The cancer journey and domains of specialist nursing practice

Aim

The aim of this module is to develop your understanding of key principles and concepts fundamental to specialist cancer nursing practice. The module focuses specifically on developing an understanding and appreciation of the experience of people affected by cancer throughout the cancer journey, and the key domains of specialist cancer nursing practice which reflect nursing responses to these experiences.

Rationale

The EdCaN National Professional Development Framework for Cancer Nursing identifies several principles which underpin the contribution that nurses make to care of people with cancer. These principles include:

- The priorities, needs and experiences of people affected by cancer should be central to the development of cancer control programs and to specialist cancer nursing practice.
- Nurses make an important contribution to meeting the needs of people affected by cancer across the entire trajectory of the experience of people affected by cancer, including:
    - Reducing the risk of developing cancer
    - Finding cancer as early as possible, if early treatment is effective
    - Having the best treatment and support during active treatment
    - Having the best treatment and support after and between periods of active treatment
    - Having the best care at the end of life if the cancer is not cured.
- Nurses' involvement in cancer control is governed by the values, guidelines and principles set out by regulatory and professional bodies, taking account of current evidence, population health needs and Australian Government priorities in cancer control.
- Nurses need to be responsive to the needs of people affected by cancer, by incorporating new practice areas and capabilities as they evolve, as well as negotiating the scope of practice with other health professionals involved in cancer control.

Key concepts

- The experience of people affected by cancer.
- Cancer care delivery systems.
- Scope of practice for specialist cancer nursing.
- Professional and regulatory standards relevant to SCN practice.
- SCN contribution to cancer control.

Objectives

On completion of this supporting resource, you should be able to:

1. Appreciate the experience and common concerns of people affected by cancer across the cancer journey.
2. Describe contemporary models and principles for delivering cancer services and factors influencing these systems.

3. Evaluate the contribution of specialist cancer nursing practice in responding to the experience of people affected by cancer.
4. Analyse the domains and associated professional standards that inform specialist cancer nursing practice.
5. Evaluate role of specialist cancer nursing in national and international cancer control programs.
6. Analyse factors influencing the development of contemporary cancer nursing

Learning activities

At times, you will have learning activities to complete. Click on the learning activities button and a list of questions will pop up. The questions will relate to the content you've just read or the video you've just watched.

Resource links

Resource links are included throughout the resource. These links lead to interesting articles or websites, and are designed to encourage you to explore other available resources.

PDF of EdCaN module: The cancer journey

You can download a PDF version of the module.

Suggested citation:

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The cancer experience: the person diagnosed with cancer

A diagnosis of cancer has a profound effect on an individual and their family member's health and wellbeing. Cancer is a multisystem disease and its treatments can also have multiple systemic effects. As a potentially life-threatening disease, it is also a condition that is associated with significant fears and concerns. As a result, people affected by cancer can experience consequences across various physical, social, emotional, psychological, information, spiritual and practical aspects. These effects are likely to change over time.

Every individual's experience throughout the cancer experience is unique and affected by a range of factors including:[1]

- developmental stage
- socioeconomic status
- psychosocial supports
- culture.

Common responses to cancer include:[1]

- Psychological issues:
  - body image
  - sexuality
  - interpersonal problems
  - new relationships post diagnosis
  - stress and adjustment reactions/severe emotional distress
  - anxiety, depression, post-traumatic stress disorder (PTSD).

- Practical issues:
  - costs
  - reconstructive surgery
  - lymphoedema
  - travel and accommodation
  - other support needs
  - loss of income
  - difficulties with business dealings
  - legal issues related to advanced disease.

