Royal Brisbane and Women's Hospital

2023

6th Annual

CANCER PRECEPTORSHIP

FOR GENERAL PRACTITIONERS

Metro North Health | Queensland Government

Survivorship for cancer patients

David Wyld

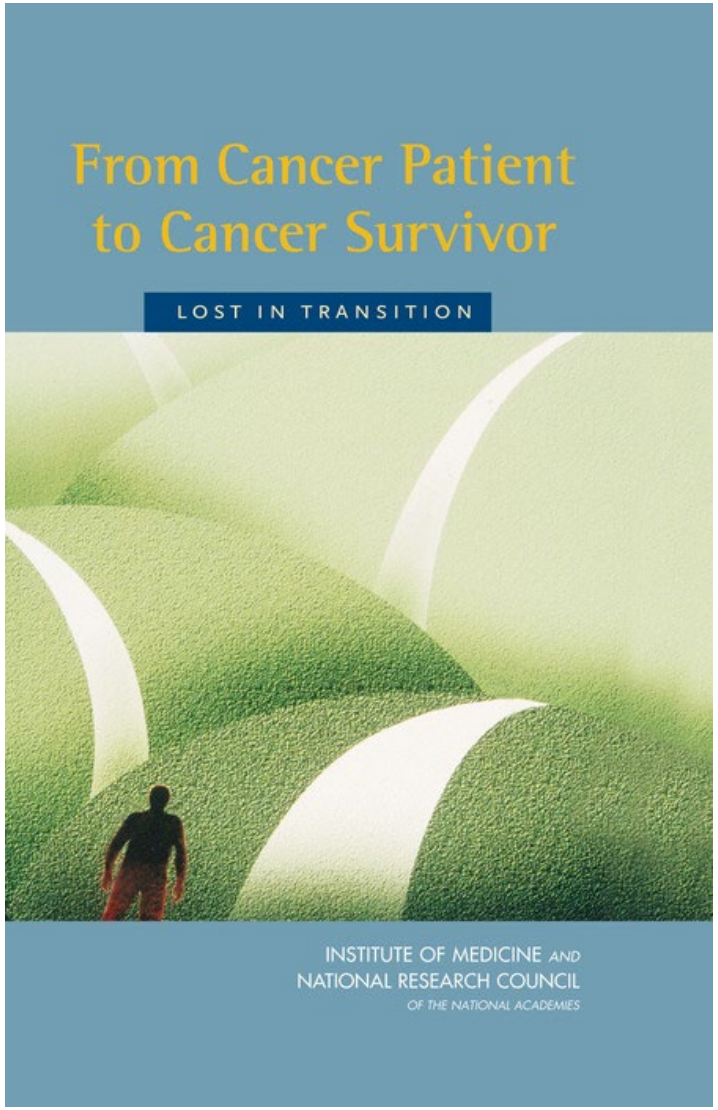
Director Medical Oncology RBWH

July 2023

Cancer Survivorship

- **Cancer survivor / Cancer survivorship**
- How much of an issue is it?
- What should optimal survivorship care encompass
- Models of care
- Cancer Survivorship care in routine practice

Cancer Survivorship



BOX ES-1
Essential Components of Survivorship Care

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.

Institute of Medicine 2005

What is "Cancer Survivorship"

- In the past cancer care focused on diagnosis and treatment
- Follow up concentrated on surveillance for 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

- As cancer survival improved, it was recognised that cancer survivors experienced increased rates of comorbid, chronic health conditions, and their healthcare needs may be quite complex
- As such there has been a substantial move towards the development of better models of survivorship care aiming to **optimise survival times and quality of life**

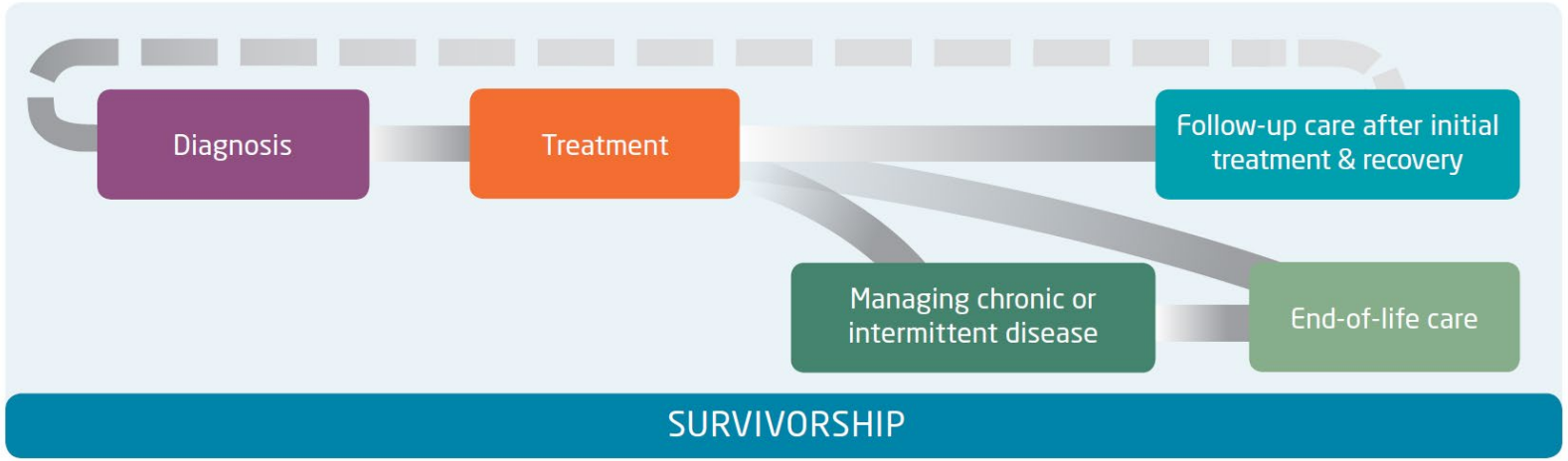
Definition of cancer survivorship

Cancer Australia
Leadership in cancer control

Principles of Cancer Survivorship

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

FIGURE 1 CANCER CARE CONTINUUM *



Cancer Australia (2017)

Model of Survivorship Care: Appendix 1

Cancer Survivorship: Living well with and beyond a cancer diagnosis

PRINCIPLES OF CARE
- Survivor centred (enabling, engaging, empowering)
- Integrated care across all service levels at every time point
- Coordinated care
- Promote, prevent, manage
- Accessible and equitable

Clinical Oncology Society of Australia

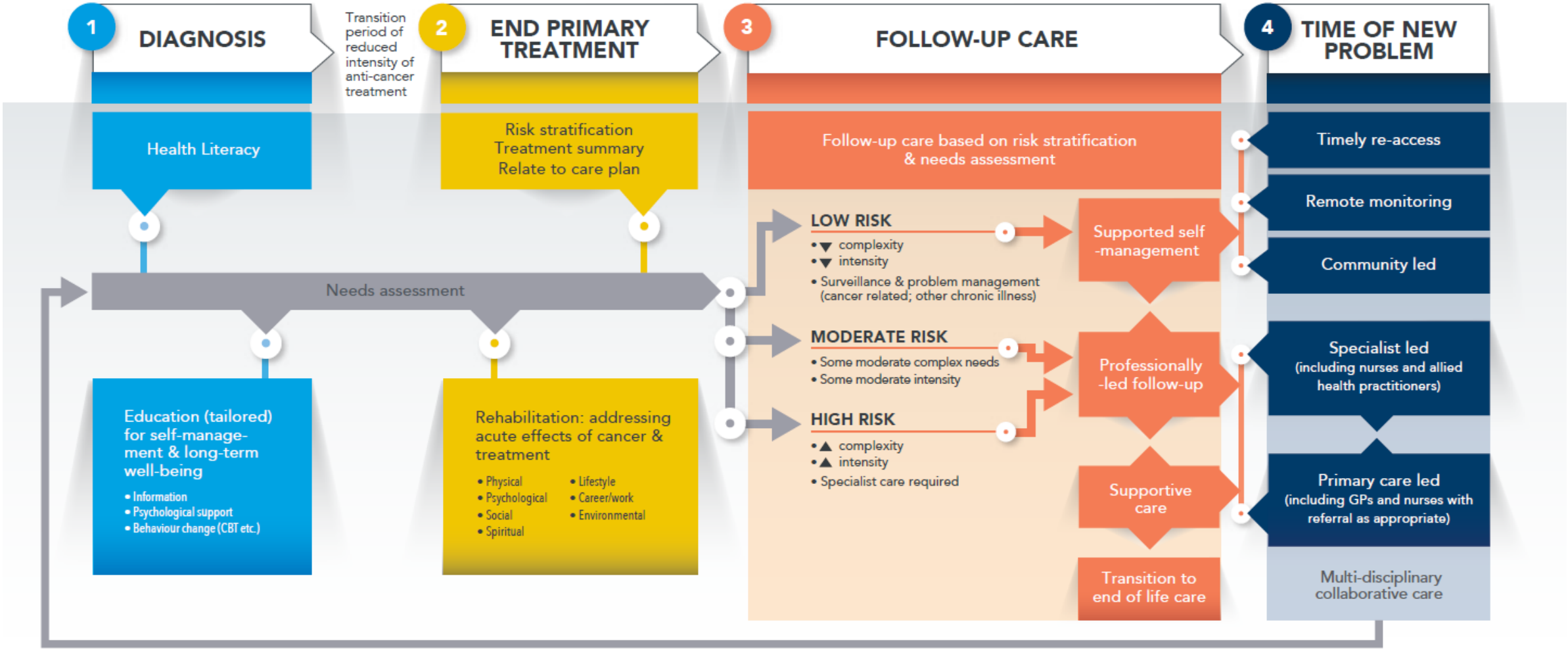


Figure 1. Model for wellness in cancer survivorship

Cancer Survivorship

- Cancer survivor / Cancer survivorship
- **How much of an issue is it?**
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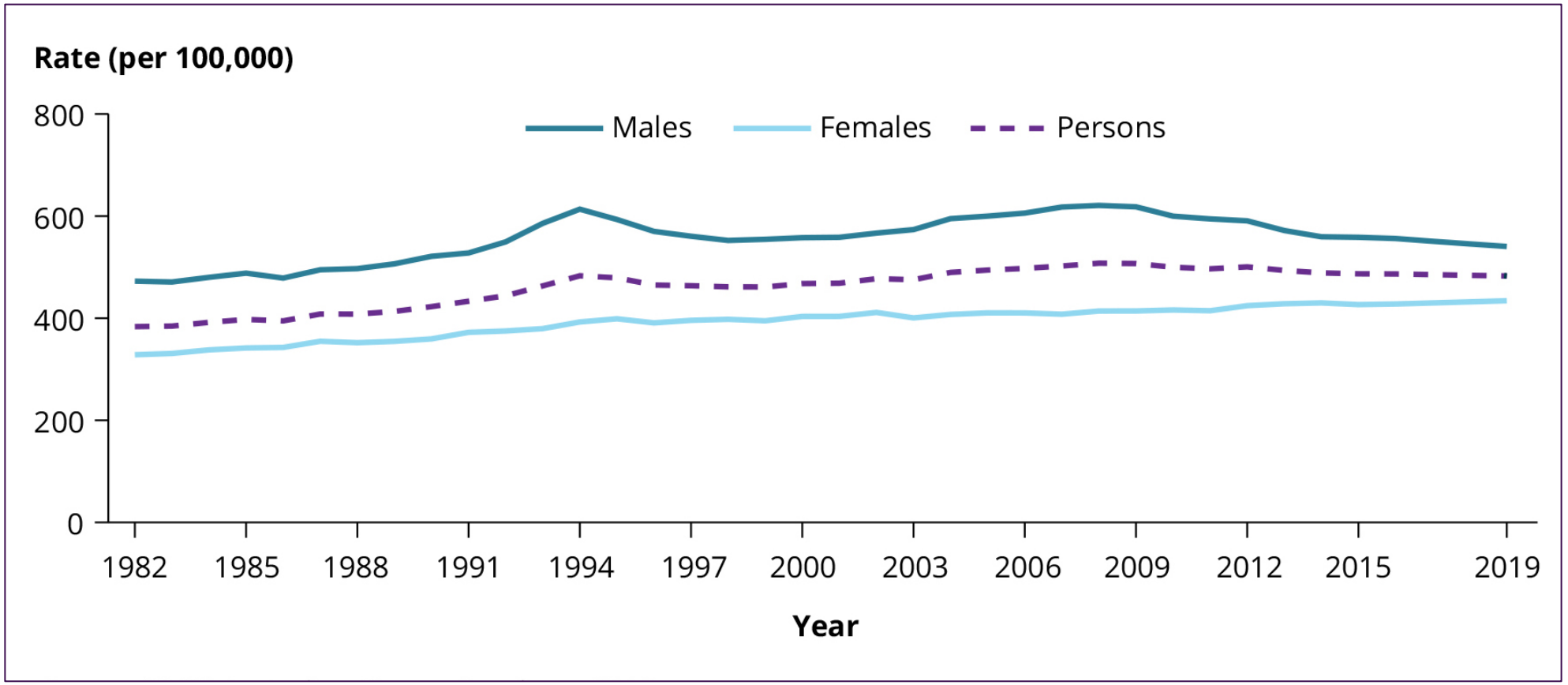
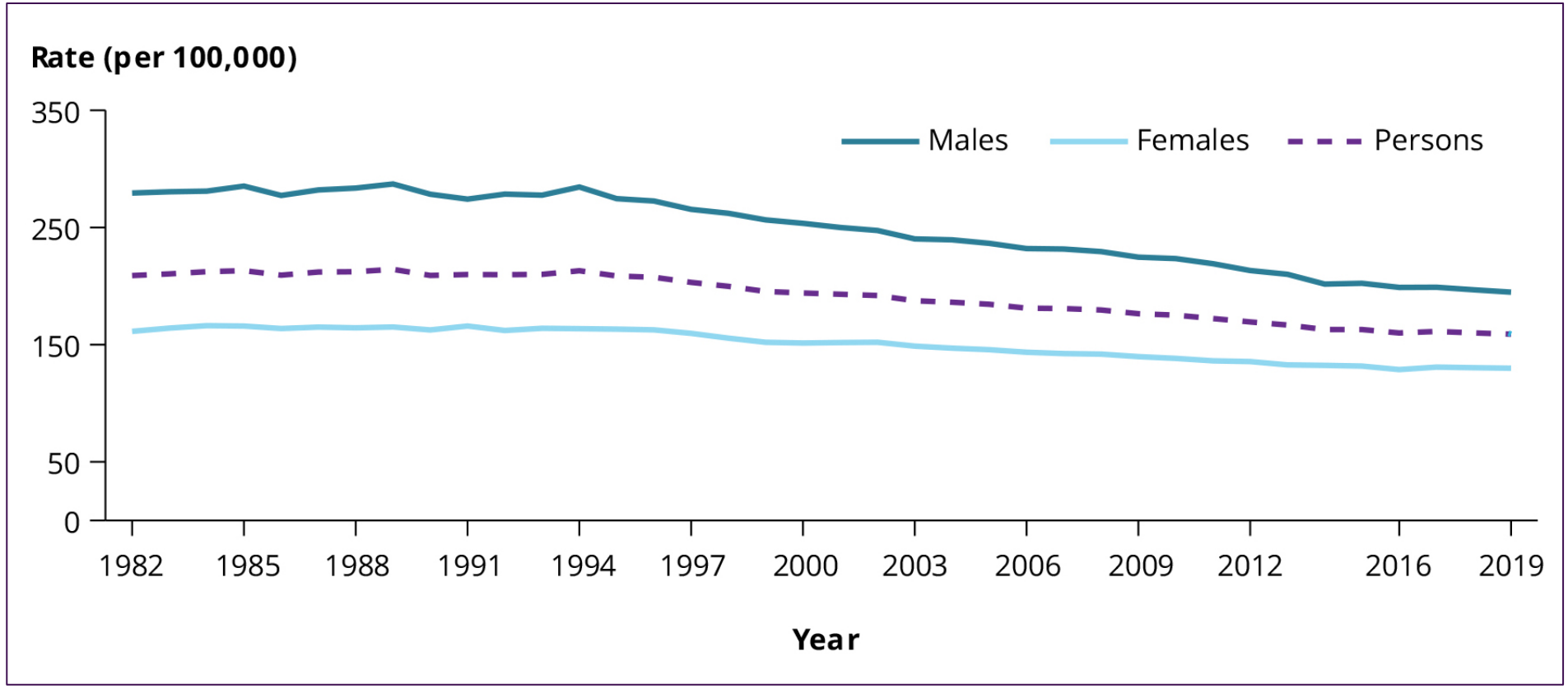
Trends in incidence of all cancers combined, by sex, 1982 to 2019



