



# Addressing variation in outcomes related to disadvantaged groups

SCOPING REPORT

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We acknowledge the Traditional Owners of Country throughout Australia and their continuing connection to the land, sea and community. We pay our respects to them and their cultures and to Elders past and present.

In this report, in keeping with use by the Victorian Government, 'Aboriginal' refers to Aboriginal and Torres Strait Islander people. 'Indigenous' is retained when part of the title of a report, program or quotation.



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## Executive summary

The *Victorian public health and wellbeing plan 2015–2019* (DHHS 2015) reports persistent inequalities in health status, whereby life expectancy varies by up to seven years between local government areas in Victoria. Variation in cancer outcomes also exists across the state.

Socioeconomic status is a major predictor of health outcomes (VicHealth 2015). However, there are other key markers of disadvantage in the context of cancer care, including characteristics of the area in which people live (e.g. rural, urban fringe, farming/agricultural); cultural diversity; being Aboriginal; identifying as lesbian, gay, bisexual, gender diverse, trans or intersex (LGBTI); age and functional status; mental health status; and comorbidity. The reasons for overall poorer outcomes among people in these groups range from limited access to services to factors associated with culture and lifestyle.

Improving access to cancer care for disadvantaged groups is important for achieving health equity. Limited evidence exists for effective interventions on a national/international, state or local/ICS level that would lead to improved access to cancer care for populations included in one or more of these groups. However, key themes emerge in the literature to inform possible approaches and areas of focus to improve outcomes for disadvantaged groups across Victoria. These are:

- *Increased investment in 'demand' side interventions:* Interventions aimed at improving access should be patient oriented and focused on self-management.
- *Improved functional and interactive health literacy:* Successful approaches facilitate community participation, leadership and ownership-based approaches.
- *Multi-sectorial collaboration and collective impact:* Shared community-wide responsibility is necessary to achieve equity of access.
- *Integration of social and health determinants of access:* Incentives are needed for multiple social and health service sectors to be involved in the efforts directed at enhancing access.
- *True integration of care:* Management techniques can ensure patients' needs are identified early and achieve greater integration of care.
- *System capability – data collection:* Improving data collection and management in rural areas, of Aboriginal status and experience of care, and recording comorbidity, may significantly influence cancer outcomes.
- *System capability – workforce:* Improved geographic distribution of health service provision and interventions may improve health outcomes.

A strategy that allows for tailored, place-based interventions might involve:

- building on existing good practice and supporting tailored sub-regional initiatives with a focus on better responding to local conditions
- identifying key organisations (including in social care) to develop a joint approach at a local level and communities of practice
- expanding and embedding existing pilots focusing on shared care, care coordination, self-management and health literacy across Victoria
- measuring novel pilot programs, more precise data collection and more needs-based targeting
- progressing with the development of the Clinical Services Capability Framework (CSCF) to underpin strategy.

# Quick reference guide

Disadvantaged group	Key issues	Existing care models	Possible interventions
Residing in rural and remote areas (1.5 million in regional Victoria)	<ul style="list-style-type: none"> <li>Higher incidence of preventable cancers</li> <li>Higher cancer mortality (65% 5-year survival versus 69% in metropolitan Victoria)</li> <li>Diagnostic delays due to undersupply of medical practitioners</li> <li>Late presentation and stage at diagnosis</li> <li>Less likely to receive curative or reconstructive surgery, radiotherapy or anti-cancer drug treatment</li> <li>Variable staffing and service quality and capability</li> <li>Limited access to regional or tertiary centres</li> <li>More privatised care</li> <li>Lifestyle and occupational factors that encompass increased cancer risk</li> </ul>	<p><b>National</b></p> <ul style="list-style-type: none"> <li>Regional cancer centres</li> <li>Clinical Services Capability Framework (CSCF)</li> </ul> <p><b>State</b></p> <ul style="list-style-type: none"> <li>Rural Health Outreach Fund – Victoria</li> <li>Telehealth specialist initiatives – Victoria</li> </ul> <p><b>Local/ICS</b></p> <ul style="list-style-type: none"> <li>Western Alliance – Grampians Small Towns Cancer strategy – GICS</li> <li>Regional:Metropolitan Interface Study – WCMICS/LMICS</li> <li>Gippsland Oncology Teletrials model – GRICS</li> <li>Ophelia (Optimising Health Literacy and Access) – GICS</li> </ul>	<ul style="list-style-type: none"> <li>Development of Victorian CSCF</li> <li>Evaluation and expansion of WCMICS/LMICS metropolitan/regional engagement project</li> <li>A project to utilise regional cancer centres as platforms for research with access to clinical trials / Evaluation and expansion of Gippsland teletrials model and general expansion of telehealth hardware infrastructure</li> <li>Development of a region-wide locum service</li> <li>Project to improve linkages to comprehensive centres</li> <li>Investigate factors that influence specific rural–metro referral pathways / completeness of patient information transfer</li> <li>Develop a regional cancer patient transfer plan – expanding transport and accommodation role of metro neighbourhood houses</li> </ul>
Farming and agricultural workers	<ul style="list-style-type: none"> <li>Unique sociodemographic characteristics</li> <li>Elevated rates of cancer mortality</li> </ul>	As above	
Urban fringe residents (8 million in Melbourne by 2050, currently 4.5 million)	<ul style="list-style-type: none"> <li>Urban fringe population is increasing by 2.3% per year</li> <li>Issues associated with high population growth with few resources (including health services) to support such growth</li> <li>Sociocultural impacts</li> </ul>	<p><b>National</b></p> <ul style="list-style-type: none"> <li>CSCF</li> </ul> <p><b>Local/ICS</b></p> <ul style="list-style-type: none"> <li>Better Care Victoria Grant Exercise physiology and discharge planning – LMICS</li> <li>Regional:Metropolitan Interface Study – WCMICS/LMICS</li> </ul>	

Disadvantaged group	Key issues	Existing care models	Possible interventions
Culturally diverse groups (28% of Victorians were born overseas and 23% speak languages other than English)	<ul style="list-style-type: none"> <li>• Lower cancer incidence and mortality</li> <li>• A different spectrum of cancers (e.g. more liver cancer due to exposure to hepatitis B)</li> <li>• Mistrust of health system</li> <li>• Communication and health literacy barriers leading to non-compliance and non-attendance</li> <li>• Poorer health-related quality of life and psychological wellbeing</li> <li>• Lower screening participation</li> <li>• Higher proportion of lung, stomach, liver, cervix, thyroid and bladder cancers</li> <li>• Under-representation in clinical trials</li> </ul>	<p><b>National/international</b></p> <ul style="list-style-type: none"> <li>• IMPACT (Innovative Models Promoting Access-to-Care Transformation)</li> </ul> <p><b>State</b></p> <ul style="list-style-type: none"> <li>• Health Translations – Victoria</li> </ul> <p><b>Local/ICS</b></p> <ul style="list-style-type: none"> <li>• ‘Hard-to-Reach’ Consumers Study – NEMICS</li> <li>• Ophelia (Optimising Health Literacy and Access) – GICS</li> </ul>	<ul style="list-style-type: none"> <li>• Undertake research on treatment disparities for people from culturally diverse communities</li> <li>• Analyse the data to better understand non-compliance (e.g. referred to tertiary care but do not complete treatment)</li> <li>• Strategy to improve uptake to clinical trials</li> </ul>
Groups with low socioeconomic status (80% of the most socially disadvantaged areas in Victoria are rural)	<ul style="list-style-type: none"> <li>• Overall elevated risk of cancer death</li> <li>• Advanced cancer stage at diagnosis</li> <li>• Poorer survival</li> <li>• Higher prevalence of smoking and obesity</li> <li>• Cost of unsubsidised treatments</li> <li>• High level of social disadvantage</li> </ul>	<p><b>National/international</b></p> <ul style="list-style-type: none"> <li>• IMPACT (Innovative Models Promoting Access-to-Care Transformation)</li> <li>• The Australian Centre for Social Innovation (TACSI)</li> </ul> <p><b>State</b></p> <ul style="list-style-type: none"> <li>• The G21 Regional Opportunities for Work (GROW) Initiative – Geelong</li> <li>• Local Health District Demonstrator Sites – New South Wales (NSW)</li> </ul> <p><b>Local/ICS</b></p> <ul style="list-style-type: none"> <li>• Population based registry data modelling on socioeconomic indicators – BSWRICS</li> <li>• Ophelia (Optimising Health Literacy and Access) – GICS</li> <li>• Western Alliance – Grampians Small Towns Cancer strategy – GICS</li> <li>• Identifying gaps in cancer care for Victorian prisoners – WCMICS</li> </ul>	<ul style="list-style-type: none"> <li>• Intervention to provide coverage for care not covered by Medicare Benefits Schedule (e.g. dental reconstruction, fertility preservation)</li> <li>• Redevelopment of supportive care screening to identify disadvantaged groups with the aim of accurate needs assessment and appropriate referral to supportive care services (early scoping currently being undertaken in Barwon Health)</li> </ul>

Disadvantaged group	Key issues	Existing care models	Possible interventions
<p>Aboriginal population (Est. 51,000 Aboriginal Victorians. Just over half live in regional and rural areas)</p>	<ul style="list-style-type: none"> <li>• Different pattern of cancer incidence</li> <li>• Significantly higher mortality rates from cancer than non-Aboriginal Victorians</li> <li>• Advanced cancer stage at diagnosis</li> <li>• Lower screening participation</li> <li>• Higher levels of modifiable risk factors</li> <li>• Higher levels of infection such as HPV and hepatitis B leading to higher incidence of preventable cancers more likely to be fatal (lung and liver cancers)</li> <li>• Less likely to receive adequate treatment or be hospitalised</li> <li>• Cultural barriers to the prevention, detection and treatment of cancer</li> <li>• Discontinuity of treatment due to relocation away from home and community</li> <li>• Service providers' lack of knowledge and need for more culturally appropriate services</li> </ul>	<p><b>National/international</b></p> <ul style="list-style-type: none"> <li>• IMPACT (Innovative Models Promoting Access-to-Care Transformation)</li> <li>• Culture is Healing – Breast Cancer Network Australia</li> </ul> <p><b>State</b></p> <ul style="list-style-type: none"> <li>• The Aboriginal Collaborative Grants Program – Victoria</li> <li>• Cancer Data and Aboriginal Disparities (CanDAD) Project – South Australia</li> </ul> <p><b>Local/ICS</b></p> <ul style="list-style-type: none"> <li>• 'Hard-to-Reach' Consumers Study – NEMICS</li> <li>• Aboriginal Services Pamper and Paps Day – LMICS</li> <li>• The Parkville Precinct Aboriginal Health Directorate – WCMICS</li> <li>• Gippsland Survivorship Grant – GRICS</li> </ul>	<ul style="list-style-type: none"> <li>• Implementation of the <i>Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer</i> (Cancer Australia 2018)</li> <li>• Roll out of Parkville Precinct Aboriginal Health Directorate operating service model across state</li> <li>• Establish formal partnership arrangements with the Aboriginal Health Worker Network to allow facilitation of support between provider and patient. Model on NSW demonstrator sites</li> <li>• Project to survey aboriginal experience of cancer care</li> <li>• Registry data collection to record Aboriginal status</li> </ul>
<p>LGBTI</p>	<ul style="list-style-type: none"> <li>• Lower screening participation</li> <li>• Higher incidence of certain cancers and higher cancer mortality rates</li> <li>• Additional psycho-social complexities post diagnosis: sexual side effects, depression, and social isolation</li> <li>• Some evidence of higher prevalence of several risk factors</li> <li>• Reduced access to healthcare due to discrimination and discrimination uncertainty</li> <li>• Overall lack of health provider knowledge</li> </ul>		<ul style="list-style-type: none"> <li>• Adaptation of Mildura Aboriginal Services Pamper and Paps Day for LGBTQI sub-groups</li> </ul>

Disadvantaged group	Key issues	Existing care models	Possible interventions
Elderly (aged 80 years and older or particularly frail)	<ul style="list-style-type: none"> <li>• Late presentation and diagnosis, poor response to treatment contributing to poorer outcomes</li> <li>• Complicated management due to comorbidities and functional status</li> <li>• Polypharmacy issues: multiple medications being taken for comorbid conditions</li> <li>• Management of drug interactions required</li> <li>• Lack of evidence-based information negatively affects clinical practice</li> <li>• Exclusion from clinical trials</li> <li>• Social isolation</li> </ul>	<p><b>National/international</b></p> <ul style="list-style-type: none"> <li>• Nurse navigators – Canada</li> <li>• The Australian Centre for Social Innovation (TACSI)</li> </ul> <p><b>State</b></p> <ul style="list-style-type: none"> <li>• Local Health District Demonstrator Sites – NSW</li> </ul> <p><b>Local/ICS</b></p> <ul style="list-style-type: none"> <li>• Monash Geriatric Oncology Clinic – SMICS</li> </ul>	<ul style="list-style-type: none"> <li>• Interventions for improving polypharmacy</li> <li>• Develop evidence-based guidelines</li> <li>• Strategy for recruitment to clinical trials</li> <li>• Evaluation and expansion of Monash geriatric oncology clinic</li> <li>• Registry to record comorbidity</li> </ul>
People with mental health issues and comorbid health conditions	<ul style="list-style-type: none"> <li>• Poor management of comorbid conditions of mental illness and chronic disease</li> <li>• Less likely to use health services</li> <li>• Less likely to adhere to medication</li> <li>• Fragmentation of mental health services and health providers presents particular navigation challenges</li> <li>• Attitudes of healthcare staff in inhibiting help-seeking by this group</li> <li>• Psychological distress related to higher cancer incidence, poorer survival and higher mortality</li> </ul>	<p><b>National/international</b></p> <ul style="list-style-type: none"> <li>• IMPACT (Innovative Models Promoting Access-to-Care Transformation)</li> <li>• Nurse navigators – Canada</li> <li>• The Australian Centre for Social Innovation (TACSI)</li> </ul> <p><b>State</b></p> <ul style="list-style-type: none"> <li>• Local Health District Demonstrator Sites – NSW</li> </ul> <p><b>Local/ICS</b></p> <ul style="list-style-type: none"> <li>• Ophelia (Optimising Health Literacy and Access) – GICS</li> <li>• Cabrini / Peninsula Health shared care mental health pilot – SMICS</li> </ul>	<ul style="list-style-type: none"> <li>• Collocation of mental health services</li> <li>• Evaluation and expansion of Cabrini/Peninsula shared care mental health pilot</li> <li>• Analyse the data to better understand non-compliance (referred to tertiary care and do not complete treatment)</li> <li>• Registry to record comorbidity</li> </ul>



# Introduction

The *Victorian public health and wellbeing plan 2015–2019* reports persistent inequalities in health status whereby life expectancy varies by up to seven years between local government areas in Victoria (DHHS 2015a). In cancer, it is well understood that variation in cancer outcomes exists across the state. It is less well understood why these variations occur and how to address them.

Many population groups experience significant health and wellbeing inequalities. Health status varies considerably between Victorian populations and geographic areas and within these populations and areas. Socioeconomic status is a major predictor of health outcomes (VicHealth 2015). However, differences in outcomes are also influenced other factors, including cultural diversity, disability, being Aboriginal, and characteristics of the area in which people live (VicHealth 2015).