- Physical issues:
  - nausea and vomiting
  - pain
  - fatigue
  - fertility
  - lymphoedema
  - disfigurement
  - odour
  - incontinence
  - bowel dysfunction
  - cognitive problems
  - communication difficulties
  - malnutrition
  - respiratory symptoms

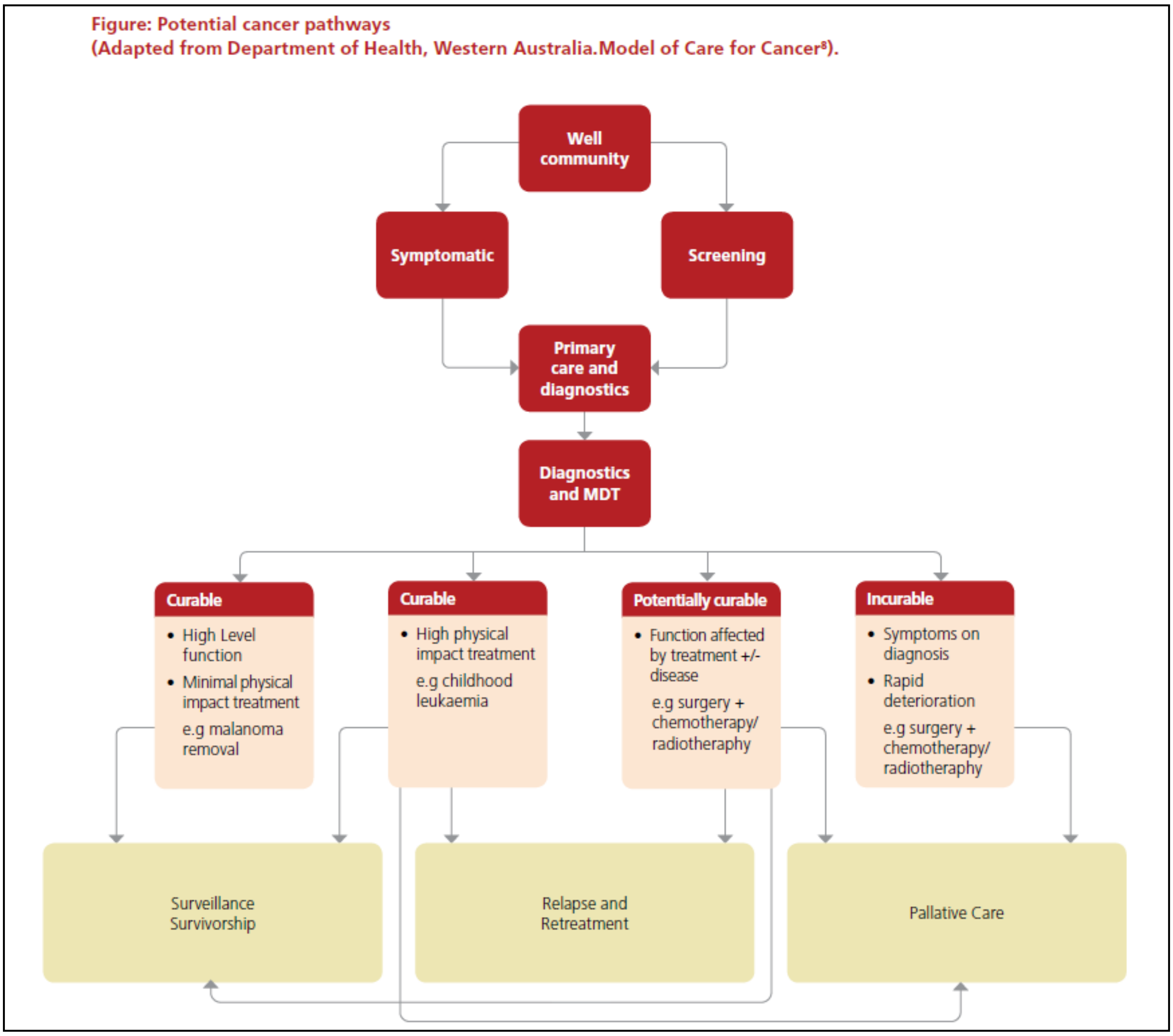
  - end of life concerns.

