

Optimal care pathway for people with oesophagogastric cancer



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Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple health care providers and covers a range of institutions, both public and private. The optimal care pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

The optimal care pathways are based on a revision of the original patient management frameworks (Department of Health 2007a) which had, for the first time, attempted to map the cancer pathway in an easily understandable form.

The purpose of this work is to improve patient outcomes by facilitating consistent cancer care based on a standardised pathway of care. The pathways are applicable to care whether it is provided in a public or private service. The principles and the expected standards of good cancer care are not expected to differ, even though treatment regimens may vary from patient to patient for a whole variety of reasons.

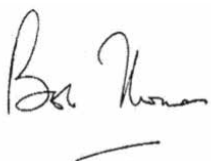
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments (COAG) in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care.

The NCERG has subsequently endorsed these new optimal care pathways, which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

A wide range of clinicians, peak health organisations, consumers and carers were consulted and/or participated in their development and I want to thank all concerned for their generous contributions.

I am sure that those providing cancer care will find the specific pathways useful in deciding how best to organise service delivery to achieve the best outcomes for those we care for.

Importantly, readers should note that these care pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.



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Summary

Please note that not all patients will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1

Prevention and early detection

Prevention: Smoking cessation is associated with a reduced risk of oesophagogastric cancers.

Risk factors: There are very few people at high risk. People with the following risk factors are at increased risk:

Oesophageal adenocarcinoma	Male gender, obesity, gastro-oesophageal reflux, barrett's oesophagus, smoking, alcohol and age.
Oesophageal SCC	Heavy alcohol consumption, tobacco smoking, age, caustic injury and achalasia.
Gastric cancer	Age, <i>helicobacter pylori</i> (<i>H. pylori</i>) bacteria, previous partial gastrectomy, especially more than 20 years ago, tobacco smoking, pernicious anaemia and family history of gastric cancer.

Early detection: Awareness of risk factors and high-risk individuals can guide appropriate referral for specialist input and potentially surveillance.

Careful monitoring of Barrett's oesophagus may lead to early detection of cancer.

Step 2

Presentation, initial investigations and referral

Signs and symptoms:

- dysphagia (difficulty swallowing)
- persistent epigastric pain/dyspepsia
- pain on swallowing
- food bolus obstruction
- unexplained weight loss or anorexia
- haematemesis (vomiting blood) and/or melena
- early satiety
- unexplained nausea/bloatedness or anaemia.

The following symptoms require urgent consultation (within two weeks):

- new onset or rapidly progressive dysphagia
- progressive/new epigastric pain persisting for more than two weeks.

General/primary practitioner investigations: All people identified in high-risk categories should be referred for diagnostic endoscopy if presenting with symptoms.

Referral: Refer to an upper gastrointestinal (GI) surgeon with expertise in oesophagogastric cancer who is an active participant in an upper GI cancer multidisciplinary team (MDT).

Urgent referral by the specialist may also be required to allied health practitioners (particularly a dietitian) prior to an MDT meeting.

Communication – lead clinician to:

- explain to the patient/carer who they are being referred to and why
- support the patient and carer while waiting for specialist appointments.

Step 3

Diagnosis, staging and treatment planning

Diagnosis and staging: Biopsy material from a diagnostic endoscopy should be reviewed by an expert pathologist prior to MDT discussion.

Staging may include the following.

For oesophageal junction cancers:

- computed tomography (CT) scan of the thorax, abdomen and pelvis
- endoscopic ultrasound
- positron emission tomography (PET) scan
- endoscopic resection.

For gastric cancer:

- CT scan of the thorax, abdomen and pelvis
- focal endoscopic resection (in early lesions)

- laparoscopy (gastric/junctional cancer).

Treatment planning: All newly diagnosed patients should be discussed in an MDT meeting within four weeks of referral to agree treatment plan.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the MDT in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

¹ Lead clinician – the clinician who is responsible for managing patient care.

The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Step 4

Treatment:

Establish intent of treatment:

- curative
- anti-cancer therapy to improve quality of life and/ or longevity without expectation of cure
- symptom palliation.

Treatment options: Given the poor prognosis of this cancer at present, for the majority of patients, treatment is often given with palliative rather than curative intent. Early specialist palliative care will be required.

Endoscopic treatments:

Suitable for high-grade dysplasia and selected cases of early cancer.