This scoping report examines key markers of ‘disadvantage’, including ‘hard-to-reach’ (or ‘disadvantaged’) groups in the context of cancer care, to provide a starting point in improving outcomes for disadvantaged groups across Victoria.

## 1.1 Scope

Section 1 outlines relevant legislation and policy.

Section 2 reviews the literature on disadvantaged groups in the context of access to cancer care and outcomes.

Section 3 documents care models at the national/international, state and local/ICS (integrated cancer service) level that are aimed at accessing disadvantaged groups at any point of the care pathway. It also documents examples of care models in other sectors that have demonstrated innovation in addressing access issues.

Section 4 provides a broad identification of key themes emerging to inform possible approaches and areas of focus to improve outcomes for disadvantaged groups across Victoria.

Section 5 provides some conclusions about information presented in the scoping report.

The issue of disparity in outcomes between metropolitan and regional patients is included in the literature review for comprehension. Establishing regional cancer centres and adopting novel approaches, such as telehealth, to improve services across Australia has begun to actively address this aspect of variation. Further detail, such as defining minimum service requirements and service capability, may assist with addressing unwarranted variation. This is out of the scope of this document.

This scoping report is premised on the assumption that ‘hard-to-reach’ groups are disadvantaged in that they have less access to cancer care and have poorer cancer outcomes. While the evidence shows that variation in cancer outcomes mostly aligns with disadvantage generally, it doesn’t always. For practicality, this document refers to ‘disadvantaged groups’ throughout.

## 1.2 The legislative and policy context

The *Improving Cancer Outcomes Act 2014* (Vic) provides the legislative framework for providing cancer services in Victoria. Australian Government priorities for cancer care include the establishment of regional cancer centres to help close the gap in outcomes for cancer patients living in rural, regional and remote communities; developing national standards to improve cancer care; and a range of promotional programs and interventions to reduce preventable chronic disease, including cancer.

### 1.2.1 Victorian public health and wellbeing plan 2015–2019

The plan sets out place-based and people-based platforms to improve health and wellbeing. Place-based actions relevant to improving access for disadvantaged groups include:

- developing a new approach to place-based prevention across Victoria

- establishing a community renewal and rebuilding program to provide targeted support for disadvantaged communities
- developing tools and resources for place-based initiatives to address social isolation and loneliness among seniors
- establishing new regional and metropolitan partnerships to significantly increase collaboration between communities, industry, businesses and government to address the most important challenges and opportunities across the partnership regions.

People-based approaches include:

- co-designing a new Aboriginal health, wellbeing and safety strategic plan
- supporting the National Disability Insurance Scheme to build relationships with mainstream service providers and local communities to improve understanding of the ways they can help people with a disability and increase accessibility and capacity of mainstream services
- strengthening support for newly arrived refugees and asylum seekers
- working through a whole-of-government LGBTI Taskforce (DHHS 2015a).

### **1.2.2 Statewide design, service and infrastructure plan for Victoria's health system 2017–2037**

The 20-year plan is based on five priority areas:

1. building a proactive system that promotes health and anticipates demand
2. creating a safety and quality-led system
3. integrating care across the health and social service system
4. strengthening regional and rural health services
5. investing in the future – the next generation of healthcare.

The plan focuses on workforce development, capability building and infrastructure investment to improve access to care in the context of unprecedented population growth.

A series of design principles are set out to guide decision-making, with a focus on joined-up planning across sectors, and linking to broader government planning to ensure a unified approach (DHHS 2017).

### **1.2.3 Victorian cancer plan 2016–2020**

The plan provides a framework to improve cancer outcomes and achieve equitable outcomes for all Victorians.

The plan identifies ways in which there are variable outcomes for Victorians who experience cancer. Relevant action areas and priorities to improve access include reducing risk factors related to lifestyle and environment, equity in screening participation and improved health literacy (DHHS 2016a).

### **1.2.4 National Aboriginal and Torres Strait Islander Cancer Framework and Cultural Respect Framework 2016–2026**

In 2015 Cancer Australia developed an evidence-based, nationally agreed strategic framework to guide future cancer control efforts for Aboriginal people. The first National Aboriginal and Torres Strait Islander Cancer Framework identifies seven priorities to guide and inform national, jurisdictional, regional and local cancer control efforts. The framework was developed in recognition that Aboriginal people continue to experience disparities in cancer outcomes. Similarly, the Cultural Respect Framework articulates the importance of redressing the barriers Aboriginal people face accessing and receiving care (Cancer Australia 2015).

### **1.2.5 Optimal cancer care pathways**

Optimal cancer care pathways (DHHS 2015–2018) outline the best cancer care for specific tumour types. The pathways are designed to promote a full understanding of the patient journey to foster quality cancer care from the point of diagnosis. The optimal care pathways are based on a revision of the original patient management frameworks (DHS 2006), which had, for the first time, attempted to map the cancer pathway from pre-diagnosis to end-of-life care.

Victoria undertook the work as part of a national work plan aimed at improving cancer care. The National Cancer Expert Reference Group developed a national work plan. Each jurisdiction's health department has responsibility

for implementing the optimal cancer care pathways in their region. In Victoria, implementation is predominantly delegated to the Victorian Integrated Cancer Services, the primary health networks and Cancer Council Victoria.

### 1.2.6 Policies and practice to support the ICS

There are various policy and program documents about quality cancer services in Victoria:

- *Targeting zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care* (Duckett, Cuddihy & Newnham 2016)
- *Achieving best practice cancer care: A guide for implementing multidisciplinary care* (DHS 2007a)
- *Providing optimal cancer care: Supporting care policy for Victoria* (DHS 2009)
- *Victoria's end of life and palliative care framework* (DHHS 2016c)
- *Linking cancer care: A guide for implementing coordinated cancer care* (DHS 2007b)
- *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services* (DHS 2007c)

# Disadvantaged groups in Victoria (literature review)

Section 2 reviews the literature on disadvantaged groups in the context of access to cancer care and outcomes.

## 2.1 Geography

### 2.1.1 Rural and remote areas

Rural–urban inequalities in health and access to healthcare have long been of concern in health policy debates. Conventional wisdom suggests that, due to distance from healthcare services, rural residents are less likely than their urban counterparts to receive early and appropriate diagnoses and effective treatments for diseases such as cancer (McLafferty et al. 2011).

In Australia, one of the obvious disparities in cancer outcomes is geography, with mortality in some cancers being worse with increasing remoteness (Olver, Franca & Grogan 2011). Nearly one-third of Australians live in rural (29%) and remote (3%) areas (Olver, Franca & Grogan 2011).

Cancer risk and poorer survival for people with cancer living in outer regional/remote areas is well documented (Olver, Franca & Grogan 2011; Tervonen et al. 2017). Rural Australians are more likely than people from metropolitan areas to die within five years of a cancer diagnosis (Underhill, Goldstein & Grogan 2006; Coory, Ho & Jordan 2013). While overall survival for most common cancers in Australia is improving, the rural–urban differential has been widening, with significant excess deaths due to lung, colorectal, breast and prostate cancer in regional Australia (AIHW 2010). Coory, Ho and Jordan reported 8878 excess cancer deaths in regional and remote areas between 2001 and 2010 compared with metropolitan areas of Australia, and cancer death rates decreasing more slowly in regional and remote areas (2013).

Considering ‘all cancers’, incidence rates in inner and outer regional areas in 2001–2003 were higher in major cities but lower for very remote areas. However, preventable cancers such as melanoma, lung, lip, and head and neck cancers, and colorectal cancer and cervical cancer, which have higher incidence, suggest that prevention campaigns may not be reaching their targets as effectively in rural and remote areas (Olver, Franca & Grogan 2011).

Of the six million people living in Victoria, around 1.5 million live in regional Victoria (DHHS 2016). In many rural areas, the proportion of older Victorians is increasing. Victorians living in some regional areas have poorer outcomes than those living in metropolitan Melbourne for cancer overall and for a range of specific cancer types (DHHS 2015a). The incidence of premature death due to cancer is higher in rural Victoria compared with metropolitan Victoria (RWAV 2017). The overall cancer five-year survival rate is 69 per cent for metropolitan and 65 per cent for non-metropolitan residents (DHHS 2015a). Between 2010 and 2014, the areas with the highest rates of avoidable deaths caused by cancer were Robinvale, Corio-Norlane and the Seymour region (RWAV 2017).

Diagnostic delays are common with increasing rurality, due to an undersupply of medical practitioners in these areas (Fox & Boyce 2014). Early detection is also limited by fewer diagnostic facilities such as computed tomography scanning and tissue biopsy services, resulting in an increase in late presentations with metastatic disease.

The Rural Health Outreach Fund (RWAV 2017) reports significant variation in positive screening results whereby the following rural local government areas were significantly above the Victorian rate over the period 2010–2014:

- bowel cancer – East Gippsland Shire – Longford – Loch Sport / Yarram, Mitchell Shire – Seymour
- cervical cancer – Rural City of Swan Hill
- breast cancer – Buloke Shire.

Almost all newly diagnosed cancer patients in Victoria require specialist treatment (DHHS 2016). Studies have shown that patients living in rural Australia are less likely to receive curative or reconstructive surgery, radiotherapy or anti-cancer drug treatment (Emery et al. 2017). Anecdotal evidence suggests that staffing and service quality and capability is extremely variable in regional and rural Victorian, with a reliance on visiting medical officers.

Significant progress has been achieved in recent years, particularly with the establishment of the regional cancer centre initiative announced by the Australian Government in 2010. With the consolidation of radiation oncology and chemotherapy services under the initiative, many rural patients are no longer required to travel to metropolitan areas for cancer therapy.

In addition, novel approaches are being increasingly adopted in rural areas to improve both the efficiency and quality of cancer services, including telehealth, shared care and surgical oncology networks. The increasing adoption of telehealth has resulted in improved service provision and substantial cost saving, particularly for remote communities. Telehealth facilities also allow regional sites to link to tertiary metropolitan centres for multidisciplinary team discussion (Fox & Boyce 2014).

Significant inequalities remain in access to specialist oncology services, especially in areas that are not recipients of regional cancer centre funding. Many patients continue to travel substantial distances to regional cancer centres. State-based road travel subsidies for rural patients are as low as 16 cents per kilometre, which is significantly below the Australian Tax Office tax-deductible rate of 65 cents per business kilometre. The cost of attending regional or tertiary centres for cancer therapy continues to remain a barrier to improved cancer survival rates.

Further, there is a link between increased remoteness and more privatised care. There has been huge private investment in radiotherapy in the regions but funding is based on per episode of care and incentivised to deliver smaller fractions. Patients having palliative low fractionated radiotherapy are not being treated locally and instead are travelling to Melbourne for their care. Similarly, GPs have a corporate model that impacts on upfront fees to visit a GP, which again may impede access to care.

Emery and colleagues (2017) point out that policy initiatives have focused on reducing disparities in access to treatment but, while this is an important determinant of outcome, later presentation and stage at diagnosis have also been observed in cancer patients from rural compared with those from urban areas (Jong, Vale & Armstrong 2005; Baade et al. 2011). The reasons for poorer outcomes in regional and remote populations extend to lifestyle and occupational factors, which encompass increased cancer risk factors compared with urban counterparts (Olver, Franca & Grogan 2011). These include greater levels of socioeconomic disadvantage, and a greater proportion of Aboriginal people who have their cancers diagnosed at more advanced stages and may receive poorer treatment (Heathcote & Armstrong 2007).

### **2.1.2 Farming and agricultural subgroups**

Farming and agricultural subgroups share unique sociodemographic characteristics as a rural subgroup. Evidence points to reduced overall cancer incidence (likely attributions include a healthy worker effect, greater levels of physical activity, differences in smoking rates and the protective effects of farm endotoxin exposure) (Depczynski et al. 2018). However, there is emerging evidence that this subgroup has access issues over and above the expected remote/rural ones. They are often relatively asset-wealthy, cash-poor individuals and are an ageing workforce (ABS 2012). Most farm businesses in Australia are family operations, with older farmers continuing to work past normal retirement age (Depczynski et al. 2018). Given these characteristics, farmers may not qualify for financial assistance and may find it difficult to find the support required to leave their farm for treatment. There is limited evidence indicating elevated rates of cancer mortality among this subgroup in Australia (Fragar, Depczynski & Lower 2011).

### **2.1.3 Urban fringe**

McLafferty and colleagues point out that there are mixed and contradictory findings about remoteness and healthcare outcomes (e.g. for some tumour streams, survival improves with remoteness) and emphasise the complexity of rural and urban place environments warranting a more dynamic view of geographic disparities (2011): there is a need to move beyond a simple binary categorisation of 'rural' and 'urban' and tackle health inequalities along a gradient of geographic settings, appreciating that rural–urban disparities are evolving over time. Changes in population, environmental and transport characteristics of rural and urban places intersect with changes in medical practices and policies (McLafferty et al. 2011).

Urban fringe, urban growth, or 'peri-urban' areas refer to areas at the interface between city and country but in the economic and social catchment of a metropolitan area, or 'areas on the urban periphery into which cities expand' (Buxton et al. 2011). They are an important consideration in Australia when looking at health inequalities across geographic settings, given there was an 18 per cent increase (1.57 million) in people living in urban fringe regions between 2006 and 2016 (id 2017).

Melbourne's population continues to grow at a rapid pace from a current 4.5 million to up to 8 million residents by 2050 (Madill 2017). Much of this predicted growth is occurring in urban fringe developments. Population rates in urban fringe regions of Melbourne have increased at a rate higher than the national average (1.7%), at 2.3 per cent per annum between 2006 and 2016 (.id 2017). Growth in population and housing are at rates in excess of those experienced in many parts of metropolitan Melbourne (Buxton et al. 2011). Since 2006, Melbourne's growth has intensified in the north-west and the urban growth zone was introduced to provide housing in designated growth areas. Over the period 2006–2016, the fastest growing urban fringe area in Victoria was Mitchell Shire (3.1% per annum) (.id 2017). In 2016, Mickleham (Yuroke) in Melbourne's outer north had the fastest growth in Australia (35%). Other urban fringe areas with the reported fastest population growth included Rockbank–Mount Cottrell (28%) and Wollert (20%) (ABS 2018).

Buxton and colleagues (2008) point out that in Victoria, urban fringe development is spatially uneven, with high growth pressure, infrastructure pressures and sociocultural impacts; it is inadequately considered in discussions of broader growth in the metropolitan area (Buxton et al. 2011). Anecdotal evidence points to a range of issues associated with high population growth with few resources, including health services, to support such growth.

As urban fringe developments grow, there will be a greater requirement for health infrastructure and services to be located in these areas to meet the increasing demand of population growth and to ensure equitable access to services (Madill 2017). While studies have shown inequities of access to health services exists in rural compared with urban areas, Madill points out there is very little published research about access to health services in urban fringe areas compared with established areas of cities (2017). In Melbourne, urban fringe areas are characterised by low-density neighbourhoods with poor access to transport, services and public open space; these factors in turn lead to lower levels of physical activity and decreased access to healthy foods, which can act as pre-cursors to chronic diseases (Madill 2017). Breen argues that without localised social and economic opportunity, residents who live on the urban fringe are required to travel long distances for employment and other non-discretionary activities, which can impact on discretionary time, leading to increased financial costs and increased social isolation; together they exacerbate health and mental health issues for the vulnerable (2011).