Learning activities	
Completed	Activities
☐	1. From your experience describe: a. Common perceptions that individuals in our community have about cancer b. The potential implications of these perceptions for how people respond to a diagnosis of cancer.
☐	2. Watch Jane’s story: meet Jane and complete the following learning activity:  a. Describe Jane’s key health and support needs at this time.

The cancer journey

The clinical pathway for individuals diagnosed with cancer varies depending on a range of disease and treatment related factors. A summary of typical clinical pathways for a person diagnosed with cancer is presented in Figure 1. Astute nursing care is based on an understanding that the needs and levels of support required by individuals or their families can vary at different points across the cancer experience.

Figure 1: Potential cancer pathways (Adapted from Department of Health, Western Australia. Model of Care for Cancer).[2]



Learning activities	
Completed	Activities
☐	1. Watch Jane’s story: meet Jane again and complete the following learning activity:  a. How are Jane’s key health and support needs likely to change in the future?
☐	2. Describe differences in support needs for individuals who are being treated for a potentially curable cancer compared to those who disease may not be curable.

The cancer experience for specific populations

Cancer in children

Over the period 2009-2013, among children aged zero-14 in Australia: [3,50]

- 922 new cases of Acute Lymphoblastic Leukaemia (ALL) were diagnosed[50]
- Incidence rates are unchanged from the previous period.
- Higher incidence rates are present for those aged zero - four (21 per 100,000 children)compared with children aged five -nine (10 per 100,000) and 10-14 (12 per 100,000)
- The most common types of new cancer diagnosed were:
    - Acute lymphoblastic leukaemia (4.2 per 100,000 children)
    - Cancer of the brain (1.9 per 100,000 children)
    - Non-Hodgkin lymphomas (0.9 per 100,000 children).

Despite being relatively uncommon in children, cancer is a leading cause of death (19% of all deaths) in children aged one to 14 years in 2009-2011.[4] The outlook for children diagnosed with cancer has improved, with the proportion of zero to 14 year olds surviving five years after diagnosis improving from 68% in 1983-1989 to 81% in 2004-2010.[4]

The family's needs for support are substantial at the time of diagnosis, as they attempt to cope with a serious physical illness and the fear that their child will not be cured.[5]

At diagnosis, parents must adjust to the emotional realisation that their child is living with a life-threatening disease, while simultaneously receiving a large amount of information on how to manage and care for their child during treatment. Parents are very vulnerable during this time, and have an intense need for support from partners, families, friends, employers, hospital staff, and other parents.[6]

How parents respond to their child's diagnosis can also have a profound effect on how the child develops and responds to his/her illness. Factors which may influence how parents react include:[5]

- reactions to previous crises
- reactions of the child
- child rearing practices and attitudes
- available support systems
- perception of the illness
- previous knowledge or experience with cancer
- cultural and religious beliefs
- beliefs about the cause of the disease
- effects of the disease on the family
- concurrent stresses in the family.

Characteristics which affect children's responses include:[5]

- age (most vulnerable - six months to four years)
- development level
- temperament
- social skills and self-concept
- pre-existing conditions and previous experiences
- intelligence level
- type of disease

- reactions of significant others.

Primary caregivers, who are important to the well-being of the child during treatment, need to understand the nature of the disease, treatment options and prognosis in order to participate in treatment decisions and to take on the care roles expected of them.[7,8] Nurses working with children who have cancer have a significant supportive role in:[5,8]

- providing information and supportive care
- helping the family understand the various therapies
- preventing or managing side effects or toxicities
- observing for early and late effects of treatment.

Resource link

Cancer Australia. (2017) EdCaN module: Acute lymphoblastic leukaemia.

Learning activities

Completed	Activities
☐	1. Watch Ellie’s story: experience of diagnosis and complete the following learning activity:  a. Outline the key social and emotional issues Ellie's family may face over the next three months related to Ellie's diagnosis with ALL
☐	2. Access the following resources: • Guidance on cancer services: improving outcomes in children and young people with cancer[8] • Clinical practice guidelines for the psychosocial care of adults with cancer[1] a. Summarise key principles in providing supportive care for people affected by childhood cancer during the diagnostic phase.

Cancer in adolescents and young adults (AYA)

As a group, young people aged 15-24 accounted for 14% of the population in Australia in 2006[9]. The most common cancers affecting AYA (aged 15-29) in the period from 2003-2007 were melanoma (26% of all cancers), gonadal germ cell cancers (13%), and Hodgkin lymphoma (10%).[10]

In the period 2004 – 2010, five-year relative survival for AYA diagnosed with cancer was 88%, which was significantly increased from 80% in 1983 – 1989.[10]

Cancer remains one of the leading causes of death among young Australians.[9] In the period 2003 – 2007:[10]

- there were 1,018 cancer deaths in AYA, comprising 9.2% of all deaths in this age group
- the leading causes of cancer death were brain cancer, bone cancer and melanoma of the skin.

Adolescence is a time of dramatic change in physical growth, awareness of body image, and concepts of personal and social self.[11] AYA affected by cancer have numerous additional challenges and require specific psychological and social support throughout their cancer journey.

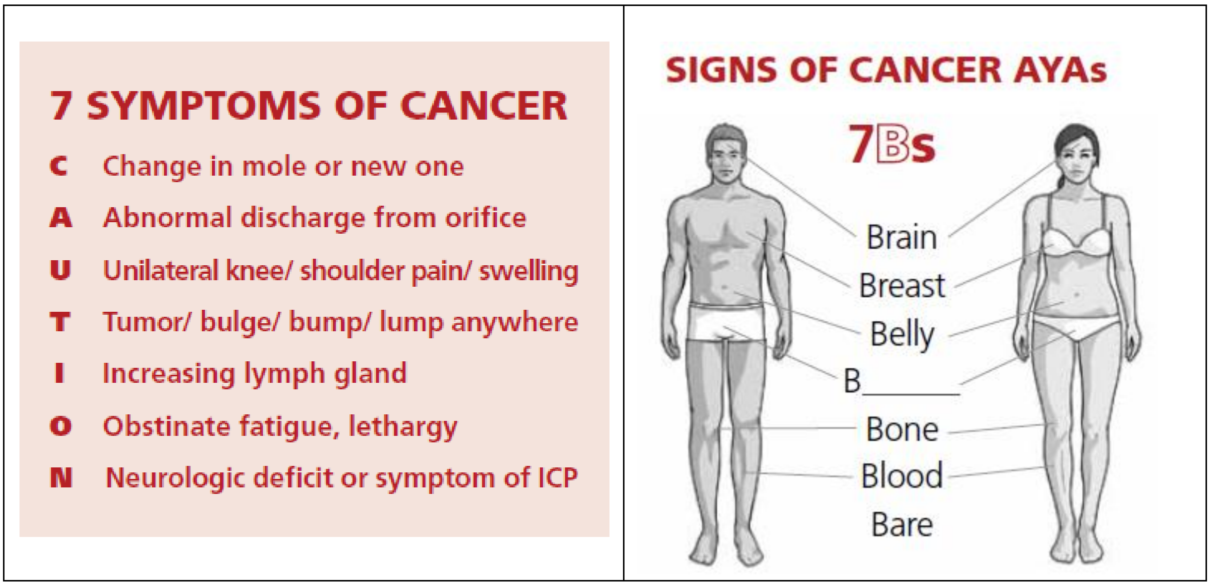
The uncertainty, self-consciousness, emotional reactivity and still developing cognitive abilities of AYA, combined with their increased exposure to risky situations, makes diagnosis particularly difficult during this life stage. AYAs need individualised care plans that recognise individual diagnoses, circumstances, and developmental stages.[12] Working with AYA affected by cancer necessitates focusing on how normal life can be maintained while minimising psychological distress.[13]

Reactions to diagnosis of cancer in AYA are complex and affected by family relationships, culture, chronological and psychological development. Any care provided must be multi-dimensional and incorporate the needs of the family. While there is limited research about the needs of AYA families specifically, there is some evidence that cancer affects the whole family and that family members can experience significant distress.[14]

The increased demands on family associated with the high care needs of a person with cancer can result in restricted social relationships, work and other responsibilities and practical problems related to disease management and finances.[14]

Generally, there is a lack of awareness in the AYA population and primary health care providers of signs and symptoms for early diagnosis of cancer in this group. Developmental, psychological and social factors may place AYA at higher risk of a delay in diagnosis.[15]

Figure 2: The '7 symptoms' increase awareness of early clues to cancer diagnosis in AYA.[16] (Permission to reproduce images provided by author).



