

# WA Cancer & Palliative Care Network

## Integrated Primary Care & Cancer Services Model of Care



Government of **Western Australia**  
Department of **Health**



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# 1. The Role of Primary Care in Cancer

## 1.1 Introduction

One in three men and one in four women in Australia will be diagnosed with cancer in the first 75 years of life, overtaking heart disease as the biggest cause of death in some states in Australia.<sup>1</sup> It remains the most feared disease.<sup>2</sup> Nevertheless sixty per cent of patients will eventually die of unrelated causes.<sup>3</sup> However, 'surviving' cancer does not guarantee an acceptable quality of life for either the patient or their family.

Following diagnosis a person may be cured or experience troublesome sequelae, a recurrence or face death. How an individual copes depends not only upon the biological characteristics of the cancer and the treatments available, but their social supports, reserves for dealing with uncertainty and ability to participate in decisions around treatment options, as well as treatment itself. Most people experience some physical, social, economic and psychological sequelae, leading the World Health Organization to include cancer in its list of chronic conditions.<sup>4</sup>

There is no universally accepted definition of primary care. For the purposes of this paper we have adopted the following definition of primary care:

'Primary health care means essential health care based on practical, scientifically sound, culturally appropriate and socially acceptable methods. It is universally accessible to people in their communities, involves community participation, is integral to, and a central function of, the country's health system, and is the first level of contact with the health system'.<sup>5</sup>

## 1.2 Guiding principles for effective primary care involvement in cancer

1. All people affected by cancer have the right, and are likely to benefit from, having their physical, social, psychological, emotional, spiritual and functional needs treated as an integral part of their overall care.
2. The care of the patient with cancer in the community is a shared responsibility of all disciplines working with the person affected by cancer; with each clinician able to make a valued contribution to care (within the limits of their role and expertise).
3. Clinicians working with the person affected by cancer relate as an interdisciplinary team, including regular case discussion, contribution to the client's integrated medical record.
4. Clinicians operate within the parameters of the law and ethical code applicable to their profession.
5. Evidence-based assessment and intervention strategies are utilized.
6. A culture of reflective practice and audit are important in primary cancer care, quality improvement processes assessing the effectiveness of interventions and service performance/achievement of core aims and objectives, benchmarking service performance.
7. Patients have the right and are given meaningful opportunities to participate in service development and quality improvement activities.



### 1.3 Guiding principles for cancer screening

The World Health Organisation recognises that early detection of cancer greatly increases the chances for successful treatment. Whilst recognition of early warning signs and symptoms of cancer may contribute to early detection, it is screening that offers the opportunity to diagnose the disease at an asymptomatic or even pre-malignant stage of aetiology.

Screening is defined as *'the presumptive identification of unrecognised disease or defects by means of tests, examinations or other procedure that can be applied rapidly'*.<sup>6</sup> The advocacy of organised screening programs should be guided by the ten principles identified by the World Health Organisation:

- The condition should be an important health problem
- There should be a recognisable latent or early symptomatic stage
- The natural history of the condition, including development from latent to declared disease, should be adequately understood
- There should be an accepted treatment for patients with recognised disease
- There should be a suitable test of examination that has a high level of accuracy
- The test should be acceptable to the population
- There should be an agreed policy in whom to treat as patients
- Facilities for diagnosis and treatment should be available
- The cost of screening (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole, and
- Screening should be a continuing process and not a 'once and for all' project.

To date in Australia, only three screening programs have sufficiently met the aforementioned criteria to warrant implementation, namely breast, cervical and most recently bowel cancer. Although screening tests for ovarian, testicular and prostate cancer are available, there is insufficient proof of efficacy to justify their introduction on a population scale.

#### Education for the community

There is an ongoing evolution of best practice in the development and delivery of cancer vaccination and screening. The use of various media, from traditional face to face educational strategies to digitally based or on line options must be maximized to ensure up to date advice and guidance is available at the primary care level for practitioners engaged in any stage of the cancer vaccination and screening process.

Use of existing education and training infrastructure at the undergraduate, post graduate and continuing education level is vital. Use of structures such as Divisions of General Practice, as well as the relevant colleges should be supported, along with strategies such as new media and digital communication to ensure rural and remote practitioners are adequately supported in their role.

Programs for primary care practitioners are best run if supported by appropriate and consistent educational initiatives aimed at the community. These can often be well co-ordinated by programs in the NGO sector such as The Cancer Council WA.



## 1.4 Towards better prevention

Modern cancer prevention initiatives are often presenting in the context of a broader chronic disease prevention approach in that many cancer risk factors are also risk factors for other chronic diseases.

Tobacco control, programs promoting healthy weight, healthy diet, physical activity, sun protection, lower levels of alcohol consumption and the like require a comprehensive multi faceted approach which includes community education, the influence of social norms through policy and legislation, specifically targeted interventions for higher risk groups and structural reforms to the environment, both built and natural and more.

While it is unrealistic to attempt to give adequate coverage of the programs and initiatives necessary to address adequate cancer prevention activities in this document, the currently leading summary of evidence based cancer prevention strategies is available through The Cancer Council Australia in the form of the National Cancer Prevention Policy 2008 – 2010.<sup>7</sup> The leading organisation in Western Australia for responsibility for development and delivery of many of these programs and initiatives is the Cancer Council WA. With specific reference to the role of primary care, the major guidance is provided by the The Royal Australian College of General Practitioners (RACGP) Guidelines for preventive activities in general practice or “The Red book”. The Red book is currently in its 6<sup>th</sup> edition with the seventh edition under review.<sup>8</sup>

The recent introduction of the cervical cancer vaccination program, with catch up programs delivered at Primary care is another development where GP education and engagement is essential. Proper provision of resources, training and technical support is a vital part of the quality care pathway.



## 2. Primary Care through the patient pathway

### 2.1 The role of the generalist

People with serious illnesses have consistently expressed the need for continuity from a care provider who is available, is genuinely interested in them, provides emotional support and who takes the time to understand and communicate with them and important others.<sup>9</sup> We argue that modern cancer treatment should not fail in this regard. People now wish to have a say in what happens to them - in what bears upon their treatment and how they live their life during and after treatment. It remains a challenge to guide patients who may be desperate because of a bleak prognosis to accept evidence-based approaches rather than seek miracle cures. Information and care are largely delivered in specialist centres which are seldom in keeping with the variety of cultural, familial or social backgrounds. Arguably, the coordination of care could be better managed by a primary care provider with an understanding of the person's social context.

Screening asymptomatic people for treatable cancers is an established strategy for timely diagnosis of some cancers. There is some evidence that treatable cancer is not necessarily an asymptomatic condition with potential to further improve prognosis by more effective case finding.<sup>10</sup> Effective tools to alert general practitioners to the possibility of cancer among the symptomatic patients are needed. However in general practice patients present with undifferentiated illness often with a host of other needs. Symptoms may have aetiology in the physical, psychological and/or social domains. It is up to the practitioner to selectively refer those most likely to benefit from diagnostic tests. Diagnosis requires practitioners to notice deviations from normal. While the Australian model of fee-for-service offers choice, it does not encourage people to consult practitioners only at one practice, thereby reducing the scope for significant new symptoms to be fully appreciated.

The British experience also suggests that published guidelines as the basis of a strategy to stream referrals to appropriate specialists has failed to benefit patients.<sup>11</sup> Effective case finding warrants appropriate and timely referral of people with “red flag” cancer symptoms. While there is growing literature on the positive predictive value of some red flag cancer symptoms there are few recognised effective strategies to implement this evidence.<sup>12</sup>

### 2.2 The role of allied health

Landmark qualitative research on living with a chronic condition also highlights three aspects that the patient must manage: the disease/symptoms, the emotional consequences and the impact on daily function/life roles.<sup>13</sup> With acute care symptoms focused on the first, even when clinical guidelines recommend otherwise, systems of care do not ensure coordination or continuity. For example evidence based interventions for fatigue are available but rarely form part of usual care. Likewise, emotional concerns are recognized, but rarely approached systematically or comprehensively. Occupational therapists, physiotherapists, community nurses, psychologists, counsellors, social workers and nutritionists also have a valued role to play in assisting patients to manage symptoms, emotional consequences and impact on daily life roles. So called ‘Allied health’ is the umbrella term. Medicare provides a comprehensive list.<sup>14</sup> Examples where allied health can make a valuable contribution include rehabilitation to better maintain or regain independence in self care; modifications to homes; self-management programmes for common cancer



symptoms (e.g. fatigue, psychosocial distress, and anxiety), pain management techniques, lymphoedema care; graded exercise programs; carer education; and nutritional advice. While these interventions are included in algorithms for best practice (such as the NCCN Practice Guidelines in Oncology: Cancer-Related Fatigue), the mechanisms to ensure patients' access to such services do not yet exist nor do mechanisms to allow multiple professionals to communicate with each other or the patient.<sup>15-16</sup>

Partners of patients with cancer experience similar levels of psychological stress to the patient, with some studies revealing higher levels of distress in the partner. Many couples confront cancer as a team and adjustment to cancer by one partner affects the other.<sup>17</sup> However, spouses receive minimal support from the medical team. It is well documented that partners deserve greater focus as recipients of support and care, despite not being the identified patient. Children of older patients with cancer are often at a loss to know how to respect their parent's privacy but to be involved in the treatment plan and to understand the nature of the illness for their own and their parent's psychological health. Often there are supportive friends who would also like to be involved by providing assistance in day-to-day care. All too often the role of significant others and the wider impact of the diagnosis on them is an unmet need.

### **2.3 Indigenous and CALD patients**

There is a need to adapt programs to ensure they also meet the needs of minority and vulnerable groups. It remains an indictment of our health care system that Indigenous Australians experience later cancer diagnosis, lower five-year survival, higher mortality rates than non-Indigenous Australians and lower participation in screening programs.<sup>18</sup> While there has been a 30 per cent reduction in cancer mortality rates in Australia over the last two decades, there has been little change in Indigenous cancer mortality and such a situation illustrates a need for reconsideration of how all aspects of cancer control are managed for this group.<sup>19</sup> Surprisingly little is understood about the experience of Culturally and Linguistically Diverse (CALD) groups with cancer. Minority groups also include those with non-traditional sexual behaviours, which can also increase risk for some cancers. Such groups also present challenges in relation to many stages of care from prevention to routine screening programs and beyond.

### **2.4 Active treatment phase**

Of growing importance is the involvement of primary care providers during 'active' treatment as oral chemotherapeutic and biological agents are developed and in-patient stays for surgery shorten. GPs have a role in managing acute toxicities during treatment or perhaps administering chemotherapy in close consultation with the specialist team. Community pharmacists may also become more involved in advising patients about symptom management, as well as supporting patients with what may be complex adjuvant treatment regimens which by their very nature predispose to adverse effects

In most cases the acute phase of cancer treatment will continue to be managed by specialists, given the need for surgery and adjuvant therapy. However, patients today have relatively little contact with their primary care provider in the active treatment phase. With an eye to effective follow-up we argue that this is counter-productive, and that greater involvement of professionals in the community,





adopting an integrated approach could offer better practical and psychosocial support from the outset. It has recently been demonstrated that providing general practitioners with detailed information about their patient's chemotherapy increases the practitioner's confidence and satisfaction with specialist care. Moreover a central focus is the patient, their carer and their wider family. The general practitioner will remain closely involved throughout the patient journey, however after diagnosis, the support and coordination role may also be undertaken by another health professional acting as the patient's advocate able to harness input from a range of paramedical, social and welfare agencies. In this arrangements the need for special 'follow-up' arrangements in most cases are obviated by the involvement of the general practitioner and the wider primary care team from diagnosis onwards.

## **2.5 Survivorship and aftercare**

Most cancer patients are offered follow-up visits by an oncologist or surgeon for up to five years after treatment. Traditionally, the goals of follow-up include the early detection of local recurrence, screening for a new cancer, examination of the patient for treatment-related toxicities and to provide psychosocial support.<sup>20</sup> Despite the process of seeing patients at follow-up, research consistently demonstrates that in some cancers recurrences are detected by the patient themselves and are reported either during the interval between, or at the time of the scheduled visit for follow-up. In addition, 60-80% of recurrences of some cancers occur during the first three years following diagnosis and treatment and therefore, the value of 'intensive' follow-up in later years may be questionable.

Although many clinicians are involved in follow-up care for cancer patients there is a lack of published information about how this relates to specialist nurses or GPs during follow-up or how they access other services in primary care. The role of a coordinator in the long term management of cancer patients is of growing interest. However we posit that it will be necessary to work closely with all stakeholders and to frame services with an up to date understanding of the needs of cancer patients and their families. In many cases arrangements will need to be tailored to the local setting or even to the individual patient. Some may prefer that care coordinated by a hospital based nurse involved in their care from the outset. Others may prefer their general practitioner. Two other considerations also have a strong bearing on this issue. Firstly the need to factor treatment advances such as in breast cancer where there is robust evidence for switching some patients from Tamoxifen to an Aromatase Inhibitor or offering extended adjuvant therapy. Therefore treatment advances dictate that some patients will need to remain under close specialist surveillance. It is also important that robust systems are in place to capture survival data and to maintain epidemiological data for cancer. Whatever the follow up arrangements we must ensure that the coordinators are equipped to offer patients the best possible support in their individual circumstances.



## 2.6 Recommendations

See Appendices I-VIII in attached Model of Care Document.

1. The general practitioner and other health care providers in the community, including allied health, pharmacy and nursing have an active role in the care of the cancer patient from diagnosis through to palliative care.
2. It is important to consider the impact of a cancer diagnosis on significant others including partners, carers and dependents.
3. The flow of timely and accurate information to and from primary care may have a profound impact on the patients experience through the cancer journey.



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## Appendices: Model of Care Matrix

### Cancer care in Western Australia- Model of Care Matrix

Suggested care plan in respect for Primary Care, Cancer Prevention and Screening

#### Appendix I: Prevention & Screening

Stage: Prevention and Screening			
	What should be provided	Who should provide it?	Where Should it be provided?
Policy Level	<p>Screening programs that fulfil WHO principles</p> <p>Evidence based Prevention strategies</p>	<p>Australian Government</p> <p>State Governments primary care, NGO Australian and State Government and NGO sector,</p>	<p>State and Commonwealth Health departments, primary care, NGO and community</p> <p>Community</p>
Organisational level	<p>Implementation of well coordinated population based national screening programs</p> <p>Coordinated education for health professionals and the community</p>	<p>Australian Government in partnership with States and Territories</p> <p>GPs and other primary health care providers</p> <p>NGOs</p>	<p>Community</p> <p>Primary centres Tertiary Education institutions, professional bodies, Divisions of GP, NGO, internet</p>
Individual Level	<p>Equity and access to screening services for all the community</p> <p>Support and education services relating to cancer screening for the community</p>	<p>Australian Government in partnership with States and Territories</p> <p>GPs and other primary health care providers</p> <p>NGOs</p>	<p>Community</p> <p>Primary centres</p> <p>Tertiary Education institutions, professional bodies, Divisions of GP, NGO, internet</p>



## Appendix II: Diagnostic Pathways

Stage: Diagnostic Pathways			
	What should be provided	Who should provide it?	Where Should it be provided?
Policy Level	Diagnostic protocols for assessment for all cancer types and in appropriate to all subpopulations eg aged ,indigenous,remote/rural,CALD,people with disabilities, recent migrants,no social supports.	Australian Government policies To ensure that access to diagnostic tests keeps pace with increasing cancer incidence.	Primary and secondary care centres.
Organisational level	Implementation of guidelines in all General practice divisions All patients are appropriately referred for diagnostic workup	General practitioners State Government Tertiary Centres	Primary and secondary care centres.
Individual Level	All individuals and families have equity of access to appropriate diagnostic services to the extent that prognosis is not a function of timely access to appropriate investigations.		At the appropriate centre; mainly in primary care.



### Appendix III: Referral Pathways

Stage: Referral Pathways			
	What should be provided	Who should provide it?	Where Should it be provided?
Policy Level	Clearly established referral pathways for patients presenting cancer symptoms including establishing guide to appropriate psycho-social and supportive interventions	Australian Government in consultation with Royal Colleges ( e.g. RACGP)	Primary care clinics
Organisational level	General practitioner assessment of those identified at risk Eg Implementatioin of referral Guidelines (e.g. UK NICE cancer referral guidelines) Cancer Referral pathways	State Government Tertiary Centres	In and outpatient clinics
Individual Level	Assessment of clinical and psycho-social need Multi-disciplinary Assessment Service access according to assessment	Tertiary Centres Health professionals ie social workers	Primary care clinics



## Appendix IV: Treatment

Stage: Treatment			
	What should be provided	Who should provide it?	Where Should it be provided?
Policy Level	All treatment pathways include clinical and psycho-social intervention pathway including active support for carers. Appropriate delegation of treatment to general practitioners.	Australian Government	At the interface between primary care and specialist services.
Organisational level	Psycho-social and clinical intervention pathways for all those assessed as requiring treatment psycho-social support Monitoring of practical, Emotional ,spiritual Referral pathways to specific psycho-social interventions.	Health professionals Allied health	At the interface between primary care and specialist services.
Individual Level	Patients, families and carers receive appropriate treatment and other interventions to ensure help with social support services: Management of concurrent chronic illness, Information Instrumental needs: Homecare ,financial ,transport Emotional: minimizing social isolation,cultural,spiritual, interpersonal difficulties.	General practitioners NGOs Community agencies: Allied health care professionals Psychologists/ Counseling services	In Primary care centres or in partnership with other community services





## Appendix V: Surveillance

Stage: Surveillance			
	What should be provided	Who should provide it?	Where Should it be provided?
Policy Level	Appropriate protocols for surveillance of cancer patient without increasing anxiety and with regard to the need of the carer, family and community	Australian Government in consultation with Royal Colleges ( e.g. RACGP) and academic institutions.	At the interface between primary care and specialist services.
Organisational level	Referral processes to specialist services for all patients who require a specialist opinion. Referral processes to psycho-social services for previously diagnosed/treated patients.	State Government Tertiary Centres	In and outpatient clinics
Individual Level	General practitioners, patients and families are aware of systems to reengage specialist services and have timely access to gatekeepers	General practitioners, Tertiary Centres	Primary care clinics



## Appendix VI: Relapse & Retreatment

Stage: Relapse and Retreatment			
	What should be provided	Who should provide it?	Where Should it be provided?
Policy Level	Clearly established referral pathways for patients presenting recognised symptoms of recurrence or requiring psycho-social services. Establishing guide to appropriate clinical and psycho-social interventions	Australian Government in consultation with Royal Colleges ( e.g. RACGP) and academic institutions.	At the interface between primary care and specialist services.
Organisational level	Health care practitioner assessment of those identified as having a history of treated malignancy Local referral guidelines Reassessment of psychological/social need Referral to appropriate services Interventions as required	State Health Health care professionals	In and outpatient clinics Tertiary Centres Primary care clinics
Individual Level	Patients , carers and families receive continuity of care and support so that signs and symptoms of relapse are identified in timely fashion.	Health Care professionals	In and outpatient clinics Tertiary Centres Primary care clinics



## Appendix VII: Survivorship

Stage: Survivorship			
	What should be provided	Who should provide it?	Where Should it be provided?
Policy Level	Clear guidelines aimed at early detection of local recurrence, screening for a new cancer, examination of the patient for treatment-related toxicities and psychosocial support	Australian Government in consultation with Royal Colleges ( e.g. RACGP) Tailored to local circumstances by State Government & Tertiary Centres	At the interface between primary care and specialist services.
Organisational level	Education of patients and families re survivorship issues: Specific emotional issues, anxiety re recurrence, interpersonal issues. Recognition that survivorship may mean chronicity. Carers and families are monitored for psychosocial need as health status changes.	Health professionals	Primary care
Individual Level	Information to patient and family Support for carers. Tailored program subject to the needs and preferences of the patient and their significant others.	Health professionals	Where possible in primary care but with due regard to patient safety.



## Appendix VIII: Palliative Care

Stage: Palliative Care			
	What should be provided	Who should provide it?	Where Should it be provided?
Policy Level	Clearly established referral pathways for patients engaging palliative care services as soon as possible. Establishing guide to appropriate clinical and psycho-social interventions	Australian Government policies To ensure that access to palliative care keeps pace with increasing cancer incidence. Australian Government in consultation with Royal Colleges ( e.g. RACGP, Divisions of General Practice etc)	In all health care facilities
Organisational level	Referral processes to specialist palliative care services for all patients who require end of life care or symptom management.	State Government Tertiary Centres Primary care clinics Hospice organisations	In and outpatient clinics Tertiary Centres Primary care clinics
Individual Level	Patients , carers and families receive services, information and support so that the needs for specialist palliative care input is identified and accessed as soon as possible.	General practitioners, Silver Chain State Government Tertiary Centres NGOs	In the community



Delivering a Healthy WA

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