Madill points out that studies that focus on access to health services (including cancer services) in urban fringe areas are absent. This is in part due to the rapid development of urban growth areas (2017). Madill recommends that, given Melbourne is in a time of planning for its forecasted population growth (set out in frameworks such as the Statewide design, service and infrastructure plan), an integrated approach that examines the need for health services access and planning in Melbourne's urban fringe would ensure equitable health service access (2017).

## 2.2 Cultural and linguistic diversity

Of the almost six million people living in Victoria, 28 per cent were born overseas and 23 per cent speak a language other than English at home (DPC 2018). Victorians come from more than 200 countries and speak 260 languages and dialects. The top countries of birth in Victoria (over 40,000 persons) are India, China, Vietnam, Italy, Sri Lanka, Philippines, Malaysia and Greece (DPC 2018).

Victorian's migration trends are changing. Although the largest groups of overseas-born people in 2016 were from Europe, due to their long settlement history, their percentage shares are declining. Those born in South-East and North-East Asia, Southern and Central Asia have increased significantly in numbers and percentage share as a result of more recent arrivals (DPC 2018).

In Victoria, according to 2016 census data, local government areas with the highest percentage of language other than English speakers are Greater Dandenong (64.5%), Brimbank (58.4%), Monash (50.1%), Melbourne (48.1%) and Hume (44.9%) compared with an overall 26.0 per cent for whole of Victoria (DPC 2018). These local government areas include large, outlying suburbs and new residential growth areas. In regional Victoria, there are significant numbers of speakers of languages other than English in Greater Geelong, Greater Shepparton, Latrobe, Mildura, Ballarat and Greater Bendigo.

In metropolitan Melbourne, the largest percentage increases (between the 2011 and 2016 census) were in the City of Melbourne, Wyndham (in the west) and Cardinia (in the south-east). These local government areas also experienced large increases in overseas-born residents. In regional Victoria, the largest percentage increases in languages other than English speakers were in Greater Bendigo. Significant percentage increases also occurred in a number of local government areas such as Mitchell, and Moyne and Colac in the southern part of the state (DPC 2018).

In general, culturally diverse groups report lower levels of smoking and are less obese (Olver, Franca & Grogan 2011). Tervonen and colleagues (2017) showed that overseas-born people with cancer had similar/lower risk

of cancer death than Australian-born people. Immigrants to Australia from diverse backgrounds have a lower incidence of the common cancers and a lower overall mortality (Tervonen et al. 2017).

Screening participation tends to be lower in culturally diverse groups. The incidence of cancers that are most common in the non-immigrant population – colon cancer, breast cancer, prostate cancer and melanoma – is lower in culturally diverse groups (Olver, Franca & Grogan 2011). Culturally diverse groups have a different spectrum of cancers, such as more liver cancer because of their exposure to hepatitis B (Olver, Franca & Grogan 2011). A higher proportion of lung, stomach, cervix, thyroid and bladder cancers are also found in culturally diverse groups, who also generally have lower mortality rates from cancer (Olver, Franca & Grogan 2011).

Anecdotal evidence points to misunderstandings or mistrust of the health system generally, prevalent among certain cultural groups. Language and health literacy barriers may lead to non-compliance and non-attendance issues. Compared to Anglo-Australian cancer patients, culturally diverse patients have poorer health-related quality of life and psychological wellbeing and report greater difficulties communicating with their doctor and understanding the health system (Smith et al. 2017).

Little has been studied on treatment disparities in culturally diverse groups. However, migrant settlement plays an important role in contributing to population growth in regional urban centres. Thus, the health inequalities and access issues of urban fringe areas (s. 2.2) may disproportionately affect culturally diverse groups. Also, there is an under-representation of culturally diverse patients in clinical trials in Australia (Smith et al. 2017). This compromises the detection of culturally diverse-specific effects and increases disparities in cancer care and outcomes. Research suggests that many barriers to trial participation are compounded for culturally diverse populations (e.g. utilising patient reported outcomes and additional time taken with interpreter may be a significant barrier to inviting culturally diverse patients to participate, and additional resources may be required such as translation of study materials). Increasing patients' participation in research is critical to determining whether interventions are equally efficacious for all patients, and may help address current health disparities (Smith et al. 2017).

## 2.3 Socioeconomic status

The document Health and wellbeing status of Victorians (DHHS 2015b) identifies that health and wellbeing inequalities are most evident in areas and populations experiencing socioeconomic disadvantage. It reports that socioeconomic disadvantage is the greatest cause of health inequality in Victoria. Poorer socioeconomic status is a major factor associated with poorer outcomes in cancer treatment.

In terms of cancer, some international research has been undertaken in treatment disparities in lower socioeconomic groups. Belot and colleagues' large population-based study provides strong evidence that despite accounting for sex, age at diagnosis, comorbidities, stage at diagnosis, performance status and indication of having had a PET-CT scan, socioeconomic differences persisted whereby more deprived people had lower odds and lower rates of receiving surgery in early stage lung cancer (2018). In an earlier study, assessing socioeconomic disparities in access to treatment and their impact on colorectal cancer survival, it was reported that more affluent patients had received treatment earlier than less affluent patients (Lejeune et al. 2010).

Ellis, Coleman and Rachet (2012) estimated the number of excess (cancer-related) deaths that would be avoidable within three years after diagnosis if relative survival for patients in all deprivation groups in a cohort of 64,940 patients was as high as the most affluent group; they reported that 11 per cent of deaths would have been avoidable.

Tervonen and colleagues examined variations and trends in cancer survival by socioeconomic disadvantage in an Australian population over a 30-year period. After accounting for differences (in cancer site, stage at diagnosis and death from competing events), people diagnosed with cancer and living in socioeconomically disadvantaged areas had an overall elevated risk of cancer death, with an increasing comparative risk of cancer death over time with increasing socioeconomic disadvantage (Tervonen et al. 2017).

Socioeconomic disadvantage is more common in people living in rural and remote areas and is associated with advanced cancer stage at diagnosis and poorer survival (Heathcote & Armstrong 2007). The correlation with poorer survival is not clear but some evidence aligns levels of income and education with cancer knowledge and health behaviours, affordability of care and ability to access the full spectrum of cancer detection and treatment services (Heathcote & Armstrong 2007). Often, low socioeconomic status groups have lifestyles with higher levels of smoking and obesity, do not participate in screening as readily, and may not be able to afford unsubsidised treatments such as high-cost drugs (Olver, Franca & Grogan 2011). Other cancer treatments not covered by the

Medicare Benefits Schedule, such as fertility preservation and dental reconstruction (e.g. after head and neck cancer treatment), mean that those who cannot afford it, go without.

Siahpush and colleagues (2011) point out that in countries such as Australia, in the mature and declining phases of smoking epidemics, socioeconomic status is strongly related to smoking behaviour. Fewer years of formal education, lower status occupation and lower income are associated with a higher prevalence of smoking (Siahpush et al. 2011). Further, evidence suggests that Australians with lower levels of education, those who are unemployed, or those living in socioeconomically disadvantaged neighbourhoods are more likely to be inactive or do low levels of physical activity (ABS 2011).

In 2009–2013, age-standardised incidence rates in Australia were higher in the lowest socioeconomic areas compared with the highest socioeconomic areas for bladder (19% higher), cervical (52% higher), colorectal (16% higher), head and neck (58% higher), liver (53% higher), lung (72% higher), oesophagus (47% higher), pancreatic (17% higher), unknown primary site (45% higher) and uterine (16% higher) cancers (AIHW 2014).

An extensive range of sociodemographic markers are considered in the VicHealth Indicators Survey 2015 (VicHealth 2016). Data analysis shows a clear social gradient in the indicators, with disadvantaged groups generally having the least favourable outcomes for health and wellbeing.

Data on the socioeconomic profile across Victoria indicates that almost 80 per cent of the most socially disadvantaged areas are rural. Table 1 indicates the highest ranked suburbs of socioeconomic disadvantage according to the SEIFA scale in Victoria (ABS 2016).

**Table 1. Suburbs with the highest social disadvantage in Victoria**

Rank	Suburb	Rural/metropolitan	Integrated cancer service
1	Laverton North	Metropolitan	WCMICS
2	Colac	Rural	BSWRICS
3	Norlane	Rural	BSWRICS
4	Pioneer Bay	Rural	GRICS
5	Loch Sport	Rural	GRICS
6	Coolaroo	Metropolitan	WCMICS
7	Broadmeadows	Metropolitan	WCMICS
8	Whittington	Rural	BSWRICS
9	Bearii	Rural	HRICS
10	Dallas	Metropolitan	WCMICS
11	Cann River	Rural	GRICS
12	Dunolly	Rural	LMICS
13	Paradise Beach	Rural	GRICS
14	East Bairnsdale	Rural	GRICS
15	Long Gully	Rural	LMICS
16	Frankston North	Metropolitan	SMICS
17	Skidders Flat	Rural	LMICS
18	Wychitella	Rural	LMICS
19	Korong Vale	Rural	LMICS
20	Golden Beach	Rural	GRICS
21	Corio	Rural	BSWRICS
22	Morwell	Rural	GRICS
23	Moe	Rural	GRICS



Rank	Suburb	Rural/metropolitan	Integrated cancer service
24	Doveton	Metropolitan	GRICS
25	Braeside	Metropolitan	SMICS
26	Coronet Bay	Rural	GRICS
27	California Gully	Rural	LMICS
28	Goldsborough	Rural	LMICS
29	Moliagul	Rural	LMICS
30	Nyah West	Rural	LMICS

**Note: Socioeconomic index for areas (SEIFA) is a product developed by the Australian Bureau of Statistics (ABS) that ranks areas in Australia according to relative socioeconomic advantage and disadvantage.**

**Abbreviations:** BSWRICS = Barwon South West Regional Integrated Cancer Service, GICS = Grampians Regional Integrated Cancer Service, GRICS = Gippsland Regional Integrated Cancer Service, HRICS = Hume Regional Integrated Cancer Service, LMICS = Loddon Mallee Integrated Cancer Service, NEMICS = North Eastern Melbourne Integrated Cancer Service, SMICS = Southern Melbourne Integrated Cancer Service, WCMICS = Western Central Melbourne Integrated Cancer Service

Interestingly, this ranking changes when accounting for the diversity of SEIFA scores in the same suburb (SA1 areas within suburbs). Table 2 shows suburbs with the most disadvantaged areas in the state. Seven of the top 10 areas are in inner-city Melbourne, challenging conventional thought around metropolitan versus regional advantage.

**Table 2. SA1s (sub-suburbs) with the highest social disadvantage in Victoria**

Rank	Statistical local area (SA1)	Regional/metropolitan	Integrated cancer service
1	Collingwood	Metropolitan	WCMICS
2	Ascot Vale	Metropolitan	WCMICS
3	Fitzroy	Metropolitan	WCMICS
4	North Melbourne	Metropolitan	WCMICS
5	Broadmeadows	Metropolitan	WCMICS
6	Flemington	Metropolitan	WCMICS
7	Wendouree	Regional	GICS
8	Warrnambool	Regional	BSWRICS
9	Morwell	Regional	GRICS
10	Richmond	Metropolitan	WCMICS
11	Mildura	Regional	LMICS
12	Long Gully	Regional	LMICS
13	Delacombe	Regional	GICS
14	West Wodonga	Regional	HRICS
15	Maryborough	Regional	LMICS
16	Laverton North	Metropolitan	WCMICS
17	Carlton	Metropolitan	WCMICS
18	South Yarra	Metropolitan	SMICS

Rank	Statistical local area (SA1)	Regional/metropolitan	Integrated cancer service
19	Horsham	Regional	GICS
20	South Melbourne	Metropolitan	WCMICS
21	East Bairnsdale	Regional	GRICS
22	Benalla	Regional	HRICS
23	Traralgon	Regional	GRICS
24	Corio	Regional	BSWRICS
25	Norlane	Regional	BSWRICS
26	Blackburn South	Metropolitan	NEMICS
27	Moe	Regional	GRICS
28	Shepparton	Regional	HRICS
29	Sale	Regional	GRICS
30	Colac	Regional	BSWRICS

**Abbreviations:** BSWRICS = Barwon South West Regional Integrated Cancer Service, GICS = Grampians Regional Integrated Cancer Service, GRICS = Gippsland Regional Integrated Cancer Service, HRICS = Hume Regional Integrated Cancer Service, LMICS = Loddon Mallee Integrated Cancer Service, NEMICS = North Eastern Melbourne Integrated Cancer Service, SMICS = Southern Melbourne Integrated Cancer Service, WCMICS = Western Central Melbourne Integrated Cancer Service

These findings highlight the need to focus on health equity to ensure that all Victorians have a fair opportunity to attain their full health potential.

## 2.4 Aboriginal population

Cancer is the second most common cause of death for Aboriginal Australians (20%), after cardiovascular disease (Cancer Australia 2018). In the absence of more complete data, the survival pattern we see in remote parts of Australia probably represents the cancer experience of Aboriginal Australians.

There are an estimated 51,000 Aboriginal Victorians. Just over half live in regional and rural areas (DHHS 2016). The evidence of variation in cancer outcomes for Aboriginal people in remote compared with metropolitan areas is limited but does suggest Aboriginal patients are less likely to survive their cancer the further they live from urban centres (Diaz et al. 2015).

For Aboriginal Victorians, there are over 110 new diagnoses of cancer each year, and over 50 cancer-related deaths (Thursfield & Farrugia 2014). Compared with non-Aboriginal Australians, Aboriginal people have higher levels of modifiable risk factors, including smoking, risky alcohol consumption, poor diet, low levels of physical activity and higher levels of infection such as human papillomavirus (HPV) and hepatitis B leading to higher incidence of preventable cancers that are more likely to be fatal (lung and liver cancer). They are also less likely to participate in cancer screening programs (breast, cervical and bowel) and are more likely to have a late-stage diagnosis of cancer. In women, the rates of cervical cancer are double those for non-Aboriginal women (Olver, Franca & Grogan 2011). Notably, there is a different pattern of cancer incidence, whereby for prostate cancer, colorectal cancer and lymphoma, the incidences are lower than those for non-Aboriginal people (Olver, Franca & Grogan 2011).

Overall, cancer incidence rates do not differ significantly between Aboriginal and non-Aboriginal Victorian men and women; however, mortality rates are much higher for Aboriginal Victorians than for non-Aboriginal Victorians (191.1 and 153.3 deaths per 100,000 respectively compared with 111.6 and 77.3 per 100,000 for non-Aboriginal men and women) (DHHS 2016). Cancer Council Victoria reports that the greater mortality rates may be associated with diagnosis occurring at a more advanced disease stage, and possibly reflects issues around timely access to treatment and insufficient participation in cancer screening services.

Although stage at diagnosis may partly explain the survival difference, the survival for most cancers, stage for stage, is inferior to that for other Australians (Olver, Franca & Grogan 2011). Aboriginal people are less likely to receive adequate treatment or be hospitalised for cancer (Olver, Franca & Grogan 2011). Between 1998 and 2012

there was a significant increase in the mortality rate due to cancer (16%); in the same period the cancer mortality rate for non-Aboriginal people fell significantly (by 10%) (Olver, Franca & Grogan 2011). A study in Queensland demonstrated that in terms of treatment, Aboriginal patients were 24 per cent less likely to receive surgery and waited longer for surgery, and were 20 per cent less likely to receive chemotherapy and 9 per cent less likely to receive radiotherapy (AIHW 2008).