Source: AIHW Australian Cancer Database 2015.

Trends in mortality for all cancers combined, by sex, 1982 to 2019



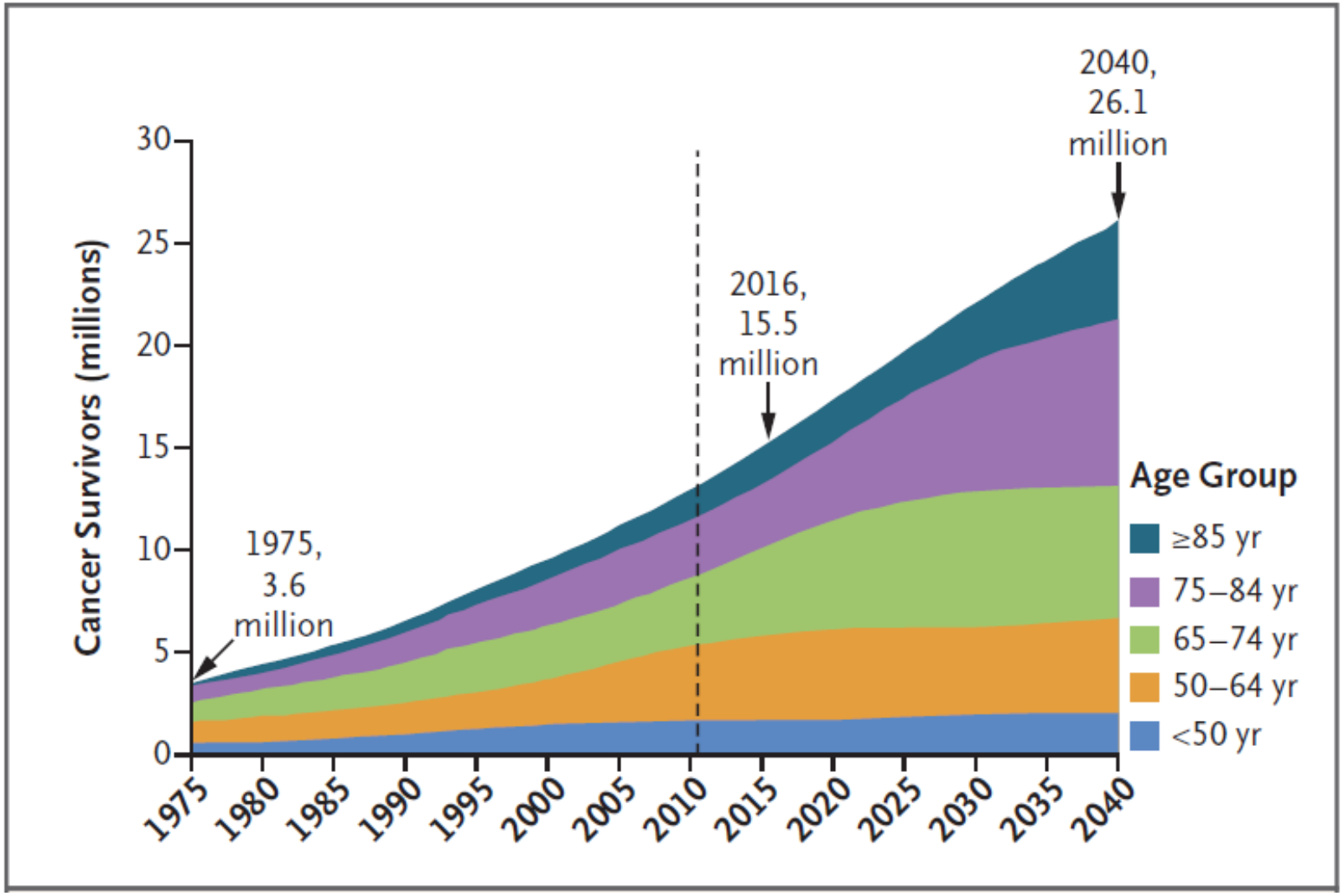
Source: AIHW National Mortality Database

Cancer Survivorship in Australia

Table 7.4: Limited-duration prevalence of all cancers combined, by sex, at end of 2016

Sex	Number	% of prevalent cases	% of population
	10-year prevalence		
Males	401,589	53.7	3.3
Females	345,803	46.3	2.8
Persons	**747,392**	**100.0**	**3.1**
	35-year prevalence		
Males	589,951	50.2	4.9
Females	586,334	49.8	4.8
Persons	**1,176,285**	**100.0**	**4.8**

Changing Demographic Characteristics of Cancer Survivors in the USA



C Shapiro NEJM Dec 20, 2018

Cancer Survivors – 1.9 million by 2040

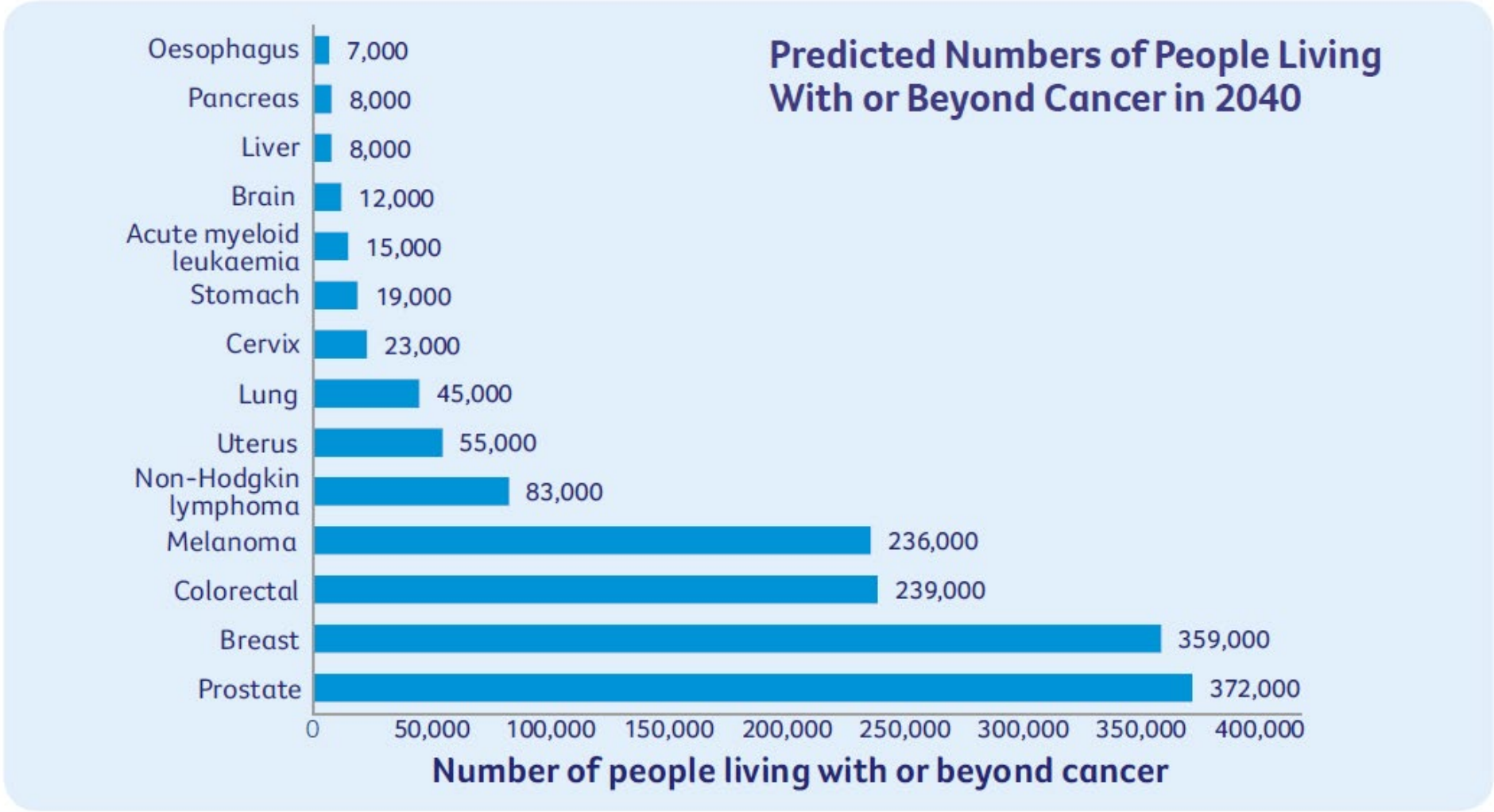


Figure 7.3: Five-year relative survival for selected cancers, 2013–2017

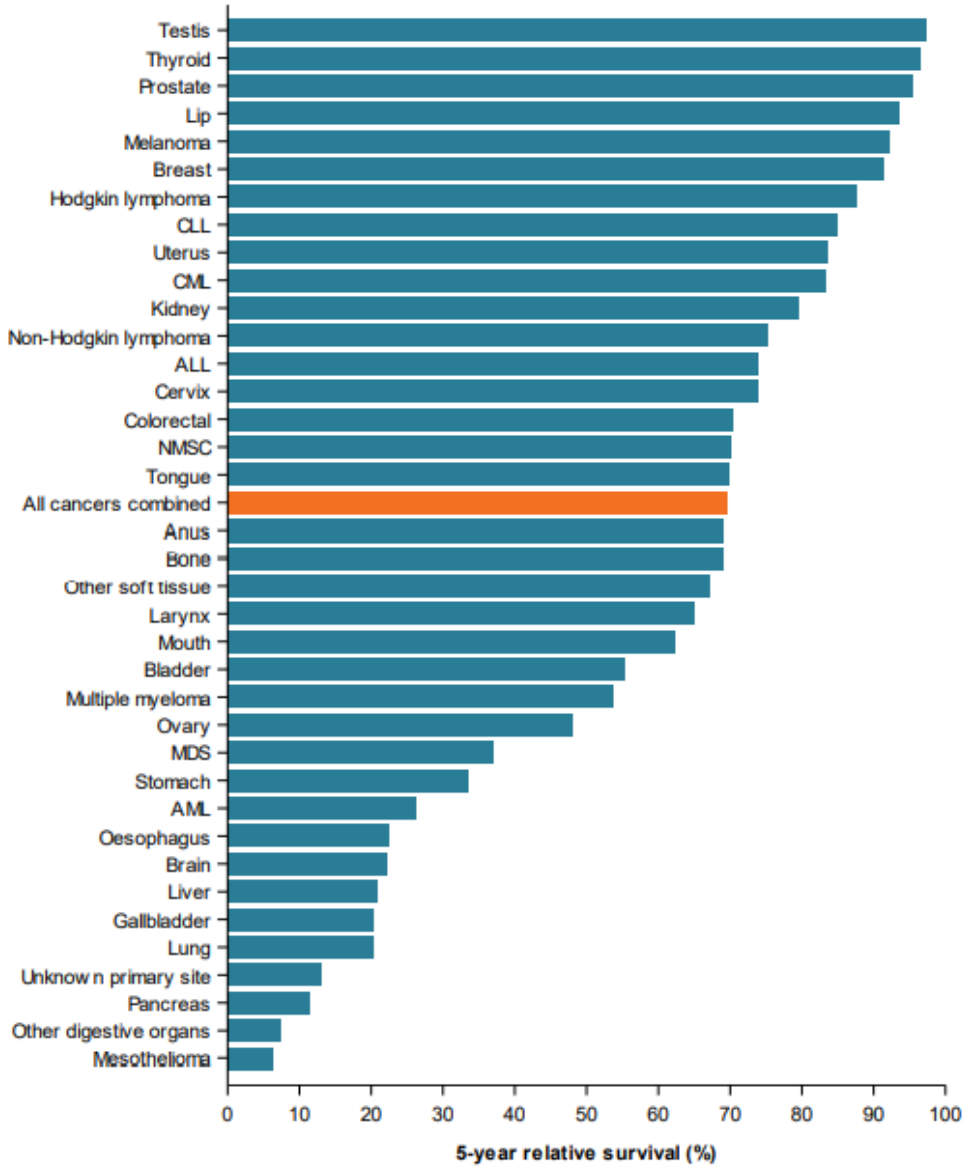
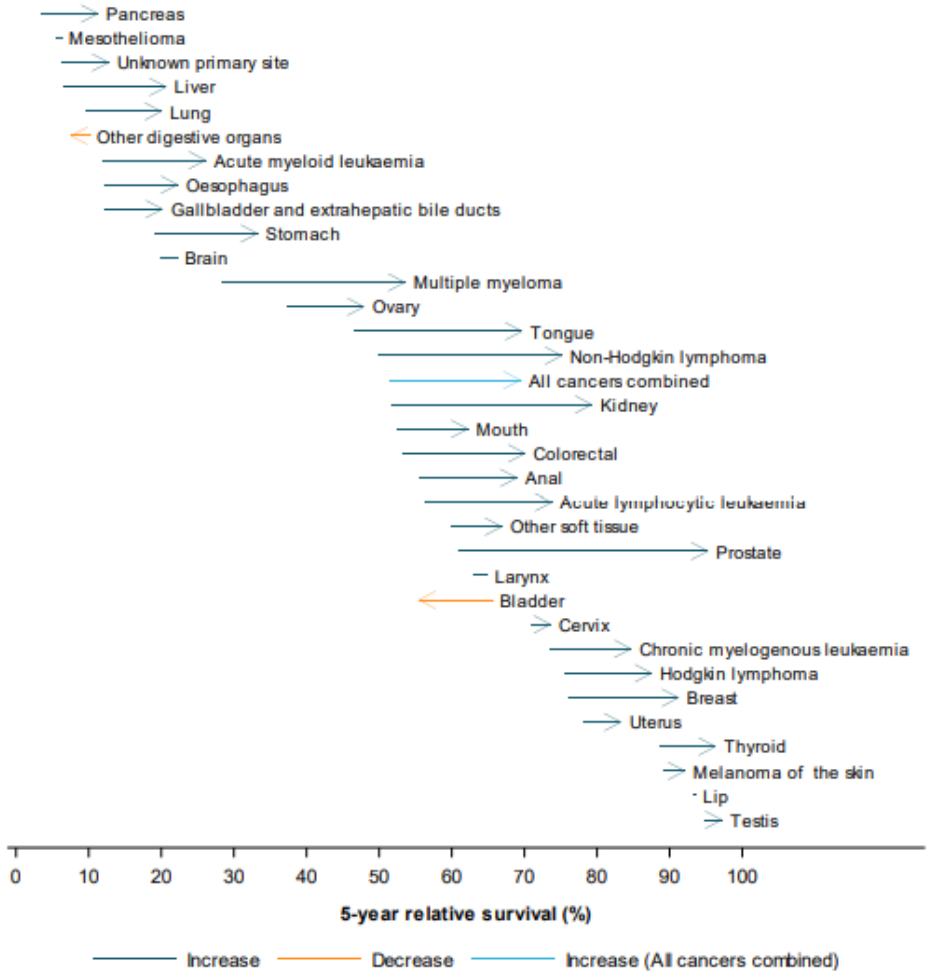


Figure 7.5: Survival trends for selected cancers, between 1988–1992 and 2013–2017

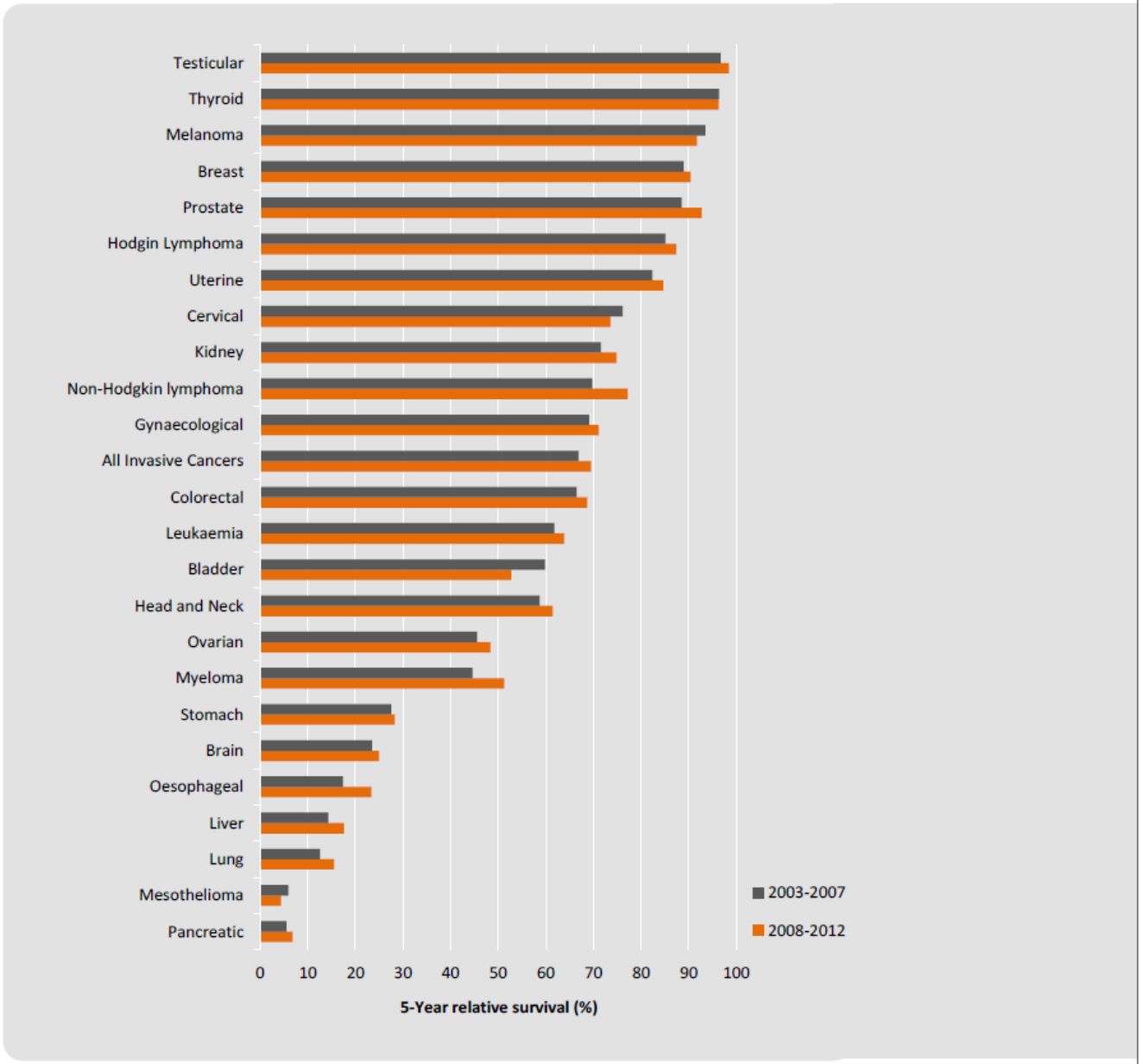


Notes

1. Arrow positions indicate survival estimates and arrow lengths indicate the change in survival between the periods 1988–1992 and 2013–2017.
2. All cancers combined comprises ICD-10 codes C00–C97, D45, D46, D47.1 and D47.3–D47.5, except basal and squamous cell carcinomas of the skin (part of C44).
3. Ovarian cancer includes serous carcinomas of the fallopian tube.
4. Data for this figure are in online Table S7.5.

Source: AIHW ACD 2017.

Figure 21: Five year relative survival for the most common cancers diagnosed in Queensland, 2003-2007 vs 2008-2012



Source: Oncology Analysis System, Queensland Cancer Control Analysis Team.

Cancer Survivorship

- Cancer survivor / Cancer survivorship
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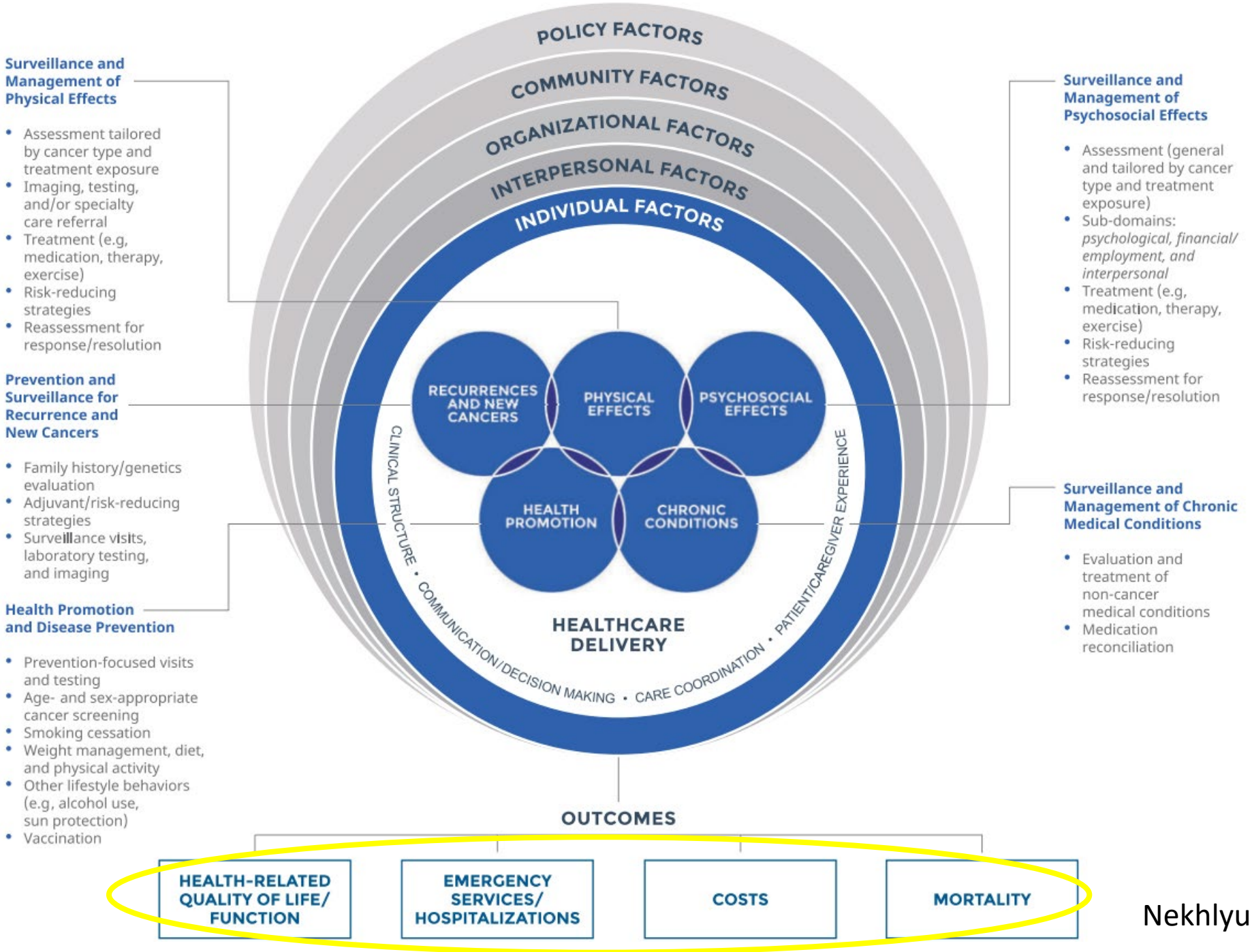
Quality cancer survivorship care should involve

- Monitoring to detect cancer coming back and new cancers
- Support and monitoring for physical, emotional, social and practical effects of cancer and cancer treatment
- Management of any other health conditions
- Supporting and promoting wellness and healthy lifestyle
- Coordinated care between all health professionals involved



Nekhlyudov 2019, JNCI

Clinical Oncology Society of Australia (COSA) Model of Survivorship Care

- Healthcare teams should implement a **multidisciplinary, systematic approach** to enhance coordinated and integrated survivorship care
- **Personalised** stratified pathways of care are required, meaning that care should be
  - **tailored** based on individual needs
  - determined by factors such as **type of cancer** and **treatment**, **current symptoms** and concerns and **risk of long-term and late effects**
- In addition to surveillance and managing treatment-related symptoms and late effects, survivorship care should support wellness, healthy lifestyle, and primary and secondary prevention

COSA Model of Survivorship Care

- At transition to follow-up care, healthcare teams should develop a **treatment summary** and **survivorship care plan**
- In reality, survivorship care plans are not routinely used in most centres
- Communication from managing hospital teams – even when appropriate is likely to be largely treatment focused

Survivorship Care Plans

Australian Cancer Survivorship Centre
After Treatment Care plan

Peter MacCallum Cancer Centre

This After Treatment Care Plan summarises information about your diagnosis, tr
symptoms to watch for, and steps you can take to stay healthy.
Keep this care plan. If you see other doctors and other health care providers in t
your cancer, its treatment, and how best to monitor your health.
Your doctor or specialist nurse will discuss healthy living recommendations that
you can achieve these.

We recommend that you make an appointment to see your GP within the next fe
plan, discuss your health and wellness needs and develop a formal health mana

GENERAL INFORMATION

Name	
Date of Birth	
Date care plan prepared	
Hospital Record Number	
Hospital Telephone number	
Treating Consultant	
Specialist Nurse	
Referring Service	
GP Details	

TREATMENT SUMMARY

Diagnosis	
Date of Diagnosis	

Clinical Trials

Principal Investigator:

Date	Study Title

Surgery

Surgeon:	Service:
Date	**Procedure**
	Other specify:

Chemotherapy/Targeted Therapy

Medical Oncologist:

Date	Agents	Numbers of Cyc

External Beam Radiation Therapy (Radiotherapy)

Radiation Oncologist:

Dates	Site	Dose

Brachytherapy

Radiation Oncologist:

Dates	Type

Hormone Therapy

Specialist:

Dates/ongoing	Type

Current side effects of treatment

Possible late or long term effects of treatment to watch out for and report

Future treatments

Dates	Type

Ongoing medications related to cancer or the cancer treatment

Medication	Reason for taking

Referral to Allied Health and Supportive Care Services:

☐ Psychology	☐ Occupational Therapy
☐ Social Work	☐ Continence Support
☐ Psychiatry	☐ Sexual Counselling
☐ Fertility	☐ Menopause Counselling
☐ Genetic Counselling	☐ Pain and Palliative Care Se
☐ Smoking Cessation	☐ Nurse Consultation
☐ Dietician	☐ Other……
☐ Physical Therapy	☐ Other……

Signs and symptoms to watch out for and report

Some symptoms you experience may be normal. However, if you have any symptoms (new, persistent for more than a week, or unexplained), please speak with your health p symptoms may not be related to your previous cancer, but it is important to have them ch

Special instructions to continue to follow

FOLLOW-UP PLAN

Your follow-up plan will depend on your type of cancer and type of treatments you have had surgery, follow up is with the surgeon. Following radiotherapy you see t you have had chemotherapy, you may require follow up with the medical oncologi follow-up includes medical History (talking about your health), examination and ot required.

Follow-up Plan

This may change throughout your follow up visits

Time	Appointments	Recommended Tests	H
First follow-up appointment	Soon after treatment completion		T
In next 1-3 weeks			Make appointment to see your GP to discuss your health needs.
In the first year after treatment	3 – 6 monthly (example)		
Years 2			
Year 3			
Year 4			
Year 5			

MAKING A PLAN TO LIVE WELL

After treatment is a great time to make some changes and commit to stayi living recommendations are for all people who have had a diagnosis of canc many of the physical and emotional effects of cancer treatment. Speak to yo about making healthy living changes.

Weight…… **Height**…… **Blood pressure**……	
Making regular appointments with your GP www.betterhealth.vic.gov.au/health/servicesprofiles/General-practitioner-services	
Healthy diet A healthy diet is recommended to reduce the risk of certain cancers, include plenty of vegetables and fruits; a high fibre and low fat and salt diet. www.cancervic.org.au/preventing-cancer/healthy-diet	
Maintaining healthy weight Research shows that a waistline over 100cm for men and 85cm for women significantly increases the risk of some cancers. www.cancervic.org.au/preventing-cancer/weight	
Limit alcohol Drinking alcohol increases the risk of certain cancers. It is recommended people limit or avoid drinking alcohol. For people who do drink alcohol, no more than two standard drinks a day, avoid binge drinking and have at least 1 or 2 alcohol-free days each week. www.cancervic.org.au/preventing-cancer/avoid-alcohol	
Be physically active Exercise is important to reduce the risk of many cancers. Up to 1 hour of moderate activity daily or 30 minutes of vigorous activity is recommended. www.cancervic.org.au/preventing-cancer/be-physically-active	
Be sun smart The sun's ultraviolet (UV) radiation is a major cause of skin cancer. In Victoria UV levels generally reach 3 and above from September to April. At UV levels of 3 and above can cause damage and increase your risk of skin cancer so a combination sun protection steps are needed. www.cancervic.org.au/preventing-cancer/be-sunsmart	
Quit / avoid smoke Smoking causes cancer. Smoke contains over 60 chemicals known to cause cancer. www.cancervic.org.au/preventing-cancer/quit-smoking	
Finding cancer early Fin4ding cancer early offers one of the best chances to cure the disease. The following link provides information. www.cancervic.org.au/preventing-cancer/attend-screening	
Health maintenance It is recommended that you receive an annual influenza vaccination. www.healthinsite.gov.au/topics/Influenza_Vaccine	☐
Emotional impact of cancer Fear of cancer coming back is common after finishing treatment. The following links provide information on ways to look after your mental health and useful strategies to implement. www.cancervic.org.au/about-cancer/types-treatments-trials/learning_to_relax	☐
Menopause One change that you may experience is the development of the symptoms of menopause. www.jeanhailes.org.au/health-a-z/menopause	☐
Bone health Bone health From 40s onwards, our bones gradually lose their density as a natural part of ageing. Ask your GP about having a bone scan and having your Vit D levels tested. www.healthdirect.gov.au/healthy-bones	☐

Cancer Wellness and Exercise Programs

Free health and wellness programs are held by cancer councils in all states. Joining these types of programs can help you make healthy lifestyle changes. They can also help you become active and eat better. Visit the cancer council website to a find a program to suit your needs
www.cancer.org.au

Goals to discuss with your GP or GP Practice Nurse

Reliable sources of information

The Australian Cancer Survivorship Centre aims to improve health outcomes for cancer survivors, and provides timely and relevant information on important issues related to cancer survivorship. The time after completing cancer treatment can bring questions or anxiety. Many cancer survivors find it helpful to access information and support services in the time after treatment:
www.petermac.org/cancersurvivorship

Common survivorship issues directory
This directory is for cancer survivors, their carers, friends, families and health professionals.
It provides information and tools to support survivors to access evidence-based and quality survivorship care.
www.petermac.org/survdirect

Cancer Council 13 11 20 is a free service that provides information and support for cancer survivors. They have a variety of programs and run a telephone based support service called Cancer Connect, where you can speak with another cancer survivor. Call 13 11 20 for more details.
www.cancer.org.au

WeCan is an Australian supportive care website to help people affected by cancer find the information, resources and support services they may need following a diagnosis of cancer. The site provides easy access to the many excellent resources, services and information developed by other organisations who specialise in cancer and community support.
www.wecan.org.au

Communication

Discussed with: *(specify)*	
Liaised with: *(specify GP, etc)*	
Faxed information to: *(specify)*	
Completed by *(specify)*	

Models of Care for Cancer Survivors

- Traditional cancer specialist led
- Follow up by general practitioners
- **Shared care between oncology providers and primary-care physicians**
- **Supported self-management**
- Long-term follow up clinics
- Oncology nurse-led survivorship care

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Cancer Survivorship Series April 2022
Jon Emery, Michael Jefford

Series

Cancer Survivorship 1

Management of common clinical problems experienced by survivors of cancer

Jon Emery, Phyllis Butow, Julia Lai-Kwon, Larissa Nekhlyudov, Meg Rynderman, Michael Jefford

Improvements in early detection and treatment have led to a growing prevalence of survivors of cancer worldwide. Models of care fail to address adequately the breadth of physical, psychosocial, and supportive care needs of those who survive cancer. In this Series paper, we summarise the evidence around the management of common clinical problems experienced by survivors of adult cancers and how to cover these issues in a consultation. Reviewing the patient's history of cancer and treatments highlights potential long-term or late effects to consider, and recommended surveillance for recurrence. Physical consequences of specific treatments to identify include cardiac dysfunction, metabolic syndrome, lymphoedema, peripheral neuropathy, and osteoporosis. Immunotherapies can cause specific immune-related effects most commonly in the gastrointestinal tract, endocrine system, skin, and liver. Pain should be screened for and requires assessment of potential causes and non-pharmacological and pharmacological approaches to management. Common psychosocial issues, for which there are effective psychological therapies, include fear of recurrence, fatigue, altered sleep and cognition, and effects on sex and intimacy, finances, and employment. Review of lifestyle factors including smoking, obesity, and alcohol is necessary to reduce the risk of recurrence and second cancers. Exercise can improve quality of life and might improve cancer survival; it can also contribute to the management of fatigue, pain, metabolic syndrome, osteoporosis, and cognitive impairment. Using a supportive care screening tool, such as the Distress Thermometer, can identify specific areas of concern and help prioritise areas to cover in a consultation.

Lancet 2022; 399: 1537–50
This is the first in a Series of three papers about cancer survivorship

Centre for Cancer Research and Department of General Practice, Faculty of Medicine, Dentistry and Health Sciences (Prof J Emery DPhil) and Sir Peter MacCallum Department of Oncology (Prof M Jefford PhD), University of Melbourne, Melbourne, VIC, Australia; PoCoG and CoMPED, School of Psychology SoHRC, Institute of Surgery, University of Sydney, Sydney, NSW, Australia (Prof P Butow PhD); Melanoma Institute Australia, Sydney, NSW, Australia (J Lai-Kwon MBBS); Department of Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, MA, USA (Prof L Nekhlyudov MD); Australian Cancer Survivorship Centre (M Rynderman OAM) and Department of Health Services Research, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia (Prof M Jefford)
Correspondence to: Prof Jon Emery, Centre for Cancer Research, Victorian Comprehensive Cancer Centre, University of Melbourne, Melbourne VIC 3010, Australia
jon.emery@unimelb.edu.au

Introduction

The number of survivors of cancer is growing worldwide due to ageing populations and improvements in early detection and treatment. In the USA alone, by 2040, there will be an estimated 26 million people living with and beyond cancer.[1,2] Worldwide, the estimated 5-year prevalence of all cancers is 50·5 million, 20·6 million of whom have breast, prostate, colorectal, or lung cancer.[3] The landmark Institute of Medicine report[4] identified four essential components of survivorship care: (1) prevention of recurrent and new cancers, and of other late effects; (2) surveillance for cancer spread, recurrence, or second cancers and assessment of medical and psychosocial late effects; (3) intervention for the consequences of cancer and its treatment; and (4) coordination between specialists and primary-care providers to ensure that all of the survivor's health needs are met. Models of care experienced by many survivors do not deliver all these components adequately. At least two-thirds of survivors of cancer have physical, psychological, health information, and supportive care needs, which might not be recognised or well managed within current models of care.[5] Common issues for survivors of cancer, identified in systematic reviews, include pain, fatigue, fear of cancer recurrence, and uncertainty about their future and how to improve their wellbeing.[6–8] Health systems need to adapt to support and coordinate more involvement of non-oncologists in the care of survivors of cancer, and clinicians need to prepare for the increasing number of their patients living with cancer and its consequences.

This Series is a response to the projected increase in survivors of cancer and the failure of our existing models of care to meet the needs of these patients. The Series aims to prepare clinicians to deliver high-quality, holistic care to survivors of cancer, and highlight to health service managers and policy makers how health-care systems should adapt to create integrated models of survivorship care. In this first paper, we describe the common issues faced by survivors of cancer and provide guidance to non-oncologists and oncologists on what to consider

Search strategy and selection criteria

From Jan 1 to July 31, 2021, we searched databases on MEDLINE, Embase, and Google using key words tailored for individual sections including "unmet needs", "cancer survivor*", "pain", "fatigue", "psychosocial", "distress", "fear of recurrence", "sexual dysfunction", "insomnia", "return to work", "peripheral neuropathy", "lymphoedema", "cardiac dysfunction", "osteoporosis", and "immunotherapy adverse effects", and cross-referenced these terms with "systematic reviews", "meta-analysis", "RCT", and "clinical guideline" for the period 2001–21, only considering papers in English. We prioritised the most recent evidence from meta-analyses of randomised control trials and recommendations from international guidelines based on systematic reviews of the evidence (eg, from the National Comprehensive Cancer Network, the National Institute for Health and Care Excellence, the American Society of Clinical Oncology, and the European Society for Medical Oncology).

Series

Cancer Survivorship 2

Improved models of care for cancer survivors

Michael Jefford, Doris Howell, Qiuping Li, Karolina Lisy, Jane Maher, Catherine M Alfano, Meg Rynderman, Jon Emery

The number of survivors of cancer is increasing substantially. Current models of care are unsustainable and fail to address the many unmet needs of survivors of cancer. Numerous trials have investigated alternate models of care, including models led by primary-care providers, care shared between oncology specialists and primary-care providers, and care led by oncology nurses. These alternate models appear to be at least as effective as specialist-led care and are applicable to many survivors of cancer. Choosing the most appropriate care model for each patient depends on patient-level factors (such as risk of longer-term effects, late effects, individual desire, and capacity to self-manage), local services, and health-care policy. Wider implementation of alternative models requires appropriate support for non-oncologist care providers and endorsement of these models by cancer teams with their patients. The COVID-19 pandemic has driven some changes in practice that are more patient-centred and should continue. Improved models should shift from a predominant focus on detection of cancer recurrence and seek to improve the quality of life, functional outcomes, experience, and survival of survivors of cancer, reduce the risk of recurrence and new cancers, improve the management of comorbidities, and reduce costs to patients and payers. This Series paper focuses primarily on high-income countries, where most data have been derived. However, future research should consider the applicability of these models in a wider range of health-care settings and for a wider range of cancers.

Lancet 2022; 399: 1551–60
This is the second in a Series of three papers about cancer survivorship

Department of Health Services Research (Prof M Jefford PhD, K Lisy PhD) and Australian Cancer Survivorship Centre (Prof M Jefford, K Lisy, M Rynderman), Peter MacCallum Cancer Centre, Melbourne, VIC, Australia; Sir Peter MacCallum Department of Oncology (Prof M Jefford, K Lisy) and Centre for Cancer Research, Faculty of Medicine, Dentistry and Health Sciences (Prof J Emery DPhil), University of Melbourne, Melbourne, VIC, Australia; Princess Margaret Cancer Research Institute, Toronto, ON, Canada (Prof D Howell PhD); Wuxi School of Medicine, Jiangnan University, Wuxi, China (Prof Q Li PhD); Macmillan Cancer Support, London, UK (J Maher FRCR); Northwell Health Cancer Institute, Lake Success, NY, USA (Prof C M Alfano PhD); Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, Hempstead, NY, USA (Prof C M Alfano); Feinstein Institutes for Medical Research, Northwell Health, Manhasset, NY, USA (Prof C M Alfano)
Correspondence to: Prof Michael Jefford, Peter MacCallum Cancer Centre, Melbourne, VIC 8006, Australia
michael.jefford@petermac.org

Introduction

The number of survivors of cancer is growing substantially.[1] Survivors of cancer commonly experience a range of issues, many of which are poorly identified and addressed within dominant specialist-led models of care.[2] Furthermore, current models of specialist-led care are unsustainable, with large numbers of survivors of cancer in follow-up, and an inadequate health workforce,[3] leading to calls for new approaches to address the needs of patients living after a cancer diagnosis.[4–6]

Policy makers and health-care managers need to determine how to implement more sustainable and effective models of care to support and coordinate greater involvement of non-oncologists in the care of survivors of cancer. Active involvement of a range of end users and stakeholders, such as public health agencies; community groups and agencies; patients and caregivers with lived experience of survivorship care; and multidisciplinary providers from differing care sectors, will be crucial to the design of relevant survivorship services based on the evidence, that address the needs of local constituents, perhaps using best practices in codesign.[7]

The first paper in this Series describes common issues faced by survivors of cancer and practical guidance for clinicians. This paper considers how care could be better planned and delivered for survivors of cancer. The focus of this paper is on high-income countries, as most published data is derived from these settings, but we provide brief consideration of survivorship care in low-income and middle-income countries.