Surgery: Surgical resection is considered to offer the best long-term survival chance.

Palliative resection for late-stage disease is not recommended.

Chemotherapy or drug therapy:

This may be indicated for:

- locally advanced disease (pre- or postoperatively or as primary treatment)
- patients with HER2-positive advanced adenocarcinoma of the stomach, combined with targeted therapy (trastuzumab).

Radiation therapy: This may be indicated as part of:

- neoadjuvant therapy prior to surgery
- definitive chemoradiation (unresectable locally advanced disease) (oesophageal/ oesophagogastric cancers)
- symptom palliation.

Patients with metastatic disease should be assessed for suitability for chemoradiation, palliative chemotherapy and/ or targeted therapy, or other treatments such as radiation therapy or stent.

Palliative care: Review by a specialist palliative care team is essential. Early referral can improve quality of life.

Communication – lead clinician to:

- discuss treatment options with the patient/carer including the intent of treatment as well as the risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

Step 5

Care after initial treatment and recovery

Treatment summary (provide a copy to the patient/carer and general practitioner) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

Follow-up care plan (provide a copy to the patient/carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)

- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the patient/carer
- inform the patient/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the patient's general practitioner.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Treatment of a recurrent, residual or metastatic oesophagogastric cancer is rarely curative.

Treatment: Where possible, refer the patient to the original MDT. For the majority of patients, cancer-directed treatment is often given with palliative rather than curative intent.

Palliative care: Review by a specialist palliative care team is essential. Referral should be based on need, not prognosis. Early referral can improve quality of life.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Ensure that an advance care plan is in place.

Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the patient/carer
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Optimal timeframes

Timeframes should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress. The following recommended timeframes are based on expert advice from the Oesophagogastric Cancers Working Group.

Step in pathway	Care point	Timeframe
Presentation, Initial Investigations and Referral	2.1 GP appointment	A patient with concerning (red flag) symptoms should be seen by their GP within two weeks.
	2.2 Referral for endoscopy	Endoscopy completed within two weeks.
	2.3 Specialist appointment	Within two weeks. Imaging/workup as directed by the specialist may precede but should not delay referral.
Diagnosis, Staging and Treatment Planning	3.1 Diagnosis	Workup needs to be complete for presentation at MDT within two weeks of diagnosis.
	3.2 Staging	
	3.3 Multidisciplinary meeting	Within four weeks of GP referral.
Treatment	4.2 Treatment	Within two weeks of MDT discussion.

Intent of the optimal care pathway

The optimal care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased care for people with cancer.

The pathway aligns with key service improvement priorities, including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The optimal care pathway can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality improvement initiatives across all aspects of the care pathway. The pathway can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

The following key principles of care underpin the optimal care pathway.

Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Patient- or consumer-centred care is increasingly being recognised as a dimension of high-quality healthcare in its own right, and there is strong evidence that a patient-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness as well as patient, family and staff satisfaction (ACSQHC 2013).

Safe and quality care

This is provided by appropriately trained and credentialed clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care. It incorporates collecting and evaluating treatment and outcome data to improve the patient experience of care as well as mechanisms for ongoing service evaluation and development to ensure practice remains current and informed by evidence. Services should routinely be collecting relevant minimum datasets to support benchmarking, quality care and service improvement.

Multidisciplinary care

This is an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient. There is increasing evidence that multidisciplinary care improves patient outcomes.

The benefits of adopting a multidisciplinary approach include:

- improving patient care through developing an agreed treatment plan
- providing best practice through adopting evidence-based guidelines
- improving patient satisfaction with treatment
- improving the mental wellbeing of patients
- improving access to possible clinical trials of new therapies
- increasing the timeliness of appropriate consultations and surgery and a shorter timeframe from diagnosis to treatment
- increasing the access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007b).

Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes. Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

All members of the multidisciplinary team (MDT) have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool) of the patient and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key points along the care pathway, particularly at times of increased vulnerability including:

- initial presentation or diagnosis (zero to three months)
- commencement of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- survivorship
- recurrence
- change in or development of new symptoms
- palliative
- end-of-life care.

Following each assessment, potential interventions need to be discussed with the patient and carer, and a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

Common indicators in patients with oesophagogastric cancers that may require referral for support include:

- malnutrition (as identified using a validated malnutrition screening tool or presenting with weight loss)
- pain
- difficulty managing fatigue
- difficulty sleeping
- distress, depression or fear
- poor performance status
- living alone or being socially isolated
- having caring responsibilities for others
- cumulative stressful life events
- existing mental health issues
- Aboriginal or Torres Strait Islander status
- being from a culturally and linguistically diverse background.

Depending on the needs of the patient, referral to an appropriate health professional(s) and/or organisations should be considered including:

- psychologist or psychiatrist
- genetic counsellor
- community-based support services (such as Cancer Council Victoria)
- dietitian
- exercise physiologist
- nurse practitioner and/or specialist nurse
- occupational therapist
- physiotherapist
- peer support groups (contact the Cancer Council on 13 11 20 for more information)
- social worker
- specialist palliative care
- speech therapist.

See the **appendix** for more information on supportive care and the specific needs of people with oesophagogastric cancer.

Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure that care is delivered in a logical, connected and timely manner so the medical and personal needs of the patient are met.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including MDT meetings, supportive care screening and assessment, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of individual patients and should therefore be considered in their practice. Enhancing continuity of care across the health sector requires a whole-of-system response – that is, initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007c).

Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families and carers are met. Every person with cancer will have different communication needs, including cultural and language differences. Communication with patients should be:

- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families.

In communicating with patients, healthcare providers should:

- listen to patients and act on the information provided by them
- encourage expression of individual concerns, needs and emotional states
- tailor information to meet the needs of the patient, their carer and family
- use professionally trained interpreters when communicating with people from culturally and linguistically diverse backgrounds
- ensure the patient and/or their carer and family have the opportunity to ask questions
- ensure the patient is not the conduit of information between areas of care (it is the providers' and healthcare system's responsibility to transfer information between areas of care)
- take responsibility for communication with the patient
- respond to questions in a way the patient understands
- enable all communication to be two-way.

Healthcare providers should also consider offering the patient a Question Prompt List (QPL) in advance of their consultation, and recordings or written summaries of their consultations. QPL interventions are effective in improving communication, psychological and cognitive outcomes of cancer patients (Brandes et al. 2014). The provision of recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway. Research and clinical trials play an important role in establishing efficacy and safety for a range of interventions in treatment of cancer, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcberg 2013).

While individual patients may or may not receive a personal benefit from the intervention, there is evidence that outcomes for participants in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation in research and clinical trials will contribute to the care of cancer patients in the future (Peppercorn et al. 2004).

Optimal care pathway

The optimal care pathway outlines seven critical steps in the patient journey. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management and patient decisions, and physiological response to treatment).

The pathway covers oesophagogastric cancers (oesophageal adenocarcinoma, oesophageal squamous cell carcinoma (SCC) and gastric malignancies). In Australia, more than 2,000 people are diagnosed with gastric cancer each year and around 1,400 with oesophageal cancer (AIHW 2014).

Special considerations

Survival outcomes for oesophageal cancer are poor when compared with other types of cancer, with only 16 per cent of people diagnosed surviving their cancer for five years or more. Approximately two-thirds of patients with oesophageal cancer have inoperable disease at the time of diagnosis. Survival outcomes for gastric cancer are also relatively poor compared with other cancers, with only 27 per cent of patients surviving five years after diagnosis (AIHW 2014).

Even if there are good initial treatment outcomes, the recurrence rate is very high. Given the poor prognosis of this cancer at present, for the majority of patients, treatment is often given with palliative rather than curative intent. Early specialist palliative care will be required for patients with oesophagogastric cancers.

The pathway describes the optimal cancer care that should be provided at each step.

Step 1: Prevention and early detection

This step outlines recommendations for the prevention and early detection of oesophageal and gastric cancers.

1.1 Prevention

Eating a healthy diet, avoiding or limiting alcohol intake, regular exercise and maintaining a healthy body weight may help reduce cancer risk. For more information see the *Lifestyle risk factors and primary prevention cancer* resource at <<http://cancer australia.gov.au/publications-and-resources/position-statements>>.

Smoking cessation is associated with a reduced risk of oesophagogastric cancers (NCI 2013; 2015).

1.2 Risk factors

Certain regions of the world have a higher incidence of oesophageal and gastric cancer. This variation of incidence by region is multifactorial and involves different environmental exposures and genetic diversity of the populations, most likely related to dietary factors. Australia has a high rate of adenocarcinoma of the oesophagus and a lower incidence of SCC – this is reversed in Asian countries. These risk factors persist in newer recent immigrants and should be factored into risk assessments.

There are very few people at high risk. However, people with the following risk factors are at increased risk:

Oesophageal adenocarcinoma	Oesophageal SCC	Gastric cancer
<ul style="list-style-type: none">• Male gender• Obesity• Gastro-oesophageal reflux• Barrett's oesophagus• Smoking• Alcohol• Age	<ul style="list-style-type: none">• Heavy alcohol consumption• Tobacco smoking• Age• Caustic injury• Achalasia	<ul style="list-style-type: none">• Age• <i>Helicobacter pylori</i> (<i>H. pylori</i>) bacteria• Previous partial gastrectomy, especially more than 20 years ago, usually for benign ulcer disease• Tobacco smoking• Pernicious anaemia• Family history of gastric cancer (hereditary gastric cancer exists)

1.3 Screening

There are no formal population-based screening programs for oesophagogastric cancers in Australia.

1.4 Early detection

Awareness of the risk factors and of who is at high-risk can guide appropriate referral for specialist input and potentially surveillance – for example, Barrett's oesophagus, achalasia, genetic predisposition.

Careful monitoring of Barrett's oesophagus may lead to an early detection of cancer, and early treatment may lead to better outcomes. Surveillance should be conducted by specialists with expertise in endoscopy and the management of Barrett's oesophagus. Surveillance of patients with Barrett's oesophagus may include regular (as per clinical guidelines) upper endoscopies and tissue biopsies. The frequency of surveillance is based on the presence or absence of dysplasia. Refer to Cancer Council Australia's guidelines available at <<http://wiki.cancer.org.au/australia/Guidelines:Barrett's>>.

Reflux symptoms in patients with Barrett's oesophagus should be adequately treated (medically or surgically). There is emerging data that suggests multifocal gastric intestinal metaplasia may also warrant specialist evaluation.

If there is high-grade dysplasia in Barrett's oesophagus, subsequent treatment is usually advised. Patients with high-grade dysplasia should be discussed in an MDT meeting (refer to section 3.3). After such discussion, treatment might include endoscopic therapies or surgery (Cancer Research UK 2014).

Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral.

2.1 Signs and symptoms

The following signs and symptoms should be investigated promptly, particularly where there is new onset or changes in long-term symptoms:

- dysphagia (difficulty swallowing, especially bread or meat)
- persistent epigastric pain/dyspepsia
- pain on swallowing
- food bolus obstruction
- unexplained weight loss or anorexia
- haematemesis (vomiting blood) and/or melena
- early satiety
- unexplained persistent nausea/bloatedness or anaemia.

The following symptoms are of particular concern and require urgent consultation:

- new-onset or rapidly progressive dysphagia
- progressive/new epigastric pain persisting for more than two weeks.

See the National Institute for Clinical Excellence's (NICE) guidelines on suspected cancer recognition and referral (NICE 2015) at <www.nice.org.uk/guidance>.

Timeframe for general practitioner consultation

Timeframes for GP consultation should be informed by evidence-based guidelines where they exist while recognising that that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on expert advice from the Oesophagogastric Cancer Working Group:¹

- A patient with red flag symptoms that may be concerning for oesophagogastric cancer should be seen by their GP within two weeks.

¹ The multidisciplinary experts group who participated in a clinical workshop to develop content for the oesophagogastric cancer optimal care pathway are listed in the acknowledgements list.

2.2 Assessments by the general or primary medical practitioner

All people identified in high-risk categories should be triaged for rapid access to endoscopy if presenting with symptoms (for example, bleeding or dysphagia) consistent with upper gastrointestinal (GI) cancer. The GP should refer to an endoscopist for diagnostic endoscopy.

Qualifications of the endoscopist

The endoscopist should be accredited by the Conjoint Committee for Endoscopy Training and be working in an accredited facility.

Timeframe for referral for endoscopy

Timeframes for referring for endoscopy should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on expert advice from the Oesophagogastric Cancer Working Group:

- A patient with suspicion of oesophagogastric cancer should have an endoscopy completed within two weeks.

2.3 Referral

If oesophagogastric cancer is diagnosed, the patient should be referred to an upper GI surgeon with expertise in oesophagogastric cancer who is an active participant in an upper GI MDT meeting.

An upper GI cancer nurse coordinator should work with the surgeon to facilitate the referral and management process in specialist units.

The specialist should provide timely communication to the GP about the consultation and should notify the GP if the patient does not attend appointments.

Referral for suspected oesophagogastric cancer should incorporate appropriate documentation sent with the patient including:

- a letter that includes important psychosocial history and relevant medical history, family history, current medications and allergies
- results of current clinical investigations (imaging and pathology reports)
- results of all prior relevant investigations
- notification if an interpreter service is required.

If access is via online referral, a lack of a hard copy (of results) should not delay referral.

Timeframe for referral to a specialist

Timeframes for referral should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on expert opinion of the Oesophagogastric Cancer Working Group:

- Where there is a confirmed diagnosis or high level of suspicion, the patient should be seen by an upper GI surgeon within two weeks.
- Imaging and workup as directed by the specialist may precede referral but should not delay referral.

Urgent referral by the specialist may also be required to allied health practitioners (particularly a dietitian) for assessment and management of symptoms prior to an MDT meeting or confirmed diagnosis.

The supportive and liaison role of the GP and practice team in this process is critical.

2.4 Support and communication

2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified needs of an individual, their carer and family; referral should be as required.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- referral to a dietitian for nutritional assessment and support
- physical and GI symptoms such as dysphagia, pain, nausea, vomiting, mucositis, anorexia, cachexia and indigestion
- may require access to urgent endoscopy for removal of food bolus obstruction
- emotional distress of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties
- financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients, caring arrangements for other family members)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

2.4.2 Communication with the patient, carer and family

Effective communication is essential at every step of the care pathway. Effective communication with the patient and carer is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults) (ACSQHC 2013).

The general or primary practitioner should:

- provide the patient with information that clearly describes who they are being referred to, the reason for referral, and the expected timeframe for appointments
- support the patient while waiting for the specialist appointment.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer, and planning subsequent treatment. The guiding principle is that interaction between appropriate MDT members should determine the treatment plan.

3.1 Diagnostic workup

Biopsy material from diagnostic endoscopy in individuals with oesophageal or gastric cancer should be reviewed by an experienced histopathologist prior to MDT discussion (Okines et al. 2010). Pathology of the resection specimen should be reviewed in an MDT meeting.

3.2 Staging

Staging is the cornerstone of treatment planning and prognosis. Pathologists should use synoptic reporting. Staging will be tailored to the cancer location, type or presentation and may include the following.

For oesophageal cancer and oesophagogastric junction cancers:

- CT scan of the thorax, abdomen and pelvis
- endoscopic ultrasound
- PET scan (Okines et al. 2010, NHS 2011, South Australia Health 2010)
- endoscopic resection, which can provide staging information for selected early cancers.

For gastric cancer:

- CT scan of the thorax, abdomen and pelvis
- focal endoscopic resection (in early lesions)
- laparoscopy, which should be considered for gastric/junctional cancer to exclude metastatic disease and assess resectability (Okines et al. 2010, NHS 2011, South Australia Health 2010).

In addition, the following tests may be required:

- full blood count
- liver and renal function tests
- pulmonary and cardiac assessment to assess fitness for therapy.

Timeframe for completing diagnostic and staging investigations

Timeframes for completing diagnostic and staging investigations should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Oesophagogastric Cancer Working Group:

- Complete staging workup needs to be done to allow presentation at the MDT meeting within two weeks of diagnosis.

3.3 Treatment planning

3.3.1 Responsibilities of the multidisciplinary team

These are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided)
- nominate a team member to coordinate patient care
- develop and document an agreed treatment plan at the MDT meeting
- circulate the agreed treatment plan to relevant team members, including the GP.

3.3.2 Responsibilities of individual team members

The general or primary medical practitioner who made the referral is responsible for the patient until care is passed to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment and coordination and continuity of care, as well as providing information and support to the patient and their family.

The care coordinator is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The care coordinator may change over the course of the pathway.

The lead clinician is responsible for overseeing the activity of the team.

3.3.3 Members of the multidisciplinary team for gastric and oesophageal cancers

The MDT should comprise the core disciplines integral to providing good care. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some patients (Department of Health 2007b).

Team members may include a(n):

- upper GI cancer care nurse (with appropriate expertise)*
- oesophagogastric surgeon*
- medical oncologist (with expertise in oesophagogastric cancers)*
- radiation oncologist (with expertise in oesophagogastