and coordinated care) and what we do (promote well-being, prevent illness and manage symptoms and problems):

- **Survivor (person) centred**⁶ in that it is:
 - *Enabling* individuals to participate in decision-making that will positively influence their health and well-being;
 - *Engaging* individuals to motivate them to make positive health choices; and,
 - *Empowering* them to seek information and support from the services most suitable to their needs at any given time.
- **Integrating care** across all service levels at all time points to ensure survivors have access to the right care, at the right intensity, at the right time.
- **Coordinating care** across all services.
- **Promoting well-being** by emphasising behaviours and actions that support wellness rather than focus on illness.
- **Preventing illness** by supporting survivors to engage in lifestyle behaviours, self-care and preventative health checks that are appropriate to maintain health.
- **Managing symptoms and problems.**

The model recognises that survivor-centred care is best from the beginning of any individual's cancer journey. Workforce and system related barriers that need to be addressed to facilitate the change from illness to wellness models of care should be considered. Inherent in this model is the recognition that individuals come to their cancer diagnosis with a range of life and health experiences. Therefore in order to appropriately meet the needs of individuals a *needs assessment* that includes assessing health literacy early (around the time of diagnosis) will contribute to survivors, caregivers, and healthcare professionals effectively establishing a partnership that enables the survivor to be an active participant in their health and treatment. During initial anti-cancer treatment and in the transition phase where intensity of treatment is reducing, it may be timely to consider intervening with education, support and referral related to survivor self-management and well-being, and that addresses the acute effects of the cancer and its treatment:

- Physical
- Psychological
- Social
- Spiritual
- Lifestyle
- Career/work

During the transition from intense, regular contact with the cancer care team to follow-up care an assessment of survivor needs is recommended. This should include three components: a risk assessment, a treatment summary, and a survivorship care plan.

Stratified pathways of care will be influenced by:

- Survivor ability and motivation to engage and self-manage;
- Assessing the level of risk for disease related comorbidity and recurrence dependent on the tumour type;
- Short, medium and long-term treatment sequelae;
- Existing comorbidities;
- Level of professional involvement required.

A *treatment summary* will be potentially useful to survivors and all healthcare professionals involved in supporting the survivor in the future, including general practitioners (GPs), allied health professionals, rehabilitation specialists, and cancer specialists. Ideally the treatment summary would:

- Be automatically generated from the electronic medical record;
- Include diagnosis and disease details (date, type, location, stage);
- Include treatment details (dates, surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy, other supportive care interventions accessed).

A *survivorship care plan* is a tool to facilitate care. It will deliver greatest benefit if it is used and regularly reviewed, that is it needs to be action based. A survivorship care plan can include the treatment summary and the outcomes of the risk assessment. It is a living resource document, not a static historical one. It should:

- Include recommendations, with priorities, for other education, supportive care and healthy lifestyle interventions, and referral to other healthcare professionals;
- Be updated by healthcare professionals involved with supporting the survivor;
- Include space for the individual to make notes themselves;
- Be regularly reviewed with the GP and other healthcare professionals;
- Be communicated to all relevant parties when changes or updates are made.

Survivorship care plans, ideally, will be owned by survivors themselves and used by all healthcare professionals to ensure seamless integration of care for the individual.

Care Coordination is a critical component of a workable model of survivorship care.

Coordinated care will:

- Place the survivor and their needs at the centre of the wellness and healthcare interactions with those providing support, assistance and care;
- Facilitate communication between all health care professionals and others involved in supporting survivors;
- Ensure that survivors are able to access the services that they need at the time they need them;
- Ensure regular review of the individual's needs in the context of their ongoing Survivorship Care Plan.

Time Factors are another set of components that are critical to the workable survivorship model. They serve to reassure the survivors and the healthcare professionals involved with their care that:

- Survivors engage with the services (healthcare, lifestyle, professional, etc) they need when they need them;
- The priorities and needs of the individual survivor will be addressed from most to least urgent;
- Will minimise survivor time in healthcare environments to that required to improve and/or maintain their health and well-being;
- Survivors have rapid access to support when required for cancer and treatment related events;
- Resource use is minimised to the level that is effective and meaningful.

There are a series of tools that may support individual survivors and the healthcare professionals involved to deliver more efficient and effective outcomes. These include, but are not limited to:

- Needs assessment tools;
- Survivorship care plan (preferably electronic);
- Directory of services and accredited healthcare professionals;
- Referral pathways;
- Motivational interviewing techniques and skills;
- Telehealth tools;
- Information and support services.

The Three Pillars of Survivorship Care

The three pillars of survivorship care are survivors themselves, the health care professionals, and the community. It is essential to understand that healthcare professionals referred to here incorporates primary health care services, allied healthcare services, and specialist services (see Figure 2).

All three have a role to play in surveillance, education, coordinated care, and advocacy. Contingent on a survivors needs they may be best met by one or other of these pillars, or more likely a combination of them. Integration of these pillars and their services is essential in achieving a wellness and self-management approach to healthcare.

It is envisaged that *survivors* will be up-skilled to ensure that they are able to advocate for themselves and their need for access to services, as well as advocating for others in the broader community. Education of themselves, their family and social group is a key role for survivors. It is also anticipated that survivors will be able to engage in self-management activities:

- Surveillance for cancer recurrence;
- Surveillance for second primary cancers;

- Self-monitoring for signs and symptoms of cancer and side-effects;
- In the context of multi-disciplinary care encompassing:
 - Physical
 - Psychological
 - Social
 - Spiritual
 - Lifestyle
 - Career/work

While we are advocating self-management in the survivorship setting we acknowledge that some survivors may prefer not to engage in self-management activities, and that some will not have sufficient health literacy and life skills to do so. It is critical that survivors and healthcare professionals alike understand that patient preference must be taken into account in planning survivorship support. Regardless of their preference, survivors will be supported in line with their values and preferences and best available evidence.

Health care professionals (at all levels) have a distinct role in education about the goals of care and wellness more broadly. They are positioned to engage in advocacy for the wellness of individual survivors at one level and for survivorship care services at the system level.

The **General Practitioners (GP), primary care doctors**, are the central point of contact between individuals and the healthcare system. Their role is to provide general, comprehensive healthcare and support to survivors and referral to specialist care when it is required.

Specialist care in the survivorship setting should be provided for those people with complex needs that may include severe and/or complex late effects of their anti-cancer treatment. Specialist care encompasses a range of healthcare professional services (exercise physiology, medical, nursing, nutrition, occupational therapy, physiotherapy, psychology, rehabilitation, and social work). Specialist care is likely to be provided across both the primary health and hospital-based settings. Although rehabilitation is rarely considered part of cancer survivorship care, individuals may derive substantial benefits from a comprehensive rehabilitation plan as an interim step between acute cancer care and wellness in survivorship.

An important part of the role of health care professionals is surveillance and multidisciplinary collaborative care for:

- Screening and assessment for:
 - Cancer
 - Other chronic health conditions
 - Physical and psychosocial issues;
- Appropriate use of diagnostic procedures;

- Treatment;
- Symptom management;
- Advice about and referral to other healthcare professionals to manage late-effects:
 - Physical
 - Psychological
 - Social
 - Spiritual

Community Services

The community services are those least integrated into models of care in the cancer setting. Community-based services may include primary care practices, allied health care services, centralised non-government organisation services, in particular the Cancer Council Australia and its affiliated state bodies, consumer groups, and so on. They have distinct roles in supporting self-management by:

- Providing information about self-management and self-monitoring;
- Advising survivors when and where to seek the most appropriate support for them;
- Providing access to educational opportunities through:
 - Support groups
 - Psycho-educational programs
 - Online support tools;
- Contributing to multidisciplinary collaborative care for self-management programs; counselling and physical activity.

The community-based services have a substantive role to play in advocating for service provision and access to services. As they have a community-based funding stream it is important that their role in service delivery and support is fully recognised. With the increasing numbers of cancer survivors and a limited pool of resources centralised organisations like the Cancer Councils are well-placed to deliver evidence-based and continuously improving services.

Health Literacy Skills

Health literacy can be defined as having the skills to ‘obtain, process and understand basic health information and services needed to make appropriate health decisions’ (Nutbeam 2000). Cancer survivors engaging in self-management will require a sufficient level of health literacy to do so effectively. However, data suggest that up to 60% of the general Australian population lack basic health literacy skills needed to understand health-related materials, and experience poorer health and clinical outcomes as a result (add alls reference).

Currently available written health materials commonly require high literacy and numeracy skills. Health professionals, themselves generally well-educated and highly literate, are known to have a low awareness of low literacy and few engage in active assessment of this skills in cancer survivors. Increased awareness of health literacy amongst Health Professionals will be essential in addressing this gap in the implementation of self-

management strategies by cancer survivors. Awareness training for health professionals will be necessary to assist them to identify this silent population, as well as evidence-based interventions to overcome health literacy challenges in communication and the ability of cancer survivors to implement self-management programs and change their lifestyle.

Wellness Plan

The proportion of people living long after their initial cancer diagnosis, either disease-free or with active cancer that they manage on a daily basis, is increasing. Consequently there has been a shift in thinking towards encouraging and supporting survivors and caregivers to develop the skills to be effective self-managers of their condition. Development of resources to support self-management is a growing area; for example, the UK-based toolkits to support health professionals support survivors to develop self-management skills (see shaded box below).

The COSA wellness model aims to incorporate the individual factors required to facilitate wellness in cancer survivors.

Existing self-management resources for long term conditions (not cancer specific) are shown in Table 1.

Table 1. Self-management resources

Resource	Link
Expert Patient Programme	http://www.expertpatients.co.uk
Long Term Conditions Alliance Scotland	http://www.alliance-scotland.org.uk
Stanford Self Management Programmes	http://patienteducation.stanford.edu/programs/
Flinders Human Behaviour & Health Research Unit	http://www.flinders.edu.au/medicine/sites/fhbhru/

The **UK National Cancer Survivorship Initiative** recommends the following pointers for effective-self management:⁷

- Tailored information – increases knowledge and prepares patients for change, and should be provided to all survivors. Additional tailored support and ongoing input from healthcare professionals will be needed to help some people use this information.
- Self-efficacy (the confidence to use self-management skills successfully). Achieved through:
 - Mastery
 - Vicarious experience
 - Verbal persuasion
 - Physiological feedback;
- One size does not fit all. There is a patient ‘self-management journey’ and individuals need to be assessed for their understanding and confidence for self-management along the continuum of skill and confidence so that self-management support can be tailored.
- Collaborative partnerships between patients and health professionals empower patients to take on responsibility for their health and well-being. Clinicians can learn specific communication skills that foster effective partnership with patients.
- Self-management support interventions can be designed, taking account of three factors:
 - Type – adjustment focused (facilitating transition to survivorship) or problem focused (e.g. exercise for fatigue, enhancing coping skills) or a combination of both;
 - Delivery – in a group; one to one; technology-based; home-based; peer led; professionally-led; or a combination designed for impact;
 - Techniques – goal setting; action plans; problem solving; self-monitoring; stress management; information provision; sharing experiences; counselling; coaching; motivational interviewing; feedback; peer modelling.

Implementation Plans

Need further consideration once the model is agreed.

Proposed Future Work and Recommendations

- Models of cancer survivorship care should include proposed screening tools (broad & specific)
- Develop tools to support healthcare professional education & training, and the implementation of guidelines in practice
- Consider models of implementation
- Consider performance indicators of quality service delivery within this or alternative models
- Consider whether the critical components as proposed adequately address these issues, particularly for adolescents and young adults

- Identify ongoing Australian and international research to consider implementation strategies/models
- Identify professional development resources for healthcare workers to upskill in cancer survivorship
- Identify and adapt effective interventions for the Australian environment
- Review existing resources to determine applicability to Australian context
- Tailor existing resources (with permission) for Australian context
- Make resources available to Australian cancer community and the community more broadly
- Identify gaps in resource implementation (e.g. CALD, low health literacy, vision impaired).

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Appendix

Additional guidelines used to develop the critical components summary and model of care include:

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