Cultural barriers to the prevention, detection and treatment of cancer have also been identified. Cancer in Aboriginal culture may be ascribed to non-biological explanations, including retribution for past behaviour. Embarrassment and shame often prevent participation in screening programs such as those for breast or cervical cancer. The relocation for treatment away from home and community is both a barrier to care and a cause of discontinuity of care (Olver, Franca & Grogan 2011).

Cancer service providers' lack of knowledge about the needs of Aboriginal people with cancer has been identified as a major issue impeding communication and optimal health outcomes (Pilkington et al. 2017). The need for more culturally appropriate services is required across the continuum of cancer care from health promotion and prevention through to palliation (Cancer Australia 2018). The Aboriginal and Torres Strait Islander Cancer Framework prioritises a need to more effectively engage Aboriginal consumers who have or are at risk of cancer (Cancer Australia 2015).

## 2.5 LGBTI Victorians

The VicHealth Indicators Survey 2015 (VicHealth 2016) showed that some health inequities were evident between those who identify as heterosexual and those who identify as LGBTI. LGBTI Victorians fared more poorly on measures of general and mental wellbeing; reported lower levels of trust in, and connection to, their local communities; and were more likely to consume alcohol at potentially risky levels.

In terms of cancer, there is some evidence that people identifying as LGBTI suffer from cancer-related disparities, including lower rates of cancer screening, higher incidence of certain cancers and higher cancer mortality rates (Cathcart-Rake 2018).

Studies show that lesbian women have a higher prevalence of several important risk factors for cancer and poor mental health and functioning outcomes (Case et al. 2004; Brown et al. 2015). Some of these risk factors are modifiable (higher levels of alcohol consumption, smoking). An analysis of secondary data from the Australian Longitudinal Study of Women's Health found that lesbian and bisexual women did not have significantly higher cancer diagnoses compared with heterosexual women but were more likely to report never having a mammogram or cervical screening test (Brown et al. 2015). They were significantly more likely to be high-risk drinkers, current smokers and report higher rates of depression.

Gender identity disparities in cancer screening persist beyond known sociodemographic and healthcare factors. There are reduced lifetime rates of breast, cervical, prostate and colorectal cancer screening behaviours in LGBTI groups (Tabaac et al. 2018). LGBTI people report a reduced access to healthcare because of discrimination and lack of knowledgeable care (Tabaac et al. 2018).

The optimal care pathways point out that for some populations, including people who identify as LGBTI, a cancer diagnosis can come with additional psychosocial complexities and that discrimination uncertainty may also make these people less inclined to seek regular medical and gynaecological care. Sexual side effects, depression and social isolation are especially common among LGBTI individuals with cancer (Cathcart-Rake 2018).

The cancer-specific needs of LGBTI people remain understudied. Banergee and colleagues (2018) suggest the delivery of culturally competent care for LGBTI patients depends on effective communication from healthcare providers. Their study, which involved surveying over 1000 oncology healthcare workers, found an overall lack of medical knowledge and the need for more education about LGBTI healthcare (Banergee et al. 2018).

## 2.6 Elderly (those aged 80 years and older or particularly frail<sup>1</sup>)

With age comes an increased risk of cancer. Older adults account for 60 per cent of incidences of cancer and 70 per cent of cancer-related deaths in Australia (Ngugan 2014). In many rural areas, the proportion of older

<sup>1</sup> The existing evidence on elderly patients tends to categorise by age, presumably due to available data. However an assessment of frailty, as distinct from age, is increasingly being used to guide appropriate management.

Victorians is increasing. Over a 10-year period to 2025 (RWAV 2017), rural Victoria is projected to experience a significant growth in its older population, which far surpasses the Victorian average. By 2025, approximately 57 per cent of the north Bendigo region is projected to be over 65 years of age, which is a growth of 40 per cent since 2015. Another area with a high proportion of older Victorians, which is also projected significantly rise by 2025, is Maryborough.

Age-related factors such as late presentation and diagnosis, poor response to treatment, and complicated management due to comorbidities and functional status contribute to poor outcomes in older cancer patients (Ngugan 2014).

The treatment of individuals who are age 80 years and older, or particularly frail, is complex and involves clearly defining the value of treatment while also weighing risks, such as the potential effects of treatment on functional loss and quality of life (Shachar, Hurria & Muss 2016). The increased age-related prevalence of comorbidities and functional impairment among elderly patients may enhance the risk of treatment-related complications and the risk of mortality. Thus, comorbidities and functional status influence clinical decisions and the pattern of referral in elderly cancer patients (Repetto et al. 1998). Further, Repetto and colleagues (1998) suggest that it is possible that cancer is more likely to be diagnosed in healthier elderly, or that primary care providers are reluctant to refer patients in poor general health for cancer care (Repetto et al. 1998). This may be because comorbidity is associated with an increased risk of death from causes other than cancer.

Many older people newly diagnosed with cancer are taking multiple medications as well as complementary and over-the-counter medicines for comorbid conditions. The commencement of cancer treatment and associated medications to treat symptoms necessitates identification and management of polypharmacy (the use of multiple medications) (Lees 2013). Challenges for the medical teams who treat elderly patients with cancer include identification of what drugs are actually being taken by the patient, avoidance or management of any adverse effects or drug interactions, and reassessing the patient's overall treatment.

There are many interventions aimed at improving appropriate polypharmacy, including educational programs for prescribers, organisational interventions such as pharmacist-led medication review services or specialist clinics, clinical decision support systems, and risk screening tools (Lees 2013).

Limited evidence-based treatment guidelines exist for the caring of this older cohort of patients. There is little data on the effectiveness and toxicities of treatment in patients age 80 years and older, which leads to major therapeutic challenges (Shachar, Hurria & Muss 2016). Many studies suggest that the lack of evidence-based information concerning the treatment of elderly patients with cancer negatively affects clinical practice (Swaminathan & Swaminathan 2015; Marosi & Köller 2016). This prejudice is responsible for the exclusion of patients from surgery, radiotherapy and chemotherapy (Swaminathan & Swaminathan 2015).

Many validated tools to assess functional status are not as effective in older patients because comorbidities in the elderly may interfere with the measurement of performance status (Repetto et al. 1998). Shachar and colleagues (2016) regard performance status as a global estimation of function for older patients inadequate and points to the benefits of geriatric assessment being used to detect major problems to evaluate older patients with cancer before treatment initiation. This takes into account an evaluation of a patient's functional status, comorbidities, cognition, social support, nutritional status and psychological state as well as in the context of the patient's life expectancy and patient preferences (Shachar, Hurria & Muss 2016).

Another issue for elderly patients is their exclusion from most clinical trials, making it difficult to find evidence to support the management of this patient cohort (Shachar, Hurria & Muss 2016).

Hurria and colleagues (2015) set out the major drivers creating the need to generate more evidence on the treatment of older adults: the ageing population, the underrepresentation of older adults in clinical research and the clinical implications of the lack of evidence in older adults on the quality of care. In the Australian context, Ngugan (2014) points out the key challenge is data collection to enable informed decision-making regarding this group, and the development of standardised guidelines for cancer control, which will consider patients in terms of both their physiological and chronological age (Ngugan 2014). To address these gaps, an American Society of Clinical Oncology task force made a series of recommendations, including the use of clinical trials to improve the evidence base for treating older adults with cancer and increasing the recruitment of older adults with cancer to clinical trials (Hurria et al. 2015).

### 2.6.1 Social isolation and older people

Repetto and colleagues (2000) point to inadequate social resources in the over 80s age group preventing access to timely cancer care. Research suggests that social isolation impacts most on those people who are most vulnerable, namely older individuals (aged 75+) and young people (aged 15–25) (VicHealth 2018).

A robust body of scientific evidence indicates that social connectedness is associated with decreased risk for all-cause mortality as well as a range of disease morbidities (VicHealth 2018). Social support has been identified as an important contributor to general wellbeing that buffers the impact of stressful experiences, including those related to physical illness (Hoey et al. 2008). In cancer, low levels of social support have been related to higher rates of breast and colon cancers (Chida et al. 2008; Hoey et al. 2008).

The optimal care pathways (DHHS 2015–2018) emphasise that a cancer diagnosis is a major stressor that can lead to physical, emotional and social crises and, as a result, many cancer patients experience a range of psychosocial difficulties, including depression, anxiety, loneliness, uncertainty and loss of control, decreased self-esteem and fears about cancer recurrence. For example, a study found that social isolation was most commonly reported as a physical consequence of treatment and/or side effects of prostate cancer (Ettridge et al. 2018).

In the cancer setting, social support can be offered in a variety of forms, including psychotherapeutic programs such as supportive expressive group therapy, educational programs such as the Living With Cancer Education Program and peer-support programs.

Hoey and colleagues (2008) argue that despite mounting evidence that the magnitude of social isolation is comparable to that of many leading health determinants, there is little recognition of human social relationships as either a health determinant or risk marker comparable to that of other public health priorities.

## 2.7 People with mental health issues and comorbid health conditions

There is increasing evidence of significant inequalities experienced by people with severe mental illnesses. Some estimates suggest that lives of people with a severe mental illness are up to 30 per cent shorter than those of the general population whereby most of this excess mortality is a consequence of physical diseases including cancer (AHPC 2016). The evidence also suggests that this occurs because of poor management of the comorbid health conditions of serious mental illness and chronic diseases. Despite higher levels of ill-health, people with mental illness are also less likely to use all health services or adhere to medication and are more likely to be more particular about their healthcare provider (AHPC 2016).

There is a clear correlation between disadvantaged rural Victorian areas and high levels of mental health problems (RWAV 2017). According to Rural Workforce Agency Victoria (RWAV 2017), after arthritis, mental health problems are the most prevalent long-term condition affecting older rural populations. Persistent and significantly high rates of psychological distress were listed for people in the Western Victorian primary health network region, Gippsland East area, Wangaratta–Benalla, Bendigo and Murray River (RWAV 2017).

In terms of cancer, Chida and colleagues (2008) found that psychological distress is related to higher cancer incidence, poorer cancer survival and higher cancer mortality. Site-specific analyses indicate that psychosocial factors are associated with a higher incidence of lung cancer and poorer survival in patients with breast, lung, head and neck, hepatobiliary and lymphoid or hematopoietic cancers (Chida et al. 2008).

The Australian Health Policy Collaboration (2016) point out that given that mental health services in Australia are typically physically and culturally displaced from both primary and acute care health providers, the fragmentation of service that this generates for people with both serious mental illness and chronic physical health conditions, including cancer, presents particular navigation challenges for this population group. Research points to disparities in the level of healthcare (including cancer care) delivered to this group compared with the general population. The Australian Health Policy Collaboration report (2016) draws on extensive research, which implicates the attitudes of healthcare staff in inhibiting help-seeking by people with mental illnesses and physical health needs.

# Evidence of effective approaches for disadvantaged groups (literature review)

Section 3 documents existing care models at a national/international, state and local/ICS level that are aimed at accessing any one or all of the disadvantaged groups described in section 2, and at any point of the care pathway.

## 3.1 National and international initiatives

### 3.1.1 IMPACT (Innovative Models Promoting Access-to-Care Transformation)

Location	Australia and Canada
Target group	Vulnerable populations
Stage in cancer pathway	Primary care – not cancer specific
Mechanisms of engagement	<ul style="list-style-type: none"> <li>• Specific strategies to promote the active contribution of individuals with lived experience:</li> <li>• Local innovation partnerships</li> <li>• Formal integration of services</li> </ul>
More information	<a href="https://www.impactresearchprogram.com/scientific-articles">https://www.impactresearchprogram.com/scientific-articles</a> <a href="https://equityhealthj.biomedcentral.com/track/pdf/10.1186/s12939-016-0459-9">https://equityhealthj.biomedcentral.com/track/pdf/10.1186/s12939-016-0459-9</a>

IMPACT is a five-year research program that brings together researchers in primary healthcare, health services research and implementation science together with communities of practice in six regions in Australia, the United Kingdom and Canada (Richard et al. 2016). The aim is to identify and trial best practice innovations to assist access to primary healthcare, particularly for vulnerable populations.

An environmental scan was undertaken to identify innovations for improving access. Examples of the types of interventions identified in the environment scan are set out in Table 3.

**Table 3. Examples of types of interventions identified by the IMPACT program**

Name of intervention	Country (C) Setting (S) Target group (TG)	Description
PACER Model of Primary Mental Health Care	C: Australia S: Mobile service TG: Mental illness	A mobile emergency mental health program that teams a police officer with mental health training and an experienced mental health clinician to respond to mental health crises encountered by police. This program offers improved coordination between emergency services and the area of mental health services, and skilled in-time assessment, treatment and referral as appropriate.
The Alex Community Health Bus	C: Canada S: Mobile service TG: Homeless	A mobile clinic, providing healthcare services to low-income individuals and homeless people. Stops at a number of locations and provides healthcare and education services, and facilitates referrals to a wide range of primary healthcare and community organisations. It is also a roaming food bank.

Name of intervention	Country (C) Setting (S) Target group (TG)	Description
Bromley By Bow Health Centre	C: UK S: Community org. TG: All	A healthy living centre in a deprived area of East London offering a wide range of health services such as consultations with primary practitioners and psychologists, home visits, antenatal and baby clinics, family planning services, blood clinics, new patient health checks and nurse clinics.
Cool Aid Community Health Centre	C: Canada S: Community health centre TG: Mental illness, disability, addiction, homeless	A centre that provides primary healthcare, shelter services, health and dental care, mental health and employment support, food supplies, community engagement programs, outreach clinics, peer-based support groups, harm reduction services, onsite pharmacy with opiate substitution program, and group medical visits for individuals with complex social, psychiatric and medical needs. A multidisciplinary team provides the services. The approach includes a strong patient-centred vision, offering opportunities for patients to take part in their care and make decisions about their health.
MyGRiST	C: United Kingdom S: Online TG: Mental illness	An online tool designed to help people self-assess and manage risks and safety associated with their mental health problems, with the aim of promoting wellbeing. It is a companion tool to a suite of clinical tools that have been developed based on a model of clinical risk assessment. MyGRiST collects identical information to the clinical tools, but using language and a format co-designed with mental health service users. This helps empower patients and enables them to tell their story and communicate risk information to clinicians.
Diabetes Coordination and Assessment Service	C: Australia S: Phone based primary healthcare TG: Diabetes	A phone-based care coordination service aiming to promote chronic disease self-management (diabetes in particular) through screening, triage, assessment, coaching, referral and follow-up. It assists primary healthcare to connect people with services that correspond to their needs.
HOME study	C: Australia S: Home-based TG: Aboriginal people with complex chronic disease	Explores novel approaches to address chronic disease management in home-based outreach settings for Aboriginal people. The program involves the engagement of families in the management and prevention of chronic disease, comprehensive needs assessment (family health, social situation, physical healthcare needs and social and emotional wellbeing), and integration of health and health-related care delivery to patients and their families to improve health outcomes.
IMAGINE (Inter-professional Medical and Allied Groups for Improving Neighbourhood Environment)	C: Canada S: Community drop-in clinic TG: Marginalised	An inter-professional, student-run community health initiative aimed at promoting and providing holistic healthcare to neighbourhoods in Toronto. It offers outreach activities with community partners as well as health promotion educational workshops with clients.
AMP (Access to Mental health in Primary care)	C: UK S: Different health and community settings TG: under-served groups	Aims to increase access to high-quality primary care mental health services for people from under-served groups. It provides services that are based on a patient-centred and culturally responsive approach. The AMP model comprises community engagement, primary care quality and psychosocial interventions.