7 SYMPTOMS OF CANCER

C Change in mole or new one
A Abnormal discharge from orifice
U Unilateral knee/ shoulder pain/ swelling
T Tumor/ bulge/ bump/ lump anywhere
I Increasing lymph gland
O Obstinate fatigue, lethargy
N Neurologic deficit or symptom of ICP

Resource link
Cancer Australia. (2017) EdCaN module: Osteosarcoma case based learning resource.

Learning activities	
Completed	Activities
☐	1. Watch Justin's story: dealing with diagnosis as he describes his reaction to a diagnosis of osteosarcoma. You may also wish to access the Adolescent and Young Adult Cancer National Service Delivery Framework[17]. Complete the following learning activity:  a. Describe Justin's key health and support needs now and into the future.
☐	2. Access the Adolescent and Young Adult Cancer National Service Delivery Framework[17], and outline the implications of this Framework for Specialist Cancer Nurses involved in the care of AYA.

Cancer in the older person

In 2012 it is estimated that 75 per cent of new cancer cases will be diagnosed in men aged 60 years and over, and 65 per cent in women aged 60 years and over. The prevalence of a previous cancer diagnosis increases with age, with the highest prevalence among those aged 80 and over. Almost one fifth (19%) of all Australians aged 80 and over had had a diagnosis of cancer within the previous 26 years (26 year prevalence). This represents approximately 3.3% of the Australian population.[18]

Psychosocial changes associated with ageing and multiple co-morbidities in older people can influence the type of treatment and support required.[19] The unique treatment and care needs of older people with cancer have been described as a new specialty termed 'geriatric oncology'.[19] Studies suggest that changes associated with ageing can sometimes lead to older people receiving suboptimal treatment, or treatment that is not consistent with their personal preferences.[19, 20] Some studies report that older people with aggressive lymphoma are less likely to be treated for cure than younger people with the same disease and are less likely to survive for five years due to limited access to clinical trials.[21]

Beneficent ageism refers to a neglect of an older person's wishes. The older person's social role is distorted and health professionals assume an ability to represent the older person’s best interests without endorsement from them.[22]

Additional complications can arise in the older person due to co-morbidity factors. Comprehensive geriatric assessments can help to support decision making in relation to treatment plans for older people.[23] The following factors should be taken into account when assessing the older person with cancer:[24-26]

- functional status
- co-morbidity
- cognition
- social support
- psychological state
- concomitant medications
- nutrition
- continence
- carer support.

Resource link

Cancer Australia. (2017) EdCaN module: Lymphoma.

Learning activities	
Completed ☐	Activities 1. Watch Arthur's story: meet Arthur. You may also wish to access the NCCN clinical practice guidelines for oncology – senior adult oncology.[26] Complete the following learning activity:  a. Describe the issues Arthur may experience across all domains of health related to a diagnosis of cancer.