The seminal US Institute of Medicine (IOM) report identified essential components of survivorship care: (1) prevention of recurrent and new cancers, and late effects from treatments; (2) surveillance for recurrence and new cancers, and for medical and psychosocial effects; (3) management of consequences of treatments, including symptom management and assistance with practical aspects; and (4) coordination between cancer and primary-care providers, to ensure that all needs of the survivor of cancer are met.[2]

This Series paper considers the randomised controlled trial (RCT) evidence for non-specialist-led models of survivorship care, and implementation evidence, specifically focusing on how all the IOM goals might be achieved. This paper considers appropriate models of care for different patient groups, and different settings, and includes considerations for implementation and future research.

Search strategy and selection criteria

Between Jan 4 and July 2, 2021, we searched MEDLINE, Embase, and Google databases using terms relevant to particular sections of the paper. We focused on reports published in English since 2005, when the pivotal Institute of Medicine report was released. We combined search terms relevant to cancer (eg, "cancer", "neoplasm", "malignancy") with search terms relevant to the post-treatment phase (eg, "follow up", "after care", "post-treatment", "surveillance", "survivorship"). We also used general search terms (eg, "models of care") and specific search terms relevant to specific models of care (eg, "shared care"). We combined these search terms with terms relevant to clinical trials, systematic reviews, and meta-analyses, and we prioritised evidence from systematic reviews and meta-analyses.

Series

Cancer Survivorship 3

Long-term care for people treated for cancer during childhood and adolescence

Emily S Tonorezos, Richard J Cohn, Adam W Glaser, Jeremy Lewin, Eileen Poon, Claire E Wakefield, Kevin C Oeffinger

Worldwide advances in treatment and supportive care for children and adolescents with cancer have resulted in a increasing population of survivors growing into adulthood. Yet, this population is at very high risk of late occurring health problems, including significant morbidity and early mortality. Unique barriers to high-quality care for this group include knowledge gaps among both providers and survivors as well as fragmented health-care delivery during the transition from paediatric to adult care settings. Survivors of childhood and adolescent cancer are at risk for a range of late-occurring side-effects from treatment, including cardiac, endocrine, pulmonary, fertility, renal, psychological, cognitive, and socio-developmental impairments. Care coordination and transition to adult care are substantial challenges, but can be empowering for survivors and improve outcomes, and could be facilitated by clear, effective communication and support for self-management. Resources for adult clinical care teams and primary care providers include late-effects surveillance guidelines and web-based support services.

Lancet 2022; 399: 1561–72
This is the third in a Series of three papers about cancer survivorship

Office of Cancer Survivorship, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD, USA (E S Tonorezos MD); Kids Cancer Centre, Sydney Children's Hospital, Randwick, NSW, Australia (Prof R J Cohn MBBCh, Prof C E Wakefield PhD); School of Women's and Children's Health, UNSW Medicine, UNSW Sydney, Kensington, NSW, Australia (Prof R J Cohn, Prof C E Wakefield); Leeds Institute of Medical Research, University of Leeds, Leeds, UK (Prof A W Glaser DM FRCPCH); ONTrac at Peter MacCallum Adolescent and Young Adult Cancer Service, Sir Peter MacCallum Department of Oncology, University of Melbourne, Melbourne, VIC, Australia (J Lewin MBBS); Division of Medical Oncology, National Cancer Centre, Singapore (E Poon MD); Department of Medicine, Duke University, Durham, NC, USA (Prof K C Oeffinger MD)
Correspondence to: Dr Emily S Tonorezos, Office of Cancer Survivorship, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD 20854, USA
emily.tonorezos@nih.gov

Introduction

Over the past five decades, cancer during childhood and adolescence has slowly risen in incidence. In 2020, approximately 300 000 cancers were diagnosed among those aged 19 years and younger, worldwide.[1] At the same time, treatment and supportive care for children and adolescents with cancer has improved substantially. In many settings, cancers that were once uniformly fatal are now treatable. For those diagnosed during childhood in the USA, the overall proportion surviving 5 years from diagnosis has increased from 77·8% for those diagnosed in the 1990s, to 82·7% for those diagnosed in the 2000s, and to 85·4% for those diagnosed between 2010–16.[2] Similar successes have been described in Australia, Canada, the UK, and Europe. Notably, for children in low-middle income countries, survival gains have been more modest.[3,4]

Following cancer diagnosis at a young age, survivors confront a long survivorship phase, often spanning six decades. Over this follow-up phase, the risk of cancer recurrence decreases whereas the risk of treatment-related health problems increases. Organ systems that are developing during childhood and adolescence can be irreversibly affected by cancer treatment. Thus, although cure rates among this population are high, many survivors of childhood and adolescent cancer face a long follow-up period with numerous long-term health risks. In 2005, the seminal Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,[5] was published, highlighting this population. Since then, an increasing body of evidence has documented significantly higher levels of morbidity and early mortality in survivors diagnosed during childhood and adolescence, compared with survivors diagnosed during adulthood (figure).[2,6] Among 5522 survivors of childhood cancer who underwent comprehensive follow-up exams, the cumulative incidence of a severe, disabling, life-threatening, or fatal chronic condition was 96%. By age 50 years, survivors have, on average, 17·1 chronic health conditions, including 4·7 graded as severe, disabling, life-threatening, or fatal. Additionally, the cumulative burden among survivors was nearly two-fold than matched community-controls (p<0·001).[7] Common late effects include cardiovascular disease, respiratory dysfunction, endocrine abnormalities, and subsequent malignant neoplasm (panel, late effects). Many survivors experience multiple late effects, which act synergistically such that the burden of morbidity is compounded.[8]

Search strategy and selection criteria

We searched PubMed, Scopus, and Google Scholar for human studies published in English between Jan 1, 2000 and Dec 31, 2021 with the search terms "child", "adolescent", "neoplasm", "survivor*", "cancer", "onco*", "tumour", "long-term care", "late effects", and "paediatric". A search for ("child" OR "adolescent") AND "neoplasms" AND "survivor*" identified 9917 manuscripts; addition of the term "late effects" restricted the search to 1701 manuscripts. Of these studies, 609 were published in the years 2016–22. Studies were selected for relevance to long-term follow-up of survivors of childhood cancer; the most recent evidence from randomised controlled trials and meta-analyses, and recommendations from international guideline committees, were prioritised. We excluded studies that did not focus on childhood cancer, addressed issues for children on treatment, or were case reports. During the revision process, we further excluded old studies in favor of updated analyses, where relevant. On the basis of these results, and input from the authors and expert advisers, we included 68 references on childhood cancer survivorship in this Series paper.

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What to consider in a consultation with a cancer survivor

- Review the patients cancer history and past treatment to
  - Highlight potential long-term or late effects
  - Determine the risk of recurrence
  - Recommended surveillance
  - Review the family history

- Reducing the risk of recurrence and second cancers through behavioural change
  - Smoking, obesity, alcohol
  - Physical activity

What to consider in a consultation with a cancer survivor

- Assess for physical long-term and late effects, eg
  - Lymphoedema
  - Pain
  - Peripheral Neuropathy
  - Bone Health
  - Immunotherapy and immune-related adverse effects
  - Cardiac dysfunction
  - Cancer treatment related metabolic syndrome

What to consider in a consultation with a cancer survivor

- Review psychological issues
  - Anxiety and depression
  - Fear of cancer recurrence
  - Chemotherapy-associated cognitive impairment
  - Fatigue
  - Sleep problems
  - Sex and intimacy
  - Return to work
  - Financial toxicity

What to consider in a consultation with a cancer survivor

Managing comorbidities

- Majority of survivors over 65 years old, and as such are more likely to have additional long term conditions and attend general more frequently for management of these, as well as their cancer
- Some will be due to common risk factors
- Some will be cancer treatment related – eg cardiovascular, osteoporosis
- Potential for existing conditions to deteriorate due to cancer treatment, potential for drug interactions

Quality cancer survivorship care should involve

- **Monitoring to detect cancer coming back and new cancers**
- Support and monitoring for physical, emotional, social and practical effects of cancer and cancer treatment
- Management of any other health conditions
- Supporting and promoting wellness and healthy lifestyle
- Coordinated care between all health professionals involved

Monitoring for recurrence and subsequent cancers

- Most Australian and International *disease-specific guidelines* make recommendations about surveillance for recurrence
- However, the evidence to support many recommendations, including the frequency of follow-up appointments, or use of specific tests, is often poor and often based on expert opinion
- As such there can be variation between guidelines on recommended practice.
  - Targeted clinical examination
  - Guideline recommended surveillance tests
  - Encourage participation in nationally recommended screening

Guidelines for detection of recurrence

	Types of recommended surveillance tests*	Examples of international guidelines
Breast cancer	History and clinical examination, mammogram	National Comprehensive Cancer Network,[77] American Society of Clinical Oncology,[78] National Institute for Health and Care Excellence,[79] and European Society for Medical Oncology[80]
Bowel cancer	History and clinical examination, carcinoembryonic antigen colonoscopy, CT chest, abdomen, and pelvis	National Comprehensive Cancer Network,[77] American Society of Clinical Oncology,[81] National Institute for Health and Care Excellence,[82] and European Society for Medical Oncology[83]
Prostate cancer	History and clinical examination, prostate-specific antigen	National Comprehensive Cancer Network,[77] American Society of Clinical Oncology,[84] National Institute for Health and Care Excellence,[85] and European Association of Urology[86]
Melanoma	Self-examination, history, and clinical examination, CT, MRI, and PET ultrasound	National Institute for Health and Care Excellence[87] and Cancer Council Australia[88]

Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for NCCN Clinical Practice Guidelines in Oncology. National Comprehensive Cancer Network, 2022. Accessed Jan 10, 2022. To view the most recent and complete version of the guideline, go online to NCCN.org. NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way. *Frequency of tests varies according to different guidelines.

Table 2: **International guidelines for detection of recurrence for common cancers**

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Surveillance for cancer spread, recurrence

Table 1. Suggested Site-Specific Surveillance Recommendations for Cancer Survivors.*

Disease Site	Recommendations	Comments
Head and neck cancer[5]†	Physical examination every 1–3 mo for 1 yr, then every 2–6 mo for 2–5 yr and annually after 5 yr Baseline imaging 6 mo after completion of treatment Indirect laryngoscopy performed by an ENT physician periodically Low-dose CT scans for lung-cancer screening, indicated for persons at high risk because of a history of smoking	If new or persistent symptoms develop, imaging is performed as appropriate to the clinical situation
Breast cancer[6]†	Physical examination every 3–4 mo for 3 yr, then every 6 mo for 2 yr, and annually after 5 yr‡ Breast imaging annually	Imaging or measurement of tumor markers is not indicated in women without symptoms; if new or persistent symptoms develop, imaging is indicated as appropriate to the clinical situation
Prostate cancer[7]§	Digital rectal examination annually for 5 yr PSA test every 6–12 mo for 5 yr	Imaging in men without symptoms is not indicated; if new or persistent symptoms develop, imaging is indicated as appropriate to the clinical situation
Colorectal cancer[10]§	Physical examination and CEA test every 3–6 mo for 5 yr CT imaging of chest, abdomen, and pelvis annually for 3 yr Colonoscopy annually for 6 yr after surgery	If new or persistent symptoms develop, imaging is indicated as appropriate to the clinical situation
Non–small-cell lung cancer[12]	History taking and physical examination every 3–6 mo for 1–2 yr, then annually for 3–5+ yr Low-dose axial CT scanning every 6 mo for 1–2 yr, then annually for 3–5+ yr¶	If new or persistent symptoms develop, imaging is indicated as appropriate to the clinical situation
Testicular cancer[13]	Follow-up guidelines, which depend on histologic features (e.g., seminoma or nonseminoma) and stage	If new or persistent symptoms develop, imaging is indicated as appropriate to the clinical situation
Gynecologic cancer[14]	Follow-up guidelines, which depend on histologic features (e.g., endometrial, cervical, or ovarian cancer) and stage	If new or persistent symptoms develop, imaging is indicated as appropriate to the clinical situation
Lymphoma[15]	Follow-up guidelines, which depend on histologic features (diffuse large lymphoma, follicular lymphoma, or Hodgkin's disease) and stage	If new or persistent symptoms develop, imaging is indicated as appropriate to the clinical situation

C Shapiro
NEJM Dec 20, 2018

ANZUP Cancer Trials Group Limited

ANZUP Stage 1 Testicular Cancer Surveillance recommendations

Developed by a working group
Consensus Guidelines
Well accepted and widely followed

ANZUP STAGE I TESTICULAR CANCER SURVEILLANCE RECOMMENDATIONS					
Seminoma, No adjuvant therapy					
Year	Physical Examination (month)	Tumour Marker (month)	CT Abdo/Pelvis (month)	CXR (month)	Testosterone Assessment (month)
1	6, 12	6, 12	6, 12	-	6
2	18, 24	18, 24	18, 24	-	24
3	36	36	36	-	
4	48	48	-	-	
5	60	60	60	-	60
5-10	Some clinicians recommend follow up beyond 5 years. See below for discussion				
Seminoma, Post adjuvant carboplatin					
Year	Physical Examination (month)	Tumour Marker (month)	CT Abdo/Pelvis (month)	CXR (month)	Testosterone Assessment (month)
1	6, 12	6, 12	12	-	6
2	18, 24	18, 24	24	-	24
3	36	36	36	-	
4	48	48			
5	60	60	60	-	60
5-10	Some clinicians recommend follow up beyond 5 years. See below for discussion				
Non Seminoma, No adjuvant therapy					
Year	Physical Examination (month)	Tumour Marker (month)	CT Abdo/Pelvis (month)	CXR (month)	Testosterone Assessment (month)
1	1, 2, 3*, 4, 5*, 6, 8, 10, 12	1, 2, 3*, 4, 5*, 6, 8, 10, 12	4, 8, 12	4, 8, 12	6
2	15, 18, 21, 24	15, 18, 21, 24	18, 24	18, 24	24
3	30, 36	30, 36	36	36	
4	42, 48	42, 48			
5	60	60	60	60	60
Non Seminoma, Post adjuvant BEP chemotherapy					
Year	Physical Examination (month)	Tumour Marker (month)	CT Abdo/Pelvis (month)	CXR (month)	Testosterone Assessment (month)
1	6, 12	6, 12	6, 12	6, 12	6
2	18, 24	18, 24	18, 24	18, 24	24
3	36	36	36	36	
4	48	48			
5	60	60	60	60	60