Name of intervention	Country (C) Setting (S) Target group (TG)	Description
The Kalwun Development Corporation	C: Australia S: Community health service TG: Aboriginal people	Provides services to Aboriginal people, based on a community controlled, designed and led approach to the delivery of accessible, efficient, effective and appropriate comprehensive primary healthcare. It offers a combination of primary healthcare and community-based services such as access to GPs, comprehensive screening, onsite allied health services, mobile outreach medical clinic, immunisation and transport services. It also offers a program of care coordination to support patients with chronic diseases in accessing necessary services.
Multicultural Health Brokers	C: Canada S: Community organisation TG: Immigrants and refugees	Supports families that are new to Canada. The brokers are a group of 54 people who represent 22 different cultural and linguistic communities in Canada. The organisation offers a wide range of programs that cover social and healthcare needs.
Youth projects – The Living Room Primary Health Service	C: Australia S: mobile/ outreach TG: Homeless	A primary health service that provides free healthcare and a wide range of services to improve the physical, mental and social wellbeing of individuals who are homeless, with complex healthcare needs. It uses outreach to respond to the after-hours healthcare needs of the homeless community, delivering services in public spaces and crisis accommodation.
The Blue Mountains Aboriginal Healthy for Life program	C: Australia S: partnership community organisations, community health centres, general practice TG: Aboriginal people	An Australian Government program that is aimed at enhancing the quality of life and health outcomes of Aboriginal people living with chronic and complex illnesses, and to reduce the incidence of such illnesses over time. The team is made up of two registered nurses, a male and female Aboriginal outreach worker, an Aboriginal child and family worker, a Healthy for Life practice/project support officer and a program manager. The team assists by meeting in the family home or other preferred location to discuss health issues, providing a link to health professionals, doctors or specialists, and arranging regular health checks and transportation to health appointments.

The IMPACT authors concluded that similar interventions tended to occur in similar settings, directed at similar target groups and used comparable funding sources, suggesting that different countries may be struggling with common access-related issues, despite their own specific contextual considerations (Richard et al. 2016).

### 3.1.2 Nurse navigators

Location	Canada
Target group	Vulnerable groups and complex health needs
Step in cancer pathway	All
Mechanisms of engagement	<ul style="list-style-type: none"> <li>• Education framework to guide competency development for nurses</li> <li>• Current state review</li> <li>• Provincial program coordination and standards</li> <li>• Co-design of the navigation role with cancer care operational leaders</li> <li>• Development and utilisation of a standardised training and coaching program identification of barriers in each setting with associated strategies to manage them</li> <li>• Development of program metrics</li> <li>• Evaluation: Focus groups, patient surveys, nurse reflective practice surveys, navigator workload measures, health system utilisation data</li> </ul>



Location	Canada
More information	<a href="http://www.canadianoncologynursingjournal.com/index.php/conj/article/view/693/662">www.canadianoncologynursingjournal.com/index.php/conj/article/view/693/662</a> <a href="https://www.researchgate.net/publication/309448852_Developing_a_Provincial_Cancer_Patient_Navigation_Program_Utilizing_a_Quality_Improvement_Approach_Part_Three_Evaluation_and_Outcomes">https://www.researchgate.net/publication/309448852_Developing_a_Provincial_Cancer_Patient_Navigation_Program_Utilizing_a_Quality_Improvement_Approach_Part_Three_Evaluation_and_Outcomes</a> [accessed Dec 18 2018].

This program involves ‘navigators’ (usually oncology nurses) who work with patients and families to assess needs, provide supportive care, answer questions, identify and address any barriers to quality care, and facilitate access to needed resources and services (So et al. 2016). The navigation model meets the needs of the local population and is designed to fit within existing cancer services. Nurse navigators are placed at different points along the cancer trajectory, in various care settings (rural, urban, community, hospital) and to serve diverse populations (grouped by type of cancer, vulnerable groups, or complex health needs).

### 3.1.3 The Australian Centre for Social Innovation (TACSI)

Location	Australia (Adelaide based)
Target group	Disadvantaged, elderly, people with illness of social origin (loneliness, obesity, poverty)
Step in cancer pathway	Not cancer specific
Mechanisms of engagement	Service design, policy and commissioning, systems innovation, funding innovation, building skills for innovation
More information	<a href="https://www.tacsi.org.au/work/">https://www.tacsi.org.au/work/</a>

The Australian Centre for Social Innovation (TACSI) works in breaking cycles of disadvantage and welfare dependency, solving housing stress for people as they age (‘redesigning ageing’) and using social innovation to improve health outcomes. TACSI partners with health organisations to develop peer support models, improvement systems using co-design and commissioning that encourages self-management of individual and community health. Innovative solutions include:

- a peer-to-peer model of carer support that is being trialled in caring situations involving cognitive decline and palliative care – the model creates positive outcomes for the supporting peer and the carer, including mental health outcomes
- a collaborative project between three South Australian disability service providers to design and test a shared service approach to better coordinate after-hours, on-call support
- the Regional Innovators Network (RIN) to develop regionally relevant social innovation resources, strengthen the skills and confidence of community workers, and support peer-to-peer connections between community workers across regions
- an online platform that provides access to learning content and growing the body of knowledge on what it takes to do innovation work in regional and rural communities.

### 3.1.4 Regional cancer centres

Location	Australia
Target group	Regional and rural cancer patients
Step in cancer pathway	Secondary care
Mechanisms of engagement	Service design, policy and commissioning
More information	<a href="https://www2.health.vic.gov.au/about/health-strategies/cancer-care/regional-cancer-centres">https://www2.health.vic.gov.au/about/health-strategies/cancer-care/regional-cancer-centres</a>

In the 2009–2010 Budget, the Australian Government committed \$1.3 billion to build new regional cancer centres around Australia. In Victoria, centres were built/upgraded in Ballarat, Bendigo, Traralgon, Gippsland and Wodonga. The regional cancer centres are the cornerstone of regional cancer care in the Victorian cancer system and plan and deliver services based on their size and capability to safely provide specialist cancer care. However, workforce and infrastructural barriers persist.

### 3.1.5 Capability and service mapping

Location	Australia
Target group	All/regional/rural
Step in cancer pathway	Secondary care
Mechanisms of engagement	n/a
More information	Not published

Implementing a Clinical Services Capability Framework (CSCF) across Victoria to inform referral pathways is a focus area of the Victorian Cancer Plan 2016–2020. A pilot CSCF is being developed as part of an agreed national work plan for a systematic and robust approach to delivering safe and sustainable cancer services. It seeks to promote a system that supports clinical management and decision-making through an understanding of the supports required to enable cancer patients to be safely treated in which locations as appropriate.

The draft pilot CSCF defines the Victorian minimum requirements for cancer services for the safe provision of different levels of care by defining the scope of service, staffing, infrastructure and clinical support services, thus promoting greater consistency in how to map and describe cancer services across jurisdictions. It is intended to define the minimum requirements for cancer services to provide progressively higher and more complex levels of care.

### 3.1.6 Primary health networks

Location	Australia
Target group	Disadvantaged groups
Step in cancer pathway	Prevention and screening (not cancer specific)
Mechanisms of engagement	Service design, policy and commissioning
More information	<a href="http://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Home">www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Home</a>

In 2015, the Australian Government established 31 primary health networks across the country to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor outcomes. From 2016, primary health networks moved from delivering health services directly to the community to delivery through a commissioning approach. Needs-based commissioning includes analysing population health data and providing services to address mental health, chronic disease, alcohol and other drugs, cancer screening and Aboriginal health.

### 3.1.7 Culture is Healing

Location	Australia
Target group	Aboriginal people
Step in cancer pathway	Secondary care
Mechanisms of engagement	Think tank, national reference group, memorandum of understanding, education and training of workforce, social media platforms
More information	<a href="https://www.bcna.org.au/media/4769/action-plan-9-may-v4.pdf">https://www.bcna.org.au/media/4769/action-plan-9-may-v4.pdf</a>

The program, from Breast Cancer Network Australia, aims to create culturally appropriate spaces in treating hospitals, to encourage Aboriginal women with breast cancer to return to the facility knowing it is a culturally safe space. This will increase survivorship rates among Aboriginal women with breast cancer and other cancers.

The program was initiated with a two day think tank that brought together 48 Aboriginal women who had had breast cancer. The think tank gathered insight from their own communities and discussed how outcomes could be improved.

Recent local initiatives as part of the program include, at Peter MacCallum Cancer Centre in Victoria, a possum skin cloak was made available to all Aboriginal patients undergoing cancer treatment. The possum skin cloak is

of cultural significance to communities throughout Victoria. In Queensland, a weaving workshop was held with Aboriginal breast cancer survivors and the art was gifted to the oncology ward of the local hospital most used by Aboriginal women.

Breast Cancer Network Australia has also created an online platform for Aboriginal people affected by breast cancer.

## 3.2 State initiatives

### 3.2.1 The Aboriginal Collaborative Grants Program

Location	Victoria
Target group	Aboriginal people
Step in cancer pathway	All
Mechanisms of engagement	Guidelines and criteria
More information	<a href="http://www.victoriancanceragency.org.au/index.php/2018funding-round/improving-cancer-outcomes-for-aboriginal-victorians">www.victoriancanceragency.org.au/index.php/2018funding-round/improving-cancer-outcomes-for-aboriginal-victorians</a>

The Improving Cancer Outcomes Collaborative Research Grants are designed to support the acceleration of translational cancer research in areas of unmet need to ultimately reduce the disparities in outcomes for certain cancers and/or populations. The Aboriginal Collaborative Grants Scheme aims to drive collaborative research and promote effective translation of research into health policy and/or practice across Victoria with the specific aim of improving cancer outcomes for Aboriginal Victorians.

### 3.2.2 The G21 Regional Opportunities for Work (GROW) Initiative

Location	Geelong
Target group	Disadvantaged groups
Step in cancer pathway	Other sector
Mechanisms of engagement	Co-design, demand-led employment brokerage, development of a shared measurement framework, utilisation of collective impact framework
More information	<a href="https://grow.g21.com.au/">https://grow.g21.com.au/</a>

The initiative is based on the premise that place-based disadvantage can be changed through active collaboration across sectors with effective resourcing and investment. It is based on the ‘collective impact theory’, which acknowledges a multisector approach to address entrenched social issues.

In Geelong, GROW seeks to address joblessness in areas of high unemployment (including Colac, Norlane/Corio and Whittington). It is based on significant international evidence that the best way to reduce areas of persistent disadvantage in a community is to reduce unemployment rates in those areas.

It is in the start-up phase of a 10-year plan with 57 local businesses involved. Initiatives include:

- regional procurement economic modelling to collect key baseline data and set regional targets and development of a social procurement toolkit with tools and tips on how to reach targets
- development of a regional local supplier platform and Regional Innovative Procurement Program (GRiPP), including linking procurers and suppliers with employment and training brokers
- tracking change in local spend by partner organisations on a regional shared measurement dashboard as part of a broader aim to ensure public and private sector organisations in the region understand the value of their procurement spend to increase local content and target social outcomes
- a joint longitudinal study investigating individual and systemic barriers to employment and a study to map employment programs in the region.

### 3.2.3 Local Health District Demonstrator Sites

Location	New South Wales
Target group	Comorbidity / complex needs
Step in cancer pathway	Primary care, not cancer specific
Mechanisms of engagement	<p>Large investment</p> <p>Design of statewide enablers: risk stratification, patient reported outcome and experience measures, e-enablement</p> <p>Local enablers: selection of patient cohort informed by local population health needs assessment, identification of individual patients via routine data collection and additional screening tool, patient consent, patient matching to relevant intervention; clinical repositories for information share</p>
More information	<a href="https://www.health.nsw.gov.au/integratedcare/Publications/strategic-framework-for-integrating-care.PDF">https://www.health.nsw.gov.au/integratedcare/Publications/strategic-framework-for-integrating-care.PDF</a>

The NSW Government has committed \$180 million over six years to implement innovative, locally led models of integrated care across the state to transform the healthcare system. It is across three areas:

1. three integrated care demonstrators – large-scale integrated care initiatives in partnership with other sectors in Western Sydney, Central Coast and Western NSW (representing metropolitan, regional and remote rural areas).
2. 17 projects across local health districts and specialty health networks that are not demonstrators
3. Information technology systems including Health-eNet, linking patient information between hospitals and primary care.

Successful approaches to integrated care will be scaled up and rolled out across the state. Demonstrator projects are summarised as follows.

- *Southern NSW – Innovation and Integration:* Developing a model responsive to the needs of aged ‘chronic and complex’ patients in Eurobodalla. The ‘rapid response’ model of care enables responding to people who require urgent intervention to stay healthier at home (and avoid hospital admission). The pilot focuses on aged patients but will extend to vulnerable families and other groups across the district.
- *Illawarra Shoalhaven – Geriatrician in the Practice:* The program is supporting GPs and practice nurses to increase their skill set in assessing and managing dementia. The initiative involves a geriatrician and dementia clinical nurse consultant accompanying the GP and practice nurse in their rooms and providing a joint, integrated GP and specialist appointment, more easily accessible for patients.
- *Central Coast – Commissioning of care coordination for vulnerable older people in North Wyong:* care coordination for 600 vulnerable older people has been commissioned with a focus on redirecting patients to more appropriate locations of care. The outcomes-based commissioning model gives a higher payment to providers based on outcome (reduced unplanned bed days) rather than activity (care coordination) undertaken.
- *Central Coast – Central Coast Alternative Pathway Initiative:* A training program for local paramedics and GPs on diversion pathways to avoid hospital presentations for low acuity patients.
- *Western NSW – Meeting the Needs of Rural and remote Communities:* The district is testing innovative care models across 10 demonstration sites. The focus is on tailoring existing healthcare services to meet the needs of rural and remote communities. A simplified risk stratification process is used to select patients and e-health technologies and remote monitoring tools have been developed.

### 3.2.4 Cancer Data and Aboriginal Disparities (CanDAD) Project

Location	South Australia
Target group	Aboriginal people
Step in cancer pathway	Secondary care
Mechanisms of engagement	<ul style="list-style-type: none"> <li>• Pilot projects for the advanced cancer data system (ACaDS) and the Aboriginal cancer stories study (ACceSS)</li> <li>• Data integration</li> <li>• Recruitment through care coordinators</li> <li>• Narratives from Aboriginal people with cancer collected and analysed using patient pathway mapping and thematic analysis</li> <li>• Developed a protocol for linking each case</li> <li>• Aboriginal community engagement</li> </ul>
More information	<a href="https://bmjopen.bmj.com/content/6/12/e012505">https://bmjopen.bmj.com/content/6/12/e012505</a>

The project aims to develop an integrated, comprehensive cancer monitoring and surveillance system for Aboriginal people in South Australia that incorporates epidemiological and narrative data to address disparities and advocate for clinical system change (Yerrell, Roder & Cargo 2016). Routinely collected unit record data from the South Australian Population Cancer Registry will be integrated with a range of other data sources for a cohort of Aboriginal people with cancer.