The cancer experience in culturally and linguistically diverse (CALD) groups

Access to and effective engagement with health services by CALD individuals and communities may be impeded by their lack of familiarity with the health system, and lack of consideration of the health and spiritual beliefs of different cultures.[27]

Cultural safety extends beyond cultural awareness and cultural sensitivity and has at its core the experience of the person receiving care.[28]Cultural safety principles aim to ensure:

- individuals receive care that meets their cultural needs and promotes feelings of being safe[28, 29]
- individuals are not afforded less favourable outcomes because they hold a different cultural outlook[29]
- care provided is respectful towards culture[29]
- there is no assault, challenge or denial of an individual's identity, of who they are and what they need.[30]

A culturally safe approach to care requires health professionals to:

- be aware and mindful of their personal attitudes and values towards gender, race, religion and sexuality
- be self-aware and reflect on their practice
- understand post-colonisation
- apply the principles of effective communication and be aware of different styles of communication
- be inclusive
- act respectfully to empower individuals[29]
- promote shared respect, meaning, knowledge and experiences.[30]

Unsafe cultural practice occurs when actions diminish, demean or disempower the cultural identity of an individual.[29]

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Three steps towards cultural safety

Developing culturally safe practice requires the capacity to make adjustments to services that accommodate culturally different needs. The process of developing culturally safe practices requires the participation of individuals and organisations in three broad steps:[31]

Step 1: Cultural consciousness or awareness of the constructs of one's own culture and recognition of unique and similar qualities of other cultural groups. Engagement with minority cultural groups is imperative to the process of cultural consciousness and building collaborative cancer control programs.
Step 2: Cultural appraisal or assessment to identify cultural domains of difference that need to be considered in the plan of person-family centred cancer care.
Step 3: Cultural safety skill development of appropriate behaviours, attitudes, and communication strategies that reduce the gap of inequities in cancer outcomes.

Resource link

Cancer Australia. (2017) EdCaN module: head and neck cancer.

Learning activities	
Completed	Activities
☐	1. Describe strategies you can use to avoid stereotypes and ensure that you apply the principles of cultural safety to every individual in your care.
☐	2. Watch Mrs Li's story: symptoms and complete the following learning activities:  a. Reflect on the family relationships and cultural background within the case study, and explain how you would develop an understanding the implications of Mrs Li's beliefs, values and customs in planning her care. b. If Mrs Li was admitted to your health facility, describe how you would ensure access to an appropriate interpreter service.

The cancer experience of Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander peoples experience great disparity throughout the cancer journey. The incidence of cancer in Aboriginal and Torres Strait Islander peoples is lower or similar to the general population. However, they experience higher morbidity and mortality rates.[32]

Epidemiological data demonstrate a number of differences in cancer incidence, survival and patterns of care between Indigenous and non-Indigenous peoples in Australia. Compared to non-Indigenous peoples, Indigenous people are more likely to:[33]

- be diagnosed with cancer at a later stage of the disease
- have poorer survival rates
- show increasing rates for some types of cancer
- have higher rates of preventable and particularly smoking-related cancers
- be less likely to have timely access to diagnostic methods and to continue cancer treatment.

To respond to these disparities, effective and culturally appropriate cancer control measures are required which consider the health beliefs influencing Aboriginal and Torres Strait Islander people's perception of cancer. Indigenous views, understandings and perspectives on cancer can vary between geographical location, communities and individuals. However some common themes concerning Indigenous beliefs in Australia that can influence the cancer experience and responses to a diagnosis of cancer for Indigenous people include:[32]

- cancer means death
- cancer is a "White man's disease"
- punishment / curse / payback
- cancer is contagious
- people's minds, feelings and perceptions have the power to fight cancer
- redetermined / destiny / fatalism
- cancer is not a priority here
- bodies are sacred.

Policy documents also recommend a number of health service design strategies to reduce disparities in Australia:[32]

- Improved data infrastructure (to identify health needs and to monitor outcomes of service initiatives for Aboriginal and Torres Strait Islander peoples).
- Prevention (to reduce high risk behaviours and improve screening participation)
- Programs (need to assess the impact on Aboriginal health of all cancer control programs).
- Service delivery (comprehensive review of best approaches to facilitate and sustain Aboriginal ownership and involvement in all aspects of service delivery.

Resource link
Cancer Australia. (2017). EdCaN module: Cancer Care for Aboriginal and Torres Strait Islander Peoples.