Cancer Screening

- In individuals with potentially curable cancers, the recommended sex- and age-specific routine screenings, tests and care that are recommended for the general population should be considered

	In which cancers is this most commonly an issue?	Estimated prevalence in survivors	Recommended management	Level of evidence for recommendations
Cardiac dysfunction	Breast, sarcoma, and haematological	0·14–48% in those treated with anthracyclines;[39] 7–28% in those treated with high-dose cyclophosphamide;[40] and a 2·8–4·7 fold increased risk for those treated with ≥30 Gy radiotherapy to the cardiac region[41]	Monitoring by regular review of cardiovascular risk factors; European Society for Medical Oncology guidelines[42] recommend an echocardiogram at 6 and 12 months and possibly 2 years post treatment; and American Society of Clinical Oncology guidelines[43] recommend an echocardiogram if signs or symptoms of cardiac dysfunction are present.	European Society for Medical Oncology guideline for surveillance (from prospective cohort studies)[42] and American Society of Clinical Oncology guideline for surveillance[43] (also from prospective cohort studies)
..	..	..	Management by cardiology referral; optimisation of cardiovascular risk factors; and heart failure therapy (eg, angiotensin-converting enzyme inhibitor, angiotensin receptor blocker, and β blocker)[43,44]	..
Cancer treatment-induced metabolic syndrome	Multiple—childhood malignancies, breast, colorectal, testicular, haematological, neurological, prostate, gynaecological, and thyroid	Variable between 8 and 39%[44]	Lifestyle interventions including physical exercise, healthy diet, and smoking cessation; standard interventions for hypertension, hyperlipidaemia, and diabetes	Meta-analyses of RCTs in populations without cancer[45]
Lymphoedema	Breast, head and neck, prostate, bladder, gynaecological, and melanoma	Variable between 5 and 75%, depending on the patient populations studied[46]	Manual lymphatic drainage, compression, and exercises[47]	Systematic review of RCTs and observational studies[46]
Pain	All cancers	Meta-analysis of 122 studies showed moderate to severe pain in 38% of patients with cancer; pain was most common during treatment (55%) and in those with advanced disease (66·4%)[48]	Non-pharmacological including exercise;[49] acupuncture,[50] and psychological approaches (eg, acceptance-based interventions, meditation, and supportive group therapy);[51] pharmacological including non-steroidal anti-inflammatory drugs and paracetamol,[52,53] adjuvant analgesics, antidepressants and anticonvulsants,[54] opioids,[55] and cannabinoids[56]	American Society of Clinical Oncology guidelines for non-pharmacological and pharmacological recommendations:[54] exercise (meta-analysis of RCTs);[49] acupuncture (systematic review of RCTs);[50] psychological interventions (meta-analysis of RCTs);[51] paracetamol and non-steroidal anti-inflammatory drugs (meta-analysis of RCTs);[52,53] antidepressants and anticonvulsants (systematic review and meta-analysis of RCTs);[54] opioids (meta-analyses of RCTs of patients with advanced cancer; efficacy in long-term survivors is not well established);[54,55] and cannabinoids (meta-analysis of RCTs)[56]

Chemotherapy-induced peripheral neuropathy	Breast, prostate, colorectal, gynaecological, and head and neck	Varies between 30 and 68·1%[24] depending on time after chemotherapy	Duloxetine if chronic and painful[25] and potential benefit from exercise and acupuncture[26]	Duloxetine (RCT[25] and American Society of Clinical Oncology guideline); exercise and acupuncture (RCTs and American Society of Clinical Oncology guideline evidence quality is low; not recommended outside clinical trial[26])
Bone health	Breast, prostate, and haematological	Variable based on patient and treatment factors[27]	Diet with adequate calcium and vitamin D, exercise, and smoking cessation; bone mineral density testing and bisphosphonates[27]	American Society of Clinical Oncology guidelines[27]
Immune-related adverse effects from immune checkpoint inhibitors (eg, colitis, hypophysitis, thyroid dysfunction, and skin rashes)	Melanoma, lung, renal, and bladder	15–90% with wide range between agents and trials; 13% of severe cases warranting discontinuation[28,29]	Prompt identification and grading for severity; immunosuppression and modified immunotherapy regime[28,30]	National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology[31]
Anxiety and depression	All cancers	All survivors: depression 13%; anxiety 17·9%[32,33] (highest during and immediately after treatment); and ≥5 years post-treatment pooled prevalence of 21% for both depression and anxiety (comparable with general population)[34]	Cognitive behavioural therapy, acceptance and commitment therapy, and mindfulness strategies;[35–37] antidepressants and anxiolytics[38,39]	Non-pharmacological interventions (meta-analyses of RCTs);[35,37] pharmacological interventions (meta-analyses of RCTs of which, trials of antidepressants in patients with cancer are few and low in quality); selection of drug should be on the basis of antidepressant efficacy in the general population[40]

(Table 1 continues on next page)

	In which cancers is this most commonly an issue?	Estimated prevalence in survivors	Recommended management	Level of evidence for recommendations
(Continued from previous page)				
Fear of cancer recurrence	All cancers	Mild to moderate 49%;[8] severe 7%	Cognitive behavioural therapy and meta-cognitive therapy[9–12]	Meta-analysis of RCTs[9]
Cognitive impairment	All cancers, particularly after chemotherapy and radiotherapy	30–40% show some cognitive impairment before chemotherapy, 50–75% during chemotherapy, and approximately 35% continue to show impairment months to years after treatment completion[13]	Cognitive training and rehabilitation, exercise, and mind-body interventions[14]	Cognitive rehabilitation (systematic review of RCTs and observational studies);[15] exercise (systematic review of RCTs);[15] mind-body interventions (individual RCTs)[16]
Fatigue	All cancers, particularly during chemotherapy and radiotherapy, and advanced cancer	49% in all cancers; 60% in advanced cancers;[17] and 25–33% experience fatigue for up to 10 years after cancer diagnosis[18]	Exercise;[19] psychoeducation, mindfulness, and cognitive or behaviour therapy-oriented strategies might be helpful[20]	Exercise (meta-analysis of RCTs);[19] psychological interventions (systematic review of RCTs)[21]
Sleep problems	All cancers	25–60%, common up to 5 years after diagnosis[22–25]	Sleep hygiene[26] and cognitive behavioural therapy[27]	Cognitive behavioural therapy (meta-analysis of RCTs)[27]
Sex and intimacy	All cancers	Variable depending on population, treatment, aetiology, and manifestation; estimated 40–100%[28]	Dependent on underlying aetiology and manifestations: non-pharmacological including pelvic floor physical therapy, cognitive behavioural therapy, psychosocial counselling, and couples therapy;[29–31] and pharmacological and mechanical including phosphodiesterase-5 inhibitors, vacuum erection devices, penile prosthesis, and intracavernous injections for erectile dysfunction and vaginal dilators for stenosis, vaginal oestrogen for dryness, and dyspareunia[28]	Psychological interventions (systematic review of controlled trials);[32] pharmacological (systematic reviews of RCTs and individual RCTs for specific interventions)[28]
Returning to work	All cancers	37% relative risk of not returning to work compared with those without a cancer diagnosis[33]	Multidisciplinary intervention involving physical, psycho-educational, or vocational components tailored to patients' circumstances[34]	Meta-analysis of RCTs[34]
Financial toxicity	All cancers	28%[35]	Full early financial disclosure and screening and referral to support services[36–38]	Consensus opinion[36]

RCT=randomised control trial.

Table 1: Summary of common clinical problems and unmet needs experienced by survivors, their frequency, and recommended management

Cancer Survivorship Series April 2022
Jon Emery, Michael Jefford

Series

Cancer Survivorship 1

Management of common clinical problems experienced by survivors of cancer

Jon Emery, Phyllis Butow, Julia Lai-Kwon, Larissa Nekhlyudov, Meg Rynderman, Michael Jefford

Improvements in early detection and treatment have led to a growing prevalence of survivors of cancer worldwide. Models of care fail to address adequately the breadth of physical, psychosocial, and supportive care needs of those who survive cancer. In this Series paper, we summarise the evidence around the management of common clinical problems experienced by survivors of adult cancers and how to cover these issues in a consultation. Reviewing the patient's history of cancer and treatments highlights potential long-term or late effects to consider, and recommended surveillance for recurrence. Physical consequences of specific treatments to identify include cardiac dysfunction, metabolic syndrome, lymphoedema, peripheral neuropathy, and osteoporosis. Immunotherapies can cause specific immune-related effects most commonly in the gastrointestinal tract, endocrine system, skin, and liver. Pain should be screened for and requires assessment of potential causes and non-pharmacological and pharmacological approaches to management. Common psychosocial issues, for which there are effective psychological therapies, include fear of recurrence, fatigue, altered sleep and cognition, and effects on sex and intimacy, finances, and employment. Review of lifestyle factors including smoking, obesity, and alcohol is necessary to reduce the risk of recurrence and second cancers. Exercise can improve quality of life and might improve cancer survival; it can also contribute to the management of fatigue, pain, metabolic syndrome, osteoporosis, and cognitive impairment. Using a supportive care screening tool, such as the Distress Thermometer, can identify specific areas of concern and help prioritise areas to cover in a consultation.

Lancet 2022; 399: 1537–50
This is the first in a Series of three papers about cancer survivorship

Centre for Cancer Research and Department of General Practice, Faculty of Medicine, Dentistry and Health Sciences (Prof J Emery DPhil) and Sir Peter MacCallum Department of Oncology (Prof M Jefford PhD), University of Melbourne, Melbourne, VIC, Australia; PoCoG and CoMPED, School of Psychology SoHRC, Institute of Surgery, University of Sydney, Sydney, NSW, Australia (Prof P Butow PhD); Melanoma Institute Australia, Sydney, NSW, Australia (J Lai-Kwon MBBS); Department of Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, MA, USA (Prof L Nekhlyudov MD); Australian Cancer Survivorship Centre (M Rynderman OAM) and Department of Health Services Research, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia (Prof M Jefford)
Correspondence to: Prof Jon Emery, Centre for Cancer Research, Victorian Comprehensive Cancer Centre, University of Melbourne, Melbourne VIC 3010, Australia
jon.emery@unimelb.edu.au

Introduction

The number of survivors of cancer is growing worldwide due to ageing populations and improvements in early detection and treatment. In the USA alone, by 2040, there will be an estimated 26 million people living with and beyond cancer.[1,2] Worldwide, the estimated 5-year prevalence of all cancers is 50·5 million, 20·6 million of whom have breast, prostate, colorectal, or lung cancer.[3] The landmark Institute of Medicine report[4] identified four essential components of survivorship care: (1) prevention of recurrent and new cancers, and of other late effects; (2) surveillance for cancer spread, recurrence, or second cancers and assessment of medical and psychosocial late effects; (3) intervention for the consequences of cancer and its treatment; and (4) coordination between specialists and primary-care providers to ensure that all of the survivor's health needs are met. Models of care experienced by many survivors do not deliver all these components adequately. At least two-thirds of survivors of cancer have physical, psychological, health information, and supportive care needs, which might not be recognised or well managed within current models of care.[5] Common issues for survivors of cancer, identified in systematic reviews, include pain, fatigue, fear of cancer recurrence, and uncertainty about their future and how to improve their wellbeing.[6–8] Health systems need to adapt to support and coordinate more involvement of non-oncologists in the care of survivors of cancer, and clinicians need to prepare for the increasing number of their patients living with cancer and its consequences.

This Series is a response to the projected increase in survivors of cancer and the failure of our existing models of care to meet the needs of these patients. The Series aims to prepare clinicians to deliver high-quality, holistic care to survivors of cancer, and highlight to health service managers and policy makers how health-care systems should adapt to create integrated models of survivorship care. In this first paper, we describe the common issues faced by survivors of cancer and provide guidance to non-oncologists and oncologists on what to consider

Search strategy and selection criteria

From Jan 1 to July 31, 2021, we searched databases on MEDLINE, Embase, and Google using key words tailored for individual sections including "unmet needs", "cancer survivor*", "pain", "fatigue", "psychosocial", "distress", "fear of recurrence", "sexual dysfunction", "insomnia", "return to work", "peripheral neuropathy", "lymphoedema", "cardiac dysfunction", "osteoporosis", and "immunotherapy adverse effects", and cross-referenced these terms with "systematic reviews", "meta-analysis", "RCT", and "clinical guideline" for the period 2001–21, only considering papers in English. We prioritised the most recent evidence from meta-analyses of randomised control trials and recommendations from international guidelines based on systematic reviews of the evidence (eg, from the National Comprehensive Cancer Network, the National Institute for Health and Care Excellence, the American Society of Clinical Oncology, and the European Society for Medical Oncology).

Series

Cancer Survivorship 2

Improved models of care for cancer survivors

Michael Jefford, Doris Howell, Qiuping Li, Karolina Lisy, Jane Maher, Catherine M Alfano, Meg Rynderman, Jon Emery

The number of survivors of cancer is increasing substantially. Current models of care are unsustainable and fail to address the many unmet needs of survivors of cancer. Numerous trials have investigated alternate models of care, including models led by primary-care providers, care shared between oncology specialists and primary-care providers, and care led by oncology nurses. These alternate models appear to be at least as effective as specialist-led care and are applicable to many survivors of cancer. Choosing the most appropriate care model for each patient depends on patient-level factors (such as risk of longer-term effects, late effects, individual desire, and capacity to self-manage), local services, and health-care policy. Wider implementation of alternative models requires appropriate support for non-oncologist care providers and endorsement of these models by cancer teams with their patients. The COVID-19 pandemic has driven some changes in practice that are more patient-centred and should continue. Improved models should shift from a predominant focus on detection of cancer recurrence and seek to improve the quality of life, functional outcomes, experience, and survival of survivors of cancer, reduce the risk of recurrence and new cancers, improve the management of comorbidities, and reduce costs to patients and payers. This Series paper focuses primarily on high-income countries, where most data have been derived. However, future research should consider the applicability of these models in a wider range of health-care settings and for a wider range of cancers.

Lancet 2022; 399: 1551–60
This is the second in a Series of three papers about cancer survivorship

Department of Health Services Research (Prof M Jefford PhD, K Lisy PhD) and Australian Cancer Survivorship Centre (Prof M Jefford, K Lisy, M Rynderman), Peter MacCallum Cancer Centre, Melbourne, VIC, Australia; Sir Peter MacCallum Department of Oncology (Prof M Jefford, K Lisy) and Centre for Cancer Research, Faculty of Medicine, Dentistry and Health Sciences (Prof J Emery DPhil), University of Melbourne, Melbourne, VIC, Australia; Princess Margaret Cancer Research Institute, Toronto, ON, Canada (Prof D Howell PhD); Wuxi School of Medicine, Jiangnan University, Wuxi, China (Prof Q Li PhD); Macmillan Cancer Support, London, UK (J Maher FRCR); Northwell Health Cancer Institute, Lake Success, NY, USA (Prof C M Alfano PhD); Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, Hempstead, NY, USA (Prof C M Alfano); Feinstein Institutes for Medical Research, Northwell Health, Manhasset, NY, USA (Prof C M Alfano)
Correspondence to: Prof Michael Jefford, Peter MacCallum Cancer Centre, Melbourne, VIC 8006, Australia
michael.jefford@petermac.org

Introduction

The number of survivors of cancer is growing substantially.[1] Survivors of cancer commonly experience a range of issues, many of which are poorly identified and addressed within dominant specialist-led models of care.[2] Furthermore, current models of specialist-led care are unsustainable, with large numbers of survivors of cancer in follow-up, and an inadequate health workforce,[3] leading to calls for new approaches to address the needs of patients living after a cancer diagnosis.[4–6]

Policy makers and health-care managers need to determine how to implement more sustainable and effective models of care to support and coordinate greater involvement of non-oncologists in the care of survivors of cancer. Active involvement of a range of end users and stakeholders, such as public health agencies; community groups and agencies; patients and caregivers with lived experience of survivorship care; and multidisciplinary providers from differing care sectors, will be crucial to the design of relevant survivorship services based on the evidence, that address the needs of local constituents, perhaps using best practices in codesign.[7]

The first paper in this Series describes common issues faced by survivors of cancer and practical guidance for clinicians. This paper considers how care could be better planned and delivered for survivors of cancer. The focus of this paper is on high-income countries, as most published data is derived from these settings, but we provide brief consideration of survivorship care in low-income and middle-income countries.

The seminal US Institute of Medicine (IOM) report identified essential components of survivorship care: (1) prevention of recurrent and new cancers, and late effects from treatments; (2) surveillance for recurrence and new cancers, and for medical and psychosocial effects; (3) management of consequences of treatments, including symptom management and assistance with practical aspects; and (4) coordination between cancer and primary-care providers, to ensure that all needs of the survivor of cancer are met.[2]

This Series paper considers the randomised controlled trial (RCT) evidence for non-specialist-led models of survivorship care, and implementation evidence, specifically focusing on how all the IOM goals might be achieved. This paper considers appropriate models of care for different patient groups, and different settings, and includes considerations for implementation and future research.

Search strategy and selection criteria

Between Jan 4 and July 2, 2021, we searched MEDLINE, Embase, and Google databases using terms relevant to particular sections of the paper. We focused on reports published in English since 2005, when the pivotal Institute of Medicine report was released. We combined search terms relevant to cancer (eg, "cancer", "neoplasm", "malignancy") with search terms relevant to the post-treatment phase (eg, "follow up", "after care", "post-treatment", "surveillance", "survivorship"). We also used general search terms (eg, "models of care") and specific search terms relevant to specific models of care (eg, "shared care"). We combined these search terms with terms relevant to clinical trials, systematic reviews, and meta-analyses, and we prioritised evidence from systematic reviews and meta-analyses.

Series

Cancer Survivorship 3

Long-term care for people treated for cancer during childhood and adolescence

Emily S Tonorezos, Richard J Cohn, Adam W Glaser, Jeremy Lewin, Eileen Poon, Claire E Wakefield, Kevin C Oeffinger

Worldwide advances in treatment and supportive care for children and adolescents with cancer have resulted in a increasing population of survivors growing into adulthood. Yet, this population is at very high risk of late occurring health problems, including significant morbidity and early mortality. Unique barriers to high-quality care for this group include knowledge gaps among both providers and survivors as well as fragmented health-care delivery during the transition from paediatric to adult care settings. Survivors of childhood and adolescent cancer are at risk for a range of late-occurring side-effects from treatment, including cardiac, endocrine, pulmonary, fertility, renal, psychological, cognitive, and socio-developmental impairments. Care coordination and transition to adult care are substantial challenges, but can be empowering for survivors and improve outcomes, and could be facilitated by clear, effective communication and support for self-management. Resources for adult clinical care teams and primary care providers include late-effects surveillance guidelines and web-based support services.

Lancet 2022; 399: 1561–72
This is the third in a Series of three papers about cancer survivorship

Office of Cancer Survivorship, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD, USA (E S Tonorezos MD); Kids Cancer Centre, Sydney Children's Hospital, Randwick, NSW, Australia (Prof R J Cohn MBBCh, Prof C E Wakefield PhD); School of Women's and Children's Health, UNSW Medicine, UNSW Sydney, Kensington, NSW, Australia (Prof R J Cohn, Prof C E Wakefield); Leeds Institute of Medical Research, University of Leeds, Leeds, UK (Prof A W Glaser DM FRCPCH); ONTrac at Peter MacCallum Adolescent and Young Adult Cancer Service, Sir Peter MacCallum Department of Oncology, University of Melbourne, Melbourne, VIC, Australia (J Lewin MBBS); Division of Medical Oncology, National Cancer Centre, Singapore (E Poon MD); Department of Medicine, Duke University, Durham, NC, USA (Prof K C Oeffinger MD)
Correspondence to: Dr Emily S Tonorezos, Office of Cancer Survivorship, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD 20854, USA
emily.tonorezos@nih.gov

Introduction

Over the past five decades, cancer during childhood and adolescence has slowly risen in incidence. In 2020, approximately 300 000 cancers were diagnosed among those aged 19 years and younger, worldwide.[1] At the same time, treatment and supportive care for children and adolescents with cancer has improved substantially. In many settings, cancers that were once uniformly fatal are now treatable. For those diagnosed during childhood in the USA, the overall proportion surviving 5 years from diagnosis has increased from 77·8% for those diagnosed in the 1990s, to 82·7% for those diagnosed in the 2000s, and to 85·4% for those diagnosed between 2010–16.[2] Similar successes have been described in Australia, Canada, the UK, and Europe. Notably, for children in low-middle income countries, survival gains have been more modest.[3,4]

Following cancer diagnosis at a young age, survivors confront a long survivorship phase, often spanning six decades. Over this follow-up phase, the risk of cancer recurrence decreases whereas the risk of treatment-related health problems increases. Organ systems that are developing during childhood and adolescence can be irreversibly affected by cancer treatment. Thus, although cure rates among this population are high, many survivors of childhood and adolescent cancer face a long follow-up period with numerous long-term health risks. In 2005, the seminal Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,[5] was published, highlighting this population. Since then, an increasing body of evidence has documented significantly higher levels of morbidity and early mortality in survivors diagnosed during childhood and adolescence, compared with survivors diagnosed during adulthood (figure).[2,6] Among 5522 survivors of childhood cancer who underwent comprehensive follow-up exams, the cumulative incidence of a severe, disabling, life-threatening, or fatal chronic condition was 96%. By age 50 years, survivors have, on average, 17·1 chronic health conditions, including 4·7 graded as severe, disabling, life-threatening, or fatal. Additionally, the cumulative burden among survivors was nearly two-fold than matched community-controls (p<0·001).[7] Common late effects include cardiovascular disease, respiratory dysfunction, endocrine abnormalities, and subsequent malignant neoplasm (panel, late effects). Many survivors experience multiple late effects, which act synergistically such that the burden of morbidity is compounded.[8]

Search strategy and selection criteria

We searched PubMed, Scopus, and Google Scholar for human studies published in English between Jan 1, 2000 and Dec 31, 2021 with the search terms "child", "adolescent", "neoplasm", "survivor*", "cancer", "onco*", "tumour", "long-term care", "late effects", and "paediatric". A search for ("child" OR "adolescent") AND "neoplasms" AND "survivor*" identified 9917 manuscripts; addition of the term "late effects" restricted the search to 1701 manuscripts. Of these studies, 609 were published in the years 2016–22. Studies were selected for relevance to long-term follow-up of survivors of childhood cancer; the most recent evidence from randomised controlled trials and meta-analyses, and recommendations from international guideline committees, were prioritised. We excluded studies that did not focus on childhood cancer, addressed issues for children on treatment, or were case reports. During the revision process, we further excluded old studies in favor of updated analyses, where relevant. On the basis of these results, and input from the authors and expert advisers, we included 68 references on childhood cancer survivorship in this Series paper.

www.thelancet.com Vol 399 April 16, 2022

The important role of general practice in the care of cancer survivors

Michael Jefford, Bogda Koczwara, Jon Emery, Elysia Thornton-Benko, Janette Vardy

Background
The number of people living with and beyond cancer is increasing substantially. Primary care has an important role in the ongoing management of cancer survivors.

Objective
The aim of this article is to outline common concerns of cancer survivors, evidence to support the role of general practitioners (GP) in survivorship care and key aspects of primary care–led survivorship care.

Discussion
Clinical trials have shown that, in particular circumstances and with well-designed models, GP-led care is as effective as oncology specialist–led care. Regardless of the model of care, general practice has key roles in care coordination, management of multimorbidity, secondary prevention and health promotion, management of psychosocial care and promotion of self-management. Communication and collaboration between GPs and specialist cancer services is critical to support patients and healthcare providers in the delivery of care.

IN AUSTRALIA, the number of people living with or beyond cancer (defined as 'cancer survivors') is increasing because of population ageing, increased cancer detection and improved treatments. In 2014 there were estimated to be almost 1.1 million Australians (approximately 1 in 22) with a personal history of cancer.[1] This number is projected to increase to 1.9 million by 2040. The majority are long-term (>5 years) survivors.[1] The most prevalent groups are those with a personal history of prostate, breast or colorectal cancer or melanoma.[1] Most are >70 years of age and have other comorbid conditions.[2]

Survivors may experience a range of consequences of cancer and cancer treatments.[2–5] Many of these issues are common across cancer types and include: persistent physical symptoms, such as fatigue, pain, insomnia and difficulties with memory and thinking; psychological issues, such as anxiety and fear of cancer recurrence; and practical consequences, such as difficulty resuming work and altered relationships.[2–5] Many of these issues may be present for years after completing treatments.[2,4] Symptom burden is greater in survivors when compared with the general population, and survivors report inferior quality of life.[2–5] Survivors may have other health risk factors, such as being inactive or overweight, or smoking.[5] Survivors report a lack of information about the post-treatment phase and strategies to remain well; a predominant unmet need relates to the management of psychological worries.[3,4,6] Some survivors are at risk of developing 'late effects' that may develop years after cancer treatment, including organ damage (eg cardiac failure) or another primary cancer.

Survivors may not be aware of their health risks and may feel unprepared for the post-treatment phase.[3,7] General practitioners (GPs) have an important role in the care of these patients.[8,9] In addition to a role in cancer surveillance, GPs have key roles in the management of comorbid illness, secondary prevention, health promotion, self-management promotion and coordination of care, which are usual roles for GPs.

Existing and recommended models of care

Current models of post-treatment care tend to be oncology-led and focus on surveillance for cancer recurrence. Unfortunately, these models leave survivors with significant unmet needs. They also fail to address many aspects of holistic care. These models are not sustainable given the rising numbers of survivors and limited health workforce, and do not represent the best use of oncology specialist expertise.[7]

To overcome these limitations, there have been a number of consensus

Jon Emery

Cancer survivorship – the role of the GP

Background
Improvements in cancer detection, treatment and an ageing population mean that there are increasing numbers of people living with and beyond cancer. Current hospital-centred models of cancer follow-up have tended to focus on detection of cancer recurrence, which may result in significant unmet needs, particularly psychosocial needs.

Objective
This paper discusses the evidence from previous studies of primary care involvement in cancer survivorship and key areas to consider in the follow-up care for common cancers.

Discussion
General practice has an important role in the holistic care of cancer survivors and could take on an expanded role in cancer follow-up.

Keywords
cancer; primary care; general practitioners; therapy-related cancer; holistic medicine; survivorship

The number of people living with and beyond cancer, or 'cancer survivors', is increasing in all developed countries. This reflects an ageing population, increased cancer detection and improvements in treatment with consequent higher survival rates. The most recent estimates of cancer prevalence show that in 2007 there were approximately 775,000 people living in Australia who had been diagnosed with cancer in the previous 26 years, including 339,000 in the previous 5 years.[1]

In 2005, the US Institute of Medicine (IOM) released a landmark report, *From Cancer Patient to Cancer Survivor: Lost in Transition*.[2] This report recognised the multitude of issues facing cancer survivors and the need to address the serious medical, functional and psychosocial consequences of cancer and its treatments. For example, breast cancer survivors may experience premature menopause, infertility, lymphedema, osteoporosis, cognitive dysfunction and cardiomyopathy due to anthracycline treatment. Psychosocial issues include fear of recurrence, altered body image, sexual dysfunction and change in roles.[3,4] After breast cancer treatment, women may also become less active and gain weight, with consequent effects on cardiovascular and diabetic risk.[5] Similarly, men, following treatment for prostate cancer, experience ongoing problems with sexual function, urinary and bowel symptoms (dependent on treatment modality), and psychological concerns about their future.[6,7]

Current models of care are often focused on cancer as an acute illness during treatment, whereas follow-up appointments are centred on detection of cancer recurrence, missing out the wider range of issues that should be covered as part of good chronic disease management. The focus on recurrent disease is despite evidence that cancer recurrences often present between scheduled hospital visits and usually in primary care.[8] Internationally, there is growing recognition that cancer survivorship needs to shift towards a chronic disease model with the following four goals: (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 the consequences of cancer and its treatment; and (4) coordination between specialists and

Managing patients receiving new and unfamiliar cancer treatments

A qualitative study of general practitioners' experience

Eleanor Lynch, Jennifer McIntosh, Bogda Koczwara, Jane Crowe, Jon Emery

Background and objective
As systemic cancer treatments increase in complexity, general practitioners (GPs) need access to reliable information to support patients on new and often unfamiliar treatments. The authors explored the experience of GPs in supporting patients receiving anticancer therapy, and the barriers and facilitators to the implementation of a new resource designed to support GPs in this role.