Narratives from Aboriginal people with cancer, their families, carers and service providers will be collected and analysed using patient pathway mapping. This will inform the development of a real-time Aboriginal Cancer Measure of Experience for ongoing linkage with epidemiological data in the advanced cancer data system.

### 3.2.5 Health Translations

Location	Victoria
Target group	Culturally diverse populations
Step in cancer pathway	Not cancer specific
Mechanisms of engagement	Promotional collateral publically available for organisations to download
More information	<a href="http://healthtranslations.vic.gov.au/">http://healthtranslations.vic.gov.au/</a>

Health Translations is an initiative of the Victorian Government. It is a web portal that provides direct links to reliable translated health resources produced in Australia to enable health practitioners and those working with culturally diverse communities to easily find translated health information. Links are to multilingual resources published by government departments, peak health bodies, hospitals and community health and welfare organisations. The overarching aim is to improve the health and wellbeing of people from culturally diverse backgrounds.

### 3.2.6 Rural Health Outreach Fund

Location	Victoria
Target group	Regional and rural
Step in cancer pathway	Not cancer specific
Mechanisms of engagement	Partnership building, advocate to government, development of integrated rural generalist pathways
More information	<a href="https://www.rwav.com.au/">https://www.rwav.com.au/</a>

The Rural Health Outreach Fund provides funding to outreach health services to improve the health outcomes for people living in regional, rural and remote locations. These services are delivered by health professionals in the four priority areas of maternal and paediatric health, mental health, chronic disease management support, and eye health.

In Victoria, the fund is administered by the Rural Workforce Agency Victoria, and in the 2016–2017 financial year, the program contracted 192 providers across 27 health disciplines to deliver 2584 visits across Victoria. The program is targeted in areas of high need or health inequalities. There are also pockets of community outreach services provided by individual health services in the chronic diseases space.

### 3.2.7 Telehealth specialist initiatives

Location	Victoria
Target group	Regional and rural
Step in cancer pathway	Not cancer specific
Mechanisms of engagement	<ul style="list-style-type: none"> <li>• Education: learning modules for setting up telehealth</li> <li>• Database of protocols for participating health services</li> <li>• Hardware (Polycom desktop and mobile installations)</li> <li>• Allocated clinical time and resources</li> </ul>
More information	<a href="https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/telehealth/telehealth-projects">https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/telehealth/telehealth-projects</a>

Telehealth is a proven mechanism to help combat issues of access to services and provide specialist support for remote sites. Telehealth facilities allow regional sites to link to tertiary metropolitan centres for multidisciplinary team discussion as well as offer in-home monitoring of patients, allowing better management of chronic diseases in rural areas.

The Victorian Department of Health and Human Services funds a number of telehealth specialist initiatives to address community need:

- Alfred Health works in collaboration with partners at Mildura Base Hospital, Central Gippsland Health Service, Peninsula Health and Warrnambool Base Hospital to introduce telehealth for patients requiring burns, infectious disease, lung transplant, orthopaedics, gastroenterology, dialysis and HIV services.
- Austin Health works in collaboration with Bendigo Health and Murray primary health network to upscale the Victorian Respiratory Support Service and Victorian Spinal Cord Service.
- Barwon Health provides telehealth access in the Barwon region to specialist clinics.
- Bendigo Health Care Group has a telehealth community of practice, with an initial focus on paediatrics, respiratory medicine, endocrinology and genetics.
- Monash Health collaborates with Latrobe Regional Hospital, Bass Coast Health, Bairnsdale Regional Health and Central Gippsland Health Service to increase telehealth consultations for paediatric specialists' clinics.
- Peter MacCallum Cancer Centre provides specialist oncology outreach services in the Loddon–Mallee region (Bendigo Health and Mildura).

Telehealth requires a certain level of literacy, excluding some disadvantaged populations. Also, funding barriers remain with restrictive criteria for Medicare Benefits Schedule billing. Expanding telehealth hardware infrastructure and maintaining Medicare telehealth incentives will ensure the strength of this modality.

## 3.3 Local/ICS initiatives

### 3.3.1 'Hard to Reach' Consumers Study

Location	NEMICS – Northern-metropolitan Melbourne and Shepparton
Target group	Culturally diverse and Aboriginal people
Step in cancer pathway	All
Mechanisms of engagement	Semi-structured interviews, focus groups
More information	<a href="https://www.researchgate.net/publication/242698042">https://www.researchgate.net/publication/242698042</a>

CanNET Victoria commissioned the Health Issues Centre to examine the experiences of 'hard to reach' consumers accessing cancer services from the northern-metropolitan regions of Melbourne and the Shepparton region. The

aim was to develop a consumer participation strategy that ensures effective input and participation of ‘hard to reach’ consumers in the CanNET project. The target groups were:

- the Italian community in Shepparton
- the Aboriginal community at Rumbalara community in Shepparton
- the culturally diverse group in the catchment area of the Northern Hospital
- a group of ‘hard-to-reach’ urban consumers.

A number of themes emerged in relation to different aspects of their cancer experience, including low uptake of supportive care services, a lack of post-discharge support, challenges associated with language, low uptake of the Victorian Patient Transport Assistance Scheme (VPTAS), and a perception those who accessed the private health system received better quality of care (Health Issues Centre 2009).

The 2009 report resulted in the development of an ICS consumer participation toolkit (refreshed in 2018), an advocacy campaign to influence reform of the VPTAS system, a community ambassador program (rolled out across other ICS), ‘A common path’ videos with subtitles in other languages, and development of pictorial (rather than language other than English) treatment plans.

### 3.3.2 Better Care Victoria Grants

Location	LMICS
Target group	All
Step in cancer pathway	Supportive care
Mechanisms of engagement	Various
More information	Not published

Several grant projects provide examples of models to improve access to services in the Loddon–Mallee region. The first involved two medium-sized hospitals in the Loddon–Mallee region collaborating to Medicare Benefits Schedule (MBS)-fund an exercise physiologist in their catchment. Referrals were not being made on the basis that the target patients did not have a GP-initiated referral (i.e. a chronic disease management plan (CDMP)) (a prerequisite for MBS-billed referrals). The model involved recruiting patients direct from the Chemotherapy Chair and asking their GP in real time to produce a CDMP, which enabled the patient to have six MBS-funded exercise physiology sessions. The project also educated GPs that cancer patients are eligible for CDMPs on the basis cancer is a chronic disease. The outcome was making a new service available that wasn’t otherwise, as neither patients nor GPs would have requested it.

Another Loddon–Mallee based Better Care Victoria Grants initiative is a discharge planning service whereby a nurse practitioner completes a survivorship care plan and provides post-treatment referrals to exercise physiologists and dietetics for women with breast cancer.

### 3.3.3 Aboriginal Services Pamper and Paps Day

Location	LMICS
Target group	Aboriginal people
Step in cancer pathway	Screening
Mechanisms of engagement	Incentives to book pap (pamper packs)
More information	<a href="https://www.mdas.org.au/getattachment/ABOUT-MDAS/MDAS-Annual-Reports/MDAS_AnnualReport_2017_FA_01_WEB.pdf.aspx">https://www.mdas.org.au/getattachment/ABOUT-MDAS/MDAS-Annual-Reports/MDAS_AnnualReport_2017_FA_01_WEB.pdf.aspx</a>

A service-level example that demonstrates a novel approach to increasing cancer prevention and screening among vulnerable consumers is the Mallee District Aboriginal Services Pamper and Paps Day in Mildura. The goal was to provide a culturally appropriate forum in which local Aboriginal women could discuss health concerns and receive information about cancer, and ultimately to increase uptake in pap screens. The community gathered in a culturally appropriate place with an incentive in the form of a ‘pamper pack’ and meal. Although women who attended were also booked in for a pap smear with a female GP, this was not the focus.

Sixty-seven women attended and overall, pap smear uptake increased by 50 per cent (Health Consult 2017). This initiative formed part of a series of initiatives such as improving recall and reminder systems at the health centre. It is feasible that the event also increased referrals through word of mouth.

### 3.3.4 Population-based registry data modelling on socioeconomic indicators

Location	BSWRICS
Target group	Socioeconomic status
Step in cancer pathway	Outcomes/data
Methods of engagement	Retrospective data analysis
More information	Not published

This local report used population-based registry data to examine improvement in short-term survival between 2009–2010 and 2014–2015 across a range of socioeconomic indicators. Overall, there was no or little improvement in outcomes reported for those patients in the lowest socioeconomic group. There were improvements in people aged over 70 years, middle and upper socioeconomic status, and by tumour stream. A manuscript is currently being developed.

### 3.3.5 Ophelia (Optimising Health Literacy and Access)

Location	GICS
Target group	People with low health literacy
Step in cancer pathway	Primary and secondary care
Mechanisms of engagement	<ul style="list-style-type: none"> <li>Needs assessment using a health literacy questionnaire, workshops, community profiling, interviews</li> <li>Co-creation of intervention plans</li> </ul>
More information	<a href="https://bmcpublihealth.biomedcentral.com/articles/10.1186/1471-2458-14-694">https://bmcpublihealth.biomedcentral.com/articles/10.1186/1471-2458-14-694</a>

The project explored health literacy and related factors that may contribute to observed higher incidence of cancer and cancer mortality in the Grampians region. It comprised a survey of 1698 adults using the health literacy questionnaire.

Phase 1 identified the health literacy needs and strengths of the local community. Phase 2 and 3 used the data gathered and relationships established during Phase 1 to empower and equip local stakeholders to produce and implement fit-for-purpose, integrated and scalable interventions.

### 3.3.6 Western Alliance: Development of a Grampians Small Towns Cancer Strategy

Location	GICS
Target group	People with low health literacy
Step in cancer pathway	Primary and secondary care
Methods of engagement	Community based participation – co-design workshops
More information	<a href="http://www.gics.com.au/reports.php">www.gics.com.au/reports.php</a>

This project built on the Ophelia project and engaged two communities with populations less than 1000 that have relatively low health literacy compared to other sub-regions in the Grampians region. The co-design process sought to engage local GPs, cancer services and other health services, local pharmacists, community groups and local businesses.

The project developed a framework and toolkit to guide small town service development across the region and potentially the state. Apart from the value of the activities, the process stimulated discussion about cancer in the communities and promoted interaction between the communities and local cancer services.



Anecdotally, the project highlighted the importance of social supports and capacity to navigate a service system as key elements of health literacy (not just about accessing information).

### 3.3.7 Geriatric Oncology Clinic

Location	SMICS – Monash Health
Target group	Elderly (over 70 years)
Step in cancer pathway	Secondary care
Mechanisms of engagement	Triage tool, build on existing service provision
More information	Not published

The clinic has been funded through the ICS and is available to anyone over 70 or who is particularly frail. The clinic is run with an existing oncology clinic and a specialist oncologist. Patients are triaged based on age and vulnerability and are given a comprehensive geriatric assessment (modified by SMICS based on an international counterpart). The purpose is to identify supportive care needs, polypharmacy, optimal treatment plan, and referral to geriatric oncology or a geriatrician. There are also linkages to community services. Currently the specialist geriatric oncologist works across tumour streams. There is potential for broader rollout and the development of a multidisciplinary geriatric clinic.

### 3.3.8 Shared Care Mental Health Pilot

Location	SMICS – Cabrini and Peninsula Health
Target group	Mental health
Step in cancer pathway	Supportive care
Mechanisms of engagement	GP education, build on existing service provision
More information	Not published

A shared care model in its early phases for people with cancer and suffering depression is being trialled at two SMICS health services. The proposed model is for patients to see a psycho-oncologist in the acute sector then referred out to primary care (a community health service with GPs and psychologist service) with the option for linking in via telehealth with the referring psycho-oncologist. Simultaneously, work is underway on educating GPs about when a referral might be required.

### 3.3.9 Parkville Precinct Aboriginal Health Directorate

Location	WCMICS – Parkville Precinct
Target group	Aboriginal people
Step in cancer pathway	Secondary care
Mechanisms of engagement	Gap analysis self-assessment, nominated health service representatives, quantitative data collection via cultural safety self-evaluation tool, qualitative data collection via guiding interview, thematic analysis methodology
More information	Project report available (not published)

Peter McCallum Cancer Centre, the Royal Melbourne Hospital and The Women's are establishing a Parkville Precinct Aboriginal Health Directorate – a collaborative operating service model that will support culturally safe, accessible, quality care for Aboriginal people.

WCMICS conducted initial scoping activities, and two consistent themes emerged across the partners: improving Aboriginal patient identification on admission/presentation to hospital, and improving cultural safety with healthcare providers.

Short-term recommendations (for each health service) include:

- developing a reconciliation action plan
- individual health service Indigenous employment strategies

- cross-cultural awareness and training
- improving Indigenous patient identification and access in the acute public healthcare setting.

Long-term recommendations for consideration and implementation (collaboratively) include:

- collaborative Parkville Precinct Aboriginal health workforce
- Indigenous health workers support network
- case management and care coordination – outreach
- building and establishing relationships with key stakeholders in relation to the Aboriginal community
- establishing a Parkville Precinct Aboriginal Health Directorate: a collaborative, culturally safe, non-clinical environment.

### 3.3.10 Regional:Metropolitan Interface Study

Location	WCMICS/LMICS
Target group	Rural/regional
Step in cancer pathway	Secondary care
Methods of engagement	Greenfields approach, stakeholder consultation, standardisation of forms, pathway mapping
More information	End stage 1 report available (not published)

Consultation with key stakeholders identified deficits in the two-way transfer of patient information between LMICS and WCMICS. This study focused on the transfer of patients and patient information at key care transition points, and on clinical supportive care during treatment. A list of proposed interventions were considered, resulting in the formulation of three priority interventions:

1. governance of haematology specialist outreach services
2. communication of patient information at the conclusion of active cancer treatment
3. rapid referral to specialist gynaecology care for Loddon–Mallee region residents with high suspicion of ovarian cancer.

In addition, the feasibility of a number of initiatives to establish connections with, and build relationships between, metropolitan and regional clinicians and services is being investigated. These include:

- building an interactive map of Loddon–Mallee region cancer services
- preliminary work in collaboration with the Department of Health and Human Services Supportive Care Resources Refresh Project to develop a resource that introduces Loddon–Mallee region residents to the metropolitan/regional haematology care team
- forums that introduce metropolitan and regional haematology clinicians and that facilitate exploration of opportunities for enhancement of an integrated networked model of care
- collaborative exploration with clinical trials stakeholders of practical opportunities to address barriers to Loddon–Mallee region resident participation in haematological clinical trials.

Scalable recommendations and pilots will form a solid foundation for further expansion and application across other tumour streams and health services.

### 3.3.11 Identifying gaps in cancer care for Victorian prisoners

Location	WCMICS – St Vincent’s Hospital and Peter MacCallum Cancer Centre
Target group	Prisoners
Step in cancer pathway	All
Methods of engagement	Data audit
More information	Project report available (not published)

Incarcerated patients are considered a vulnerable population in the healthcare system, with higher rates of drug and alcohol misuse, mental illness, and medical comorbidity. With a growing and ageing prison population in Australia, there is also a growing burden of cancer-related care. St Vincent’s Hospital provides specialist healthcare to Victoria’s prison population.

WCMICs undertook a study into gaps in cancer care. The most concerning was relating to timeliness of treatment (particularly in relation to commencement of neoadjuvant chemoradiation or adjuvant chemotherapy for colorectal carcinoma, or definitive treatment for lung cancer or hepatocellular carcinomas).

A number of changes in hospital practice were recommended that could be applicable to other 'access to care' scenarios:

- introduction of telehealth in 15 correctional facilities, appropriate for any patient not requiring intravenous treatment or testing at the hospital
- development of a strategy to increase the use of regional facilities for medical imaging to improve completion rates of tests by avoiding the need for patients to be processed through the prison, addressing issues of transport/security and patient refusal
- auto-faxing of discharge summaries from St Vincent's Hospital secure inpatient ward to the prison medical centre on the day of discharge to enable improved clinical handover
- education of hospital staff to improve understanding of the issues specific to this group of patients
- a prison nurse care coordinator to oversee and coordinate the care of any complex prisoner.

### 3.3.12 Gippsland Survivorship Grant

Location	GRICS – East Gippsland
Target group	Aboriginal people
Step in cancer pathway	All
Methods of engagement	<ul style="list-style-type: none"> <li>• New referral and communication structures, systems guidelines and protocols, assessment resources</li> <li>• Clinician education</li> <li>• Patient self-management training</li> </ul>
More information	<a href="https://grics.com.au/wp-content/uploads/2017/01/Survivorshop-Presentation_MI-October-17.pdf">https://grics.com.au/wp-content/uploads/2017/01/Survivorshop-Presentation_MI-October-17.pdf</a>

Gippsland ICS has developed a shared care survivorship program between oncology specialists and primary healthcare providers and a plan to build Gippsland workforce capacity to manage survivorship care. It includes development of an Aboriginal survivorship model to address the specific needs of Aboriginal people in relation to cancer care, treatment and survivorship. Yarning circles have been used to enable this component – an ancient Aboriginal approach to sharing knowledge using mutual respect for all participants. The circles provided valuable insights into the needs of Aboriginal people in hospitals and during cancer treatment, including issues in relation to men's and women's business.

### 3.3.13 Gippsland Oncology Teletrials model

Location	GRICS – Monash and Latrobe
Target group	Regional and rural
Step in cancer pathway	Secondary care
Methods of engagement	Telehealth, build on existing service provision
More information	Not published

Monash and Latrobe Regional Health Service are in the initial stages of piloting a teletrials model to offer four clinical trials to patients from the Gippsland region that do not currently have access to trials. The pilot involves low risk trials, delivered locally utilising telehealth as required. Two fellows will rotate placements between the metropolitan and regional sites to oversee the trials and a clinical coordinator will be appointed at both sites. Latrobe will also recruit a clinical trials nurse. Local GPs will be involved as appropriate.

# Discussion

Section 2 provided a literature scan of variations in cancer outcome in particular disadvantaged groups across Victoria. Identifying variations in cancer outcomes triggers the investigation of causes and thus allows the identification of solutions (Olver, Franca & Grogan 2011).

Section 3 documented effective interventions at a national/international, state and local/ICS level. Evidence of effective interventions across these domains is limited. However, key themes emerged in the literature. Section 4 provides a broad identification of key themes emerging to inform possible approaches and areas of focus to improve outcomes for disadvantaged groups across Victoria.

## 4.1 Increased investment in 'demand'-side interventions

Trying to enhance patients' and populations' abilities to access services receives little attention (demand side), despite evidence suggestion that interventions aimed at improving access should be patient-oriented, focused on self-management and health literacy approaches. Rather, characteristics of healthcare organisations and systems (supply side) dominate (Richard et al. 2016). Several recommendations emerging from the 'Hard to Reach' Consumers Study, if consistently implemented across the state, would go some way in ensuring a balanced focus on demand- and supply-side interventions. These include:

- health professional access to professional development in community engagement, consumer participation and community development frameworks
- reorganisation of staff workload to account for additional time required for engaging and building relationships with Aboriginal and culturally diverse communities
- promotion of the participation of all consumers in the development of policies and programs.

### INNOVATIVE EXAMPLES

#### National/international

The IMPACT project examples including MyGRist and The Kalwan Development Corporation (s. 3.1.1)

Culture is Healing (s. 3.1.7)

#### State

'Hard to Reach' Consumers Study (s. 3.3.1)

#### Local/ICS

Aboriginal Services Pamper and Paps Day (s. 3.3.3)

## 4.2 Improved functional and interactive health literacy

There is very little in the literature about effectively and sustainably engaging with disadvantaged groups or assessing whether current service provision is meeting their needs.

Functional health literacy encompasses an individual's ability to obtain relevant health information (Nutbeam 2015). The 'hard to reach' study points to multifaceted issues in cancer care and information needs for vulnerable and disadvantaged groups. These include a lack of information for carers, huge variation in the quality of information by tumour type, a reliance on word of mouth to access information, low uptake of interpreters in favour of family members, and low literacy levels in their first languages limiting the benefit of translated information for some consumers. A recommendation from the 'Hard to reach' study is that ICS coordinate and are involved in the development of resources that assist consumers to navigate and understand the private and public system. A recommendation from the Ophelia project is to implement guidelines for the development and provision of written information.

Interactive health literacy encompasses more advanced literacy skills that enable individuals to interact with greater confidence with information providers such as healthcare professionals (Nutbeam 2015) and promote self-help.

There is a need to demonstrate effective strategies to engage with these groups that allow them to take an active role in defining their needs and to encourage them to reach out to resources that can help them achieve this. Richard and colleagues point to developing and rigorously evaluating initiatives with end-users, based on collaborative, participatory and co-design approaches (2016).

Existing evidence indicates that successful approaches facilitate community participation, leadership and ownership-based approaches – often coined ‘community economic development’. Interestingly, a key learning from the Grampians Small Towns Cancer Strategy was the widespread recognition of the need for and benefit of improved local discourse about cancer in general, in addition to specific interventions. This points to the importance of cross-collaboration and peer-to-peer learning at an individual and community level. In addition, the project highlighted the importance of social supports and capacity to navigate a service system as key elements of health literacy (not just about accessing information).

All of these issues fall in the realm of ‘interactive health literacy’.

### INNOVATIVE EXAMPLES

#### State

Health Translations (s. 3.2.5)

#### Local/ICS

Ophelia (Optimising Health Literacy and Access) (s. 3.3.5)

The Parkville Precinct Aboriginal Health Directorate (s. 3.3.9)

Health Brokers (Canada) (s. 3.1.1)

The Australian Centre for Social Innovation (TACSI) (s. 3.1.3)

## 4.3 Multisector collaboration and collective impact

Multisector collaboration is uncommon in the initiatives set out in Section 3. The lack of shared community-wide responsibility to achieve equity of access risks the sustainability of innovations, as many initiatives are funded by a single source (e.g. government) and are often non-recurrent (Richard et al. 2016). The private sector is much less represented in the example interventions.

An exception is the Ophelia (Optimising Health Literacy and Access) project, and subsequent Grampians Small Towns Cancer Strategy, where there was improved engagement with cancer services and health services among leaders of local agencies.

The approach was underpinned by the Collective Impact Framework – a focus on bringing cross-sector organisations together to focus on a common agenda.

Five key conditions form the basis of the framework:

1. All participants have a common agenda for change, including a shared understanding of the problem and a joint approach to solving it through agreed upon actions.
2. Collecting data and measuring results consistently across all the participants ensures shared measurement for alignment and accountability.
3. A plan of action outlines and coordinates mutually reinforcing activities for each participant.
4. Open and continuous communication is needed across the many players to build trust, assure mutual objectives and create common motivation.
5. A backbone organisation(s) with staff and specific set of skills serves the entire initiative and coordination of participating organisations and agencies.

Recommendations for improving community engagement with healthcare are presented across four levels:

### 1. Actions at the level of communities

- Work with local organisations, social groups, community leaders and health providers to deliver local campaigns promoting cancer screening programs
- Value and engage carers, peers and volunteers

### 2. Actions at the primary care and cancer services level

- Protect and promote people's relationships with their GP
- Promote and make access to screening easy (primary care)
- Undertake ongoing monitoring and review of cancer screening promotion practices at the service level (primary care)
- Participate in health promotion and service improvement activities
- Identify and address personal barriers to engagement in cancer prevention behaviours, early detection and screening activities, and cancer care
- Facilitate engagement with health information
- Undertake provider training

### 3. Actions at the regional partnership level

- Region-wide service coordination

### 4. Actions at the policy and funding level

- Partner with local services

Focus investments in the development of workforce capacity, infrastructure, health messaging, technology solutions, service quality, and community and service capacity to plan and organise local resources

Identify and communicate to local services observed gaps in service provision, issues with communications materials and technologies, and issues with pathways between services at the regional and local levels

#### INNOVATIVE EXAMPLES

##### State

G21 Regional Opportunity for Work (GROW) Initiative (s. 3.2.2)

##### Local/ICS

Grampians Small Town Cancer Strategy (s. 3.3.6)

## 4.4 Integration of social and health determinants of access

The lack of initiatives displaying multisector collaboration also shows a limited integration of health and social care for vulnerable populations. There is poor integration of social and health determinants of access in current interventions. Equity of access requires interventions to take into account social and health determinants (the needs of patients and populations, and the resources available to them) (Richard et al. 2016).

Community health is carrying an unfair share of the burden and there are limited interventions delivered outside the traditional clinical health service setting. This is despite recognition that action must take place outside the health sector to address the wide range of social determinants of health (Richard et al. 2016).

Richard and colleagues (2016) argue that to have a wider impact and capture the wide range of social and health determinants of access to reach equity, there needs to be incentives for multiple social and health service sectors to be involved in the efforts directed at enhancing access. This involves the development of multifaceted

interventions delivered at multiple levels and in different intervention settings that are not solely health-oriented (Richard et al. 2016). The development of collaborative research programs and communities of interest are examples of this approach.

## INNOVATIVE EXAMPLES

### National/international

The IMPACT project examples including IMAGINE (Canada) and Multicultural Health Brokers

## 4.5 True integration of care

Some of the initiatives described in Section 3 use multiple management techniques to achieve true integration of care. Common techniques are as follows.

- *Care coordination*: A care coordinator responsible for arranging appointments, referrals and facilitating services to better structure and simplify the care pathway is shown to increase patient satisfaction and allow ease of access. One of the key roles of care coordination is about looking at products and services holistically, and not just in the healthcare space.
- *Shared care planning*: Shared care is increasingly being adopted by Australian GPs with an interest in cancer (who are integrated with prevention, screening and detection, and treatment), but there is scope for this to be more widespread, particularly in remote communities.
- *Multidisciplinary case conferencing*: While multidisciplinary care is an embedded feature of cancer service provision in Victoria, bringing together general practice, specialists and other chronic disease partners is an extension of this to ensure the most appropriate care for patients, particularly with comorbidities.
- *Telehealth*: Telehealth can provide both in-home monitoring and enhanced specialist support for remote sites. There are pockets of excellence in specialist telehealth facilities in Victoria. A next step could be electronic devices given to chronic condition and comorbid patients that can upload health data for specialist review.
- *A central hub*: The 'hard to reach' consumer study recommends a central centre providing information and a support network in target areas that assists people with information and support in relation to all aspects of care, but in particular travel and accommodation to metropolitan and rural services.

Importantly, these techniques ensure patients' needs are identified early, and they are helped to manage their own conditions. These approaches depend on better coordination among services and sharing of best practice among doctors. Good chronic disease management and management of comorbid patients may also offer economies of scale, potentially reducing hospitalisations for many chronic diseases, not just the cancer / target disease.

## INNOVATIVE EXAMPLES

### National/international

The IMPACT project provides many examples of initiatives using a range of shared care and care coordination techniques (s. 3.1.1)

### State

NSW Local Health District Demonstrator Sites (s. 3.2.3)

### Local/ICS

Monash Health Geriatric Oncology Clinic (s. 3.3.7)

Cabrini and Peninsula Health Shared Care Mental Health Pilot (s. 3.3.8)

WCMICS/LMICS Metropolitan:Regional Interface Study (s. 3.3.10)

## 4.6 System capability: Data collection

Disparities in cancer care across populations become apparent only when there is a cancer registry to record the cancer incidence and mortality statistics and data capture is comprehensive (Olver, Franca & Grogan 2016). Currently data systems do not support detailed analyses of inequities in cancer care.

Data collection and management in rural areas can be improved through electronic medical records and dedicated data managers. It will also enable cancer centres to measure the impact of novel pilot programs.

For Aboriginal people, registry data collection is hampered by incomplete recording of Aboriginal status. A recommendation of the Parkville Precinct Aboriginal Health Directorate is to improve Indigenous Patient Identification in the acute public healthcare setting.

Further, data on the experiences of Aboriginal people with cancer are not routinely collected. Given that healthcare reform is best guided by the experience of those needing it (s. 4.1), the omission of data on Aboriginal experiences of cancer care represents a significant gap. The views and experiences of service providers, although frequently overlooked, are also critical in focusing on structural and patient-related issues for reform (Yerrell et al. 2016).

Nationally, no registries routinely record comorbidity. Yerrell and colleagues (2016) state this is a critical deficiency given that comorbidity can significantly influence the choice and prescription of cancer therapies and outcomes. To overcome such deficits, data linkage has been used to combine cancer registry and treatment data. It enables cancer outcomes to be assessed in relation to comorbidity and various sociodemographic features. However, this practice is not yet incorporated into routine registry data collection processes.

Collecting a wide range of data routinely, as part of the clinical pathway, would help answer questions about the range of treatments offered to different population sub-groups, whether treatment was completed, and reasons for non-completion (Heathcote & Armstrong 2007).

### INNOVATIVE EXAMPLES

#### State

The CanDAD project in South Australia (s. 3.2.4)

#### Local/ICS

BSRICS Population-based registry data modelling socioeconomic indicators (s. 3.3.4)

Parkville Precinct Aboriginal Health Directorate (s. 3.3.9)

## 4.7 System capability: Workforce

The Rural Health Outreach Fund initiative examined data at a local level across Victoria and reported geographic variation of health outcomes, suggesting it may be linked to the mal-distribution of health service provision or interventions (e.g. an appropriate medical workforce). There is a strong focus on the rates of preventable hospital admissions as their findings suggest that many would have been avoided had there been appropriate and adequate community-based or primary health services in place (RWAV 2017). A self-reported limitation is the lack of stakeholder consultation to substantiate or support the numerical data. It can be used as a starting point in consultation with local service providers, particularly in the context of limited regional health workforce data to truly understand the demand and supply issues. Broadly, this applies to the primary health networks, as it presents an opportunity to collaborate and align resources in the commissioning of health services to adequately meet the health needs of the local population.

Regarding regional disparities in cancer outcomes, anecdotal evidence points to a lack of service provision and workforce issues (e.g. lack of EFT, regional cancer centres staffed by visiting medical officers). Possible solutions to workforce issues include the development of a national locum service, forming linkages to comprehensive centres, and better utilising regional cancer centres as platforms for research with access to clinical trials.

Implementing a national/statewide standard staffing profile and cancer service capability framework is also essential to deliver uniform care through rural areas. In addition, the *Statewide design, service and infrastructure plan* identifies that a role delineation framework can provide the supporting architecture for the rollout of a



number of health reforms, including workforce and locality planning (DHHS 2017). The Clinical Services Capability Framework (CSCF) would contribute to clearly defining the roles and capability levels of all health services in Victoria and formalising relationships between providers. It will optimise safety and quality outcomes for patients by ensuring that patients are treated at health service campuses that can appropriately manage their level of clinical risk based on patient acuity and the complexity of care required.

## INNOVATIVE EXAMPLES

### **National**

Regional cancer centres (s. 3.1.4)

Capability and service mapping (s. 3.1.5)

### **State**

Rural Health Outreach Fund (s. 3.2.6)

### **Local/ICS**

WCMICS/LMICS Metropolitan:Regional Interface Study (s. 3.3.10)

GRICS Gippsland Oncology Teletrials model (s. 3.3.13)

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# Conclusion

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This scoping report has been useful in identifying a range of interventions to improve access to care for disadvantaged groups. It demonstrated that most of the current attempts (internationally) at improving access involve supply-side determinants of access, to transform the way that health systems and services function. Efforts directed at enhancing abilities of patients and populations to access health services (demand-side determinants) were much less prominent.

Promising interventions aiming towards equity of access could expand to take into account social as well as health determinants of access to cancer care. The specific needs of patients and populations, as well as resources available to them, using multifaceted, multilevel and multisector approaches is recommended.

Victorian ICS have already made headway in working with other services to better coordinate and collaborate. In particular, ICS have formalised primary care partnerships, work with primary health networks to integrate optimal care pathway initiatives in primary intervention and prevention, and provide local data to GPs on key information such as late stage presentations.

While there is some commonality in the access to care issues faced by the disadvantaged groups identified in Section 2, the heterogeneity of, and the uneven distribution of these populations across sub-regions of Victoria, lends itself to a strategy that allows for tailored, place-based interventions (rather than a 'one strategy fits all' approach). A report from the Grattan Institute focusing on initiatives that tackle disadvantage in health in Australia argues that 'tailored, place-based interventions capable of addressing interrelated causes of local disadvantage that sit side by side with broader system-level reforms' is required (Duckett & Griffiths 2016). While this pertains to health disadvantage more broadly, there is certainly a role for Victorian ICS to build on their data architecture for more needs-based targeting of disadvantaged groups.

The design of an overall strategy that recognises the diversity of local issues is required, to reduce contextual factors that contribute to poorer cancer outcomes in disadvantaged groups. This might involve:

- building on existing good practice and supporting tailored place-based initiatives at the sub-regional level with a focus on better responding to local conditions
- identifying key state and local organisations (including in social care) to develop a joint approach at a local level and communities of practice and shared learning between ICS
- expanding and embedding existing pilots focusing on shared care, care coordination, self management and health literacy across the state
- measuring novel pilot programs, more precise data collection, and more needs-based targeting
- progressing with the development of the Clinical Services Capability Framework (CSCF) to underpin strategy.

The Addendum provides a framework for action, including possible interventions and selection criteria.

# Addendum

Table A1 sets out a draft framework for action, embedding key success criteria for interventions documented in Section 4.

Table A2 sets out possible interventions (based on recommendations and/or pilots identified in the review) and suggested pilot locations (based on data gathered from the literature review in Section 2) for each disadvantaged group.

Table A3 lists criteria for selection of priority interventions, based on key themes emerging from the review.

**Table A1. Draft framework for action**

Dimension	Detail
Project establishment	<p>Undertake literature review</p> <p>Generate intervention ideas and selection of priority groups / areas / issues for further work-up</p> <p>Identify questions and focus for data-thon</p> <p>Identify broad approach (e.g. statewide vs. local – strategy, priority groups, priority issues, no. pilots, lead agency)</p>
Engagement	<p>Identify key partner organisations: Department of Health and Human Services, local health authorities, broader community engagement to refine problem identification and develop focus questions for data-thon</p> <p>Draft project plan (and pilot plans)</p> <p>Draft communication plan, that:</p> <ul style="list-style-type: none"> <li>ensures consumers take an active role in defining their needs</li> <li>delivers open and continuous communication across all stakeholders to build trust, assure mutual objectives, and create common motivation</li> <li>ensures all participants have a common agenda including a shared understanding of the problem and a joint approach to solving it</li> <li>allows health professional access to relevant professional development in relation to community engagement, consumer participation and community development frameworks</li> <li>values and engages carers, peers and volunteers</li> <li>facilitates end-user engagement with health information</li> </ul> <p>Work with local organisations, social groups, community leaders and health providers to deliver local pilots</p>
Co-design	<p>Develop more detailed project plan with end-users, based on collaborative, participatory and co-design approaches</p> <p>Establish:</p> <ul style="list-style-type: none"> <li>governance strategy</li> <li>business case</li> <li>evaluation strategy and systems</li> <li>action plan that outlines and coordinates mutually reinforcing activities for each participant</li> </ul> <p>Imbed strategy into optimal care pathway priority areas and ICS annual work plans</p>

Dimension	Detail
Measurement	<p>Build the data architecture for monitoring project with a focus on more precise needs-based targeting</p> <p>Collect data and measure results consistently across all the participants to ensure shared measurement for alignment and accountability</p> <p>Revisit status of Victorian Clinical Services Capability Framework</p>
Implementation	<p>Implement pilots/project(s)</p> <p>If applicable, reorganise staff workload to account for time required for engaging and building relationships with Aboriginal and culturally diverse communities</p>
Evaluation	<p>Assess whether the impact of the initiative be measured by current available data</p> <p>Monitor and evaluate pilot(s)/project (consumers take an active role in rigorously evaluating pilots)</p> <p>Share lessons from pilot(s)/project</p> <p>Draft end project report and adapt solutions as better data becomes available</p>
Wider implementation	Evaluate and expand successful interventions across ICS

**Table A2. Possible ICS interventions by disadvantaged group**

Group	Problem identification	Pilot sub-region	Possible interventions
Rural and regional	Diagnostic delay, undersupply of medical practitioners, fewer facilities, late presentation / late stage, psychological distress	Teletrials: East Gippsland - Loch Sport / Yarram, Mitchell Shire, Swan Hill, Buloke Shire	<p>Development of Victorian Clinical Services Capability Framework</p> <p>Evaluation and expansion of WCMICS / LMICS Metropolitan:Regional Interface Study (s. 3.3.10)</p> <p>A project to utilise regional cancer centres as platforms for research with access to clinical trials / Evaluation and expansion of Gippsland Oncology Teletrials model (3.3.13) and general expansion of telehealth hardware infrastructure</p> <p>Development of a region-wide locum service</p> <p>Project to improve linkages to comprehensive centres</p> <p>Investigate factors that influence specific rural-metropolitan referral pathways / completeness of patient information transfer</p> <p>Develop a regional cancer patient transfer plan – expanding transport and accommodation role of metropolitan neighbourhood houses</p>
Urban fringe	High growth pressure, infrastructure pressure, few health resources to support growth	North-west Melbourne, Mitchell Shire, Mickleham, Rockbank, Wollert	
Culturally diverse	Lung, stomach, liver, cervix, thyroid and bladder cancers, low screening participation, urban fringe issues, non-compliance/drop-out of pathway, low participation in clinical trials, poor health literacy	Greater Dandenong, Brimbank, Monash, Melbourne (city, Wyndam, Cardinia), Hume, Greater Geelong, Greater Shepparton, Latrobe, Mildura, Ballarat, Greater Bendigo	<p>Undertake research on culturally diverse treatment disparities</p> <p>Analyse the data to better understand culturally diverse non-compliance (referred to tertiary care and do not complete treatment)</p> <p>Strategy to improve culturally diverse uptake to clinical trials</p>

Group	Problem identification	Pilot sub-region	Possible interventions
SES	Advanced cancer stage, poorer survival, affordability of care, poor health behaviours, low screening participation, unequal exposure to risk factors, health literacy	Ref. list of low socioeconomic areas in	Intervention to provide coverage for care not covered by Medicare Benefits Schedule (e.g. dental reconstruction, fertility preservation)  Redevelopment of supportive care screening to identify disadvantaged groups with the aim of accurate needs assessment and appropriate referral to supportive care services. Early scoping currently being undertaken in Barwon
Aboriginal population	Significantly higher mortality, late diagnosis, rurality, low screening participation, unequal exposure to risk factors, less likely to receive adequate treatment, cultural barriers, lack of culturally appropriate services	Barwon South, Gippsland, Hume, Loddon–Mallee	Implementation of the optimal care pathway for Aboriginal people with cancer  Roll-out of Parkville Precinct Aboriginal Health Directorate operating service model across Victoria (3.3.9).  Establish formal partnership arrangements with the Aboriginal Health Worker Network to allow facilitation of support between provider and patient. Model on NSW demonstrator sites (s. 3.2.3)  Project to survey Aboriginal experience of cancer care  Registry data collection to record Aboriginal status
LGBTI	Low screening participation, higher incidence certain cancers, social isolation, reduced access due to discrimination uncertainty, psycho-social complexities, lack of knowledge among providers	Melbourne (SMICS, NEMICS, WCMICS)	Adaptation of Mildura Aboriginal Services Pamper and Paps Day for LGBTI sub-groups (s. 3.3.5)
Elderly (aged over 80 years)	Rurality, late presentation, poor response to treatment, complicated management – comorbidities / poor functional status, polypharmacy, exclusion from clinical research	North Bendigo, Maryborough	Interventions for improving polypharmacy (2.6)  Develop evidence-based guidelines  Strategy for recruitment to clinical trials  Evaluation and expansion of Monash Health Geriatric Oncology Clinic (3.3.7)  Registry to record comorbidity
Mental health	Higher incidence, poorer outcomes, poor management of comorbid conditions by providers, low adherence to medication, less likely to use services, fragmentation of service, attitudes of healthcare staff, health literacy	Western Victoria, Gippsland-East, Wangaratta-Benalla, Bendigo, Murray River	Collocation of mental health services  Evaluation and expansion of Cabrini/Peninsula Shared Care Mental Health Pilot (s. 3.3.8)  Analyse the data to better understand non-compliance (referred to tertiary care and do not complete treatment)  Registry to record comorbidity

**Table A3. Criteria for selection of priority interventions**

Criteria	Checklist	
What issue/issues does the intervention address?	Lack of facilities / health resources Poor survival Poor health behaviours Participation in clinical trials Low screening participation Psychological distress / psycho-social complexities Provider attitude/ discrimination uncertainty Comorbidity / complicated management Clinical trial uptake Health literacy	Culturally appropriate service Late presentation / late stage Affordability Unequal exposure to risk factors High incidence Non-compliance/adherence to medication Undersupply of medical practitioners Social isolation Polypharmacy Service fragmentation
Who is the target group/groups?	Urban fringe Lower socioeconomic status LGBTI Mental health	Rural and regional Culturally diverse Aboriginal Elderly (over 80 years)
Does the intervention enhance the patient's abilities to access services (demand-side intervention) or improve service provision (supply-side intervention)?	Supply side	Demand side
If applicable, does the intervention employ care integration techniques?	Telehealth Central centre Support network	Care coordinator Multidisciplinary case conferencing Shared care
Does the intervention demonstrate effective strategies to engage with target group/groups?		
Does the initiative facilitate community participation and leadership?		
Does the intervention take into account social determinants of access (the needs of patients and populations, the resources available to this group)?		
Does the intervention involve key strategic partnerships with services and organisations outside the health sector?		
If successful, is recurrent funding available for this intervention?		

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# Resources

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## Australian Bureau of Statistics (ABS)

The ABS is Australia's national statistical agency, providing statistics on a wide range of health, economic, social, population and environmental matters. Geographic areas of interest can be selected to see statistics and community profiles at the local government area (LGA) or suburb level (or by level of rurality). Aboriginal profiles are also available by LGA. Demographic, socioeconomic and ethnicity data is included in the reports.

[www.abs.gov.au/websitedbs/D3310114.nsf/Home/2016%20search%20by%20geography](http://www.abs.gov.au/websitedbs/D3310114.nsf/Home/2016%20search%20by%20geography)

### *ABS: SEIFA*

Socio-Economic Indexes for Areas (SEIFA) is an ABS product that ranks areas in Australia according to relative socioeconomic advantage and disadvantage. The indexes are based on information from the five-yearly Census of Population and Housing.

SEIFA 2016 has been created from census 2016 data and consists of four indexes: The Index of Relative Socio-economic Disadvantage (IRSD), The Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD), The Index of Education and Occupation (IEO) and The Index of Economic Resources (IER). Each index is a summary of a different subset of census variables and focuses on a different aspect of socioeconomic advantage and disadvantage.

[www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/2033.0.55.0012016?OpenDocument](http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/2033.0.55.0012016?OpenDocument)

## Australian Institute of Health and Welfare (AIHW)

The AIHW publishes cancer incidence, mortality and screening statistics (actual counts and rates) by geographic areas larger than the SA2 level used in the Australian Cancer Atlas. These geographic areas include primary health networks, SA4s, SA3s, population health areas, state by remoteness, state and territory, and greater capital city statistical area.

<https://www.aihw.gov.au/reports/cancer/cancer-incidence-mortality-small-geographic-areas/data>

## The Cancer Atlas

The atlas enables a comparison of how the burden of cancer varies across Australia and provides latest estimates for cancer diagnoses and excess deaths for 20 cancer types across 2148 geographic areas. Location is defined by Statistical Area Level 2 (SA2) of usual residence, which is a standard geographic area used by the ABS that covers Australia without gaps or overlap. Statistical Areas Level 2 (SA2) are the smallest areas that have annual estimated resident population data readily available. The SA2 geographical areas can be used as building blocks to form larger geographical regions. The larger regions used in the Australian Cancer Atlas include states and territories, greater capital city regions, remoteness categories, and categories of area-level socioeconomic status.

<https://atlas.cancer.org.au>

## VicHealth

### *VicHealth Indicators survey*

The survey provides statewide demographic analysis including gender, age, education, current main activity, main language spoken at home, country of birth, self-reported disability, Aboriginal status, sexuality, income, household structure, location, SEIFA score and internet access.

<https://www.vichealth.vic.gov.au/programs-and-projects/vichealth-indicators-survey-2015>

### *LGA Profiles*

LGA profiles provide a snapshot of wellbeing indicators for each local government area (LGA) in Victoria. All indicators are taken from the VicHealth Indicators Survey 2015.

<https://www.vichealth.vic.gov.au/media-and-resources/publications/vichealth-indicators-lga-profiles-2015>

## **Victorian Government**

### *Victorian population health survey*

The survey provides information at the state, regional and local government area levels about the health, lifestyle and wellbeing of adult Victorians aged 18 years and over.

<https://www2.health.vic.gov.au/public-health/population-health-systems/health-status-of-victorians/survey-data-and-reports/victorian-population-health-survey>



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