Learning activities	
Completed ☐	Activities 1. Access An overview of cancer and beliefs about the disease in Indigenous people of Australia, Canada, New Zealand and the US,[33] and: a. Summarise some of the cultural meanings of cancer that may be held by Indigenous peoples in Australia. b. Outline how these beliefs may influence models of care and principles for delivering cancer services to meet the needs of Indigenous people affected by cancer.

Care delivery approaches in cancer

Survival and quality of life depend on early detection and referral to an appropriate multidisciplinary team for diagnosis, and a best practice treatment plan accompanied by supportive care.[34]

People affected by cancer have multiple complex needs. Multidisciplinary care is increasingly viewed as the optimal standard of care as a range of disciplines are required to achieve optimal outcomes. Multidisciplinary care has been described as 'an integrated team approach to health care in which medical and allied health care professionals consider all relevant treatment options and develop collaboratively an individual treatment plan for the person affected by cancer'.[35]

A multidisciplinary approach is important not just in the diagnosis and treatment phase, but also in survivorship and end-of-life care. The specific contribution of various disciplines will vary, depending on the health and support needs of the individual over time. Multidisciplinary care is highlighted as a priority area in several national cancer policy documents as well as state and territory cancer plans and discussion papers. Tumour specific clinical practice guidelines also incorporate recommendations for multidisciplinary care.[36]

Care delivery approaches also need to be responsive to the needs of people living in rural and regional Australia who experience difficulties accessing services and have poorer cancer outcomes reported. Seamless coordination of care is also required to navigate the complex health system across multiple settings in both the private and public sectors.[37]

In response to identified needs of people affected by cancer in Australia, models of care have been developed at a state wide level to improve care delivery.[2] Broad national initiatives include:[38]

- establishing new infrastructure:
    - building integrated cancer centres
    - funding for regional cancer centres
- establishing nationally agreed and consistent best practice cancer protocols and pathways of care
- investing in health promotion activities to prevent cancer.

The success of significant investments and initiatives in cancer control is dependent on the availability and effectiveness of a workforce to service them. The National Cancer Workforce Strategic Framework (May 2013)[39] provides advice to governments and service providers on the key issues for the cancer workforce and identifies innovation and reform that has the potential for national application. It focuses on enabling the cancer health workforce to provide appropriate, efficient and well-coordinated care for people affected by cancer and their families, from diagnosis, treatment and support to the management of follow-up care and survivorship.

The report and initiatives in its wake will have significant implications for Specialist Cancer Nurses if the vision of the Framework is delivered upon in which the cancer workforce:[39]

- Operates to its full scope of practice
- Is flexible to changing requirements
- Uses expert clinical staff in the most efficient and effective manner
- Eliminates unnecessary duplication of activities for consumers at all points of care.

Learning activities	
Completed	Activities
☐	1. Develop a comprehensive list of service providers involved in care of people affected by cancer in your setting.
☐	2. Describe the strategies used to facilitate multidisciplinary approaches to care in your setting.
☐	3. Discuss what role a specialist cancer nurse has in facilitating the multidisciplinary approach to care.
☐	4. Access Ensuring Quality Cancer Care Through the Oncology Workforce[40] . Discuss how the strategies identified to overcome workforce shortages of the oncology workforce in USA could be relevant at in Australia.

The scope of cancer nursing practice

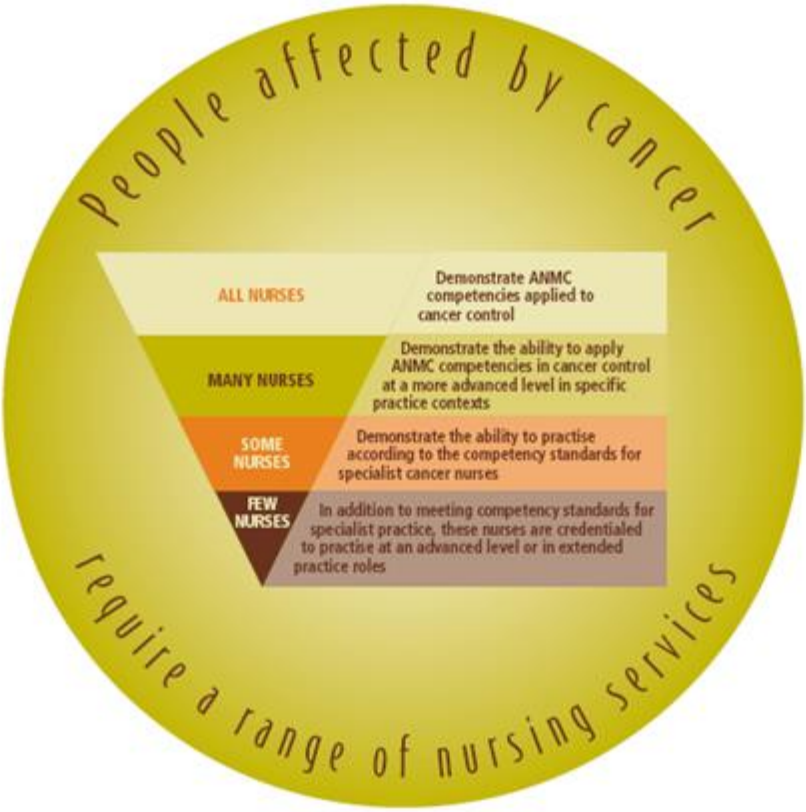
A range of health and support services from community, primary, secondary and tertiary care agencies are required to address the needs of the person with cancer. Nurses are an essential component of service provision across all stages of the cancer experience. The contribution of nurses in cancer control in Australia is guided by the National professional development framework for cancer nursing.[41]

The EdCaN Framework builds on a national service improvement framework and establishes expectations of all nurses working in cancer control. The EdCaN Framework: [41]

- Promotes a person centred approach which is population based
- Recognises that people affected by cancer have many, and often complex, needs requiring a multidisciplinary approach to which nurses can make important contributions
- Is in line with the values, guidelines and principles set out by regulatory and professional bodies
- Takes into account current evidence, population health needs and Australian government priorities in cancer control
- Recommends that nurses be responsive to new practice areas and capabilities as they evolve
- Recognises the importance of practice, education and research informing improvements to care.

The model presented in Figure 3 describes the varying contributions that nurses provide to all phases of the cancer continuum. It outlines the competencies that nurses require when working in different roles, in different settings and at different points along this continuum.

Figure 3: Professional development model for nursing in cancer control[41]



The competency standards for Specialist Cancer Nurses (SCNs) are intended for those nurses who choose to become specialists in cancer control. The standards are designed for nurses who work in dedicated cancer services and who are - primarily responsible for the care of people at a specific phase of their journey (for example, radiotherapy); across all phases of the cancer journey (for example, specialist breast nursing[42]); or who work in a broader context but provide a specialist resource in cancer control to a range of generalist providers (for example, a cancer nurse coordinator). The competency standards are intended to represent the minimum standard required for specialist practice in cancer nursing. As their specialist practice advances, SCNs will demonstrate more effective integration of theory, practice and experiences along with increasing degrees of autonomy in terms of judgments and interventions for people affected by cancer.[43]

Resource link
Cancer Learning webpage. Nursing PD Pathways

Learning activities	
Completed	Activities
☐	1. Access the EdCaN Framework[41] , and read the principles underpinning the development of this document. For each principle, provide one practical example of how you can apply the principle in your practice.
☐	2. Access the EdCaN Framework[41] and then: a. Summarise the four broad groups identified within the nursing workforce in cancer control. b. Identify examples of individuals or groups of nurses from each group within the model in your local area.
☐	3. Discuss how well you believe the Specialist Cancer Nurse Competency standards reflect your current specialist practice.
☐	4. Discuss how the EdCaN Competency standards may be used to improve cancer nursing practice.
☐	5. Access the Specialist Cancer Nurse Competency standards. Develop a professional development plan for the next 12 months based on these criteria. You may wish to use the Specialist cancer nurse professional development portfolio.

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