Methods
Semi-structured qualitative interviews were conducted with 15 GPs and oncology clinicians. Thematic analysis of interviews used inductive coding.

Results
Themes identified were GPs not feeling part of the team when looking after patients on cancer treatment, the role a new set of eviQ information resources could play in supporting GPs and barriers and facilitators to the implementation of these resources.

Discussion
GPs value reliable, published cancer treatment information, but it does not remove the need for individualised patient correspondence or the inclusion of the GP in the treating team.

CANCER DIAGNOSES IN AUSTRALIA are steadily increasing, and systemic treatments are evolving and increasing in complexity.[1,2] General practitioners' (GPs') ability to promptly recognise potentially serious side effects of treatment, especially those unique to newer therapies, can be crucial to patient safety.[3]

GPs are likely to encounter patients on an ever-expanding range of systemic cancer treatments, and while recent studies have looked at the important role that GPs have in cancer survivorship care,[4–6] there has been less focus on the GP's role during active cancer treatment, such as the management of comorbidities, being the first port of call for a treatment side effect or being the 'coordinator of care'.

A major challenge faced by GPs in the care of patients on cancer treatment is a lack of useful, timely communication from the patient's oncologist.[7,8] For GPs to safely care for these patients in the community, they require information on treatment type, including prognosis, follow-up plan and potential side effects of treatment, as well as suggested management.[8] The new eviQ resources have been proposed as one way of helping to meet this information need.

A number of online resources exist to support health professionals in the care of patients on cancer treatment. The most comprehensive Australian resource, eviQ, is an Australian Government cancer treatment resource that is freely available online to health professionals and the public.[9]

While most material published by eviQ is written for cancer professionals and patients, it has recently published a set of resources designed to support GPs in the management of patients who are prescribed any of four different types of systemic cancer treatment, including newer molecular targeted therapies and immunotherapy.[10]

However, little is known about whether GPs are even aware of eviQ, whether they will use the resources once they are aware or how the resources will translate into clinical use.

The aim of this study was to examine how supported GPs felt when managing patients on systemic cancer treatment, using the recently published eviQ information as an example of a resource that could potentially support them in this role.

Methods

A phenomenological approach using an interpretivist paradigm was chosen, as it enabled a more in-depth exploration of participants' responses to interview questions and to the GP-focused resources, and allowed researchers to answer the research question, even with a small sample size.[11]

About cancer survivorship and the Australian Cancer Survivorship Centre (ACSC)

Over one million Australians are living with or beyond their cancer diagnosis. This is due to advances in early detection, better treatments, and the ageing of the population.

Cancer survivorship care refers to the time following active cancer treatments. This may also be known as post-treatment follow-up care. While many people go on to lead normal lives, there may be mixed emotions and worry about the future. For some it's not always an easy transition and cancer can have a lasting impact including:

- ongoing side effects of treatment
- fear of cancer coming back
- other physical, emotional, financial and social concerns.

The ACSC recognise 'cancer survivors' as people who have been diagnosed with cancer, from the time of diagnosis throughout their life. Cancer can also have a lasting impact on survivors' family members, friends and caregivers.

Cancer care has traditionally focused on diagnosis and treatment. However, research shows it is just as important to focus on helping cancer survivors cope with life beyond their acute treatment. Cancer survivors may experience different issues compared to people having active treatment for cancer. It is important that survivors understand what to expect and are provided with the right information and support at the right time.

Quality cancer survivorship care should involve:

- monitoring to detect cancer coming back and new cancers
- support and monitoring for physical, emotional, social and practical effects of cancer and cancer treatment
- management of any other health conditions
- supporting and promoting wellness and healthy lifestyle
- coordinated care between all health professionals involved

Support and Wellbeing

- Support services ›
- Wellbeing programs ›
- Volunteer services ›
- Life after treatment ⌄
  - About cancer survivorship and the Australian Cancer Survivorship Centre
  - For survivors and carers: survivorship resources and information ›
  - For Health professionals: survivorship resources and information ›
  - Common Survivorship Issues Directory ›
  - Survivor stories

For Health professionals: survivorship resources and information

Over a million Australians are living with or beyond their cancer diagnosis. The Australian Cancer Survivorship Centre (ACSC) supports primary, hospital and community-based health professionals deliver optimal survivorship care.

- Resources and tools
- Survivorship in specific populations
- Events for health professionals
- Education and professional development
- Models of survivorship care
- Victorian Quality Cancer Survivorship Care Framework and Policy Template (2021)
- Directory of post-treatment, survivorship care guidelines
- Statewide survivorship care work
- Survivorship research

Resources and tools

The Australian Cancer Survivorship Centre (ACSC) supports primary, hospital, and community-based health professionals to deliver optimal survivorship care through a range of fact sheets, online resources, and tools.

Fact sheets

Topic-specific fact sheets to guide health professionals.

- Supporting health professionals to deliver optimal survivorship care
- Survivorship care planning
- Follow-up care after primary therapy
- Late effects of cancer treatments: overview
- Follow-up of survivors withh cancer-related fatigue
- Survivorship care in general practice: supporting patients to live well

Tumour-specific fact sheets for health professionals

- Follow-up of breast cancer survivors
- Follow-up of colorectal cancer survivors
- Follow-up of survivors of diffuse large B-cell lymphoma, a non-Hodgkin lymphoma subtype
- Follow-up of survivors of endometrial cancer
- Follow-up of survivors of Hodgkin lymphoma
- Follow-up of survivors of prostate cancer

Companion resources for cancer survivors are also available.

We also recommend:

- Can-Sleep: Making night-time sleep problems go away – Peter Mac: a guide for people with cancer
- CanEAT Pathway - Peter Mac: a guide to optimal cancer nutrition for people with cancer, carers, and health professionals.

Survivorship care plans

mycareplan.org.au

mycareplan.org.au is an online tool that can be used to create a survivorship care plan after treatment for:

- Early stage breast cancer
- Localised prostate cancer
- Early stage bowel cancer
- Early stage melanoma
- Uterine cancer (endometrial)
- Non-Hodgkin lymphoma (diffuse large B-cell)

The website is quick and easy to use, and freely available to health professionals and patients. The website can be accessed at www.mycareplan.org.au.

Survivorship care plan template

The ACSC also has developed two Microsoft Word versions of a survivorship care plan template.

- Survivorship Care Plan template - detailed version
- Survivorship Care Plan template - short version

The ACSC provides permission to use or adapt the survivorship care plan template for your personal use.

The ACSC provides permission for other health care providers to use or adapt the survivorship care plan template, with inclusion of the following acknowledgement: Adapted from template developed by Australian Cancer Survivorship Centre.

We also recommend:

- The ASCO (American Society of Clinical Oncology) Survivorship Care Compendium has been developed to act as a repository of tools and resources to enable health professionals to implement or improve survivorship care within their practice.

Videos

Describing the role of primary care in cancer survivorship:

- Hospital based health professionals (8 minutes)
- Hospital based health professionals - for educators (4 minutes). Use this video in workshops, and team meetings
- General practice staff (8 minutes)
- General practice staff - for educators (4 minutes). Use this video in workshops, and team meetings

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HOME › COURSES › SUPPORTIVE CARE › CANCER SURVIVORSHIP

Cancer survivorship

5.25hrs | Public | Version: 4.0 | Review due: July 2023

This introductory course is for all health professionals with an interest in cancer survivorship.

About

This course explores the health needs and experiences of cancer survivors, and presents useful frameworks, guidelines, tools and strategies to provide optimal cancer survivorship care.

Modules

- Module 1: Survivorship fundamentals — 1hrs
- Module 2: Models of survivorship care — 1hrs
- Module 3: A multidisciplinary approach — 1hrs
- Module 4: Survivorship care plans — 0.75hrs
- Module 5: Self-management — 0.75hrs
- Module 6: Wellbeing — 0.75hrs

Additional Information

Acknowledgements and funding

The original course was developed in 2013 and was funded by the Australian Cancer Survivorship Centre, based Peter MacCallum Cancer Centre, in collaboration with Cancer Australia, Queensland University of Technology and the University of Sydney.

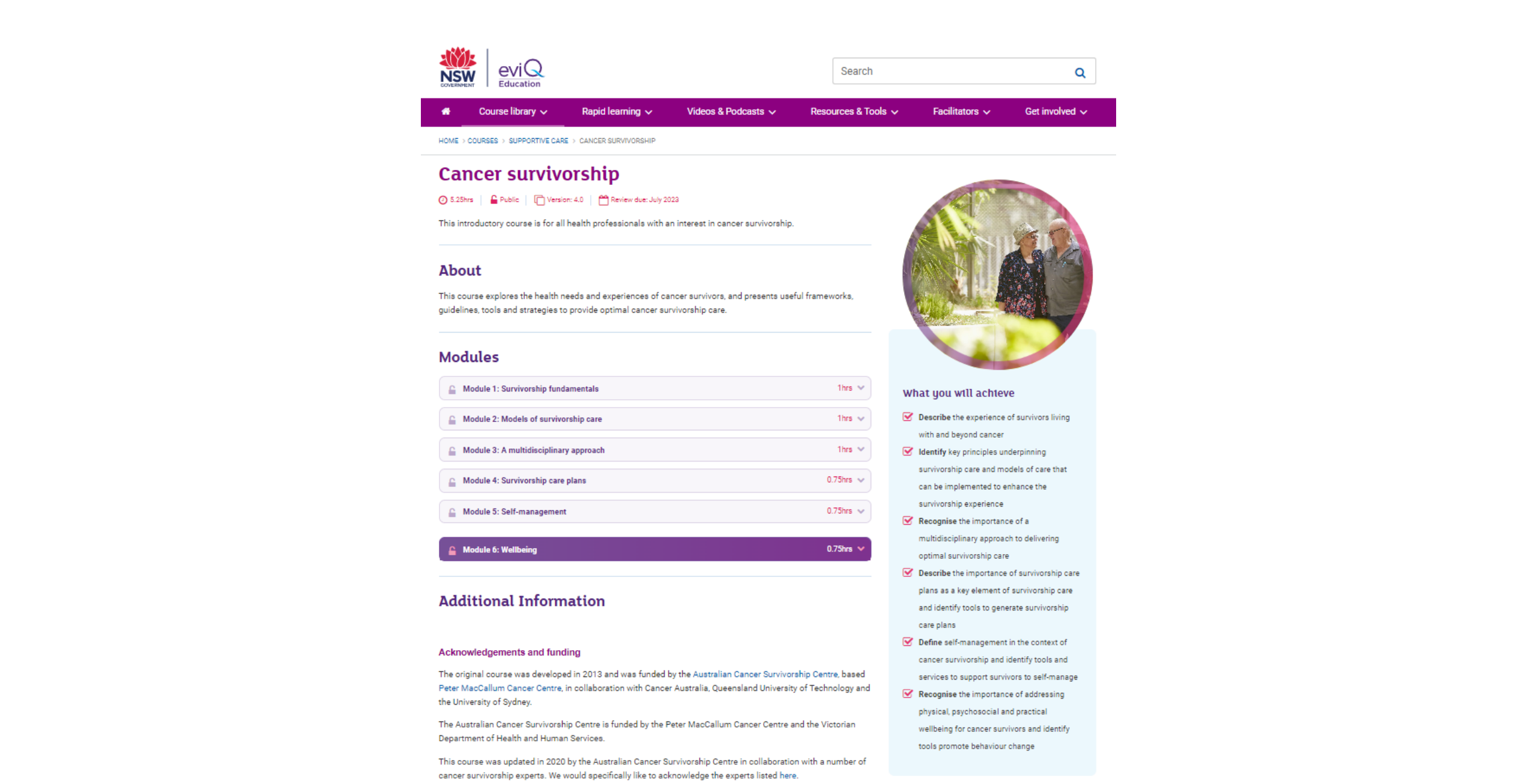
The Australian Cancer Survivorship Centre is funded by the Peter MacCallum Cancer Centre and the Victorian Department of Health and Human Services.

This course was updated in 2020 by the Australian Cancer Survivorship Centre in collaboration with a number of cancer survivorship experts. We would specifically like to acknowledge the experts listed here.

What you will achieve

- **Describe** the experience of survivors living with and beyond cancer
- **Identify** key principles underpinning survivorship care and models of care that can be implemented to enhance the survivorship experience
- **Recognise** the importance of a multidisciplinary approach to delivering optimal survivorship care
- **Describe** the importance of survivorship care plans as a key element of survivorship care and identify tools to generate survivorship care plans
- **Define** self-management in the context of cancer survivorship and identify tools and services to support survivors to self-manage
- **Recognise** the importance of addressing physical, psychosocial and practical wellbeing for cancer survivors and identify tools promote behaviour change

https://education.eviq.org.au/courses/supportive-care/cancer-survivorship



https://education.eviq.org.au/courses/supportive-care/cancer-survivorship

Cancer Council Queensland

Cancer Council

PRACTICAL SUPPORT

Living Well After Cancer

A guide for people with cancer, their families and friends

For information & support, call **13 11 20**

Contents

Key to icons

Icons are used throughout this booklet to indicate:

More information

Alert

Tips

Summary – Cancer Survivorship

- An area of significant unmet need
- Evidence is available to assist in better managing cancer survivors
- However current practices do not adequately address cancer patients or their carers needs
- New models of care are required
- How can health providers and NGOs etc in MN better collaborate to improve cancer survivorship care?

Our recommendations

Vardy, Chan et al 2019 AJGP

Clinical Oncology Society of Australia position statement on cancer survivorship care

CPD

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

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

Objective

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

Cancer survivors often experience long-term negative consequences of their cancer and cancer treatment, in addition to

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

To address these unique needs of cancer survivors, there have been a number of recommendations for delivery of survivorship care. The seminal report *From cancer patient to cancer survivor: Lost*

Our recommendations

Vardy, Chan et al 2019 AJGP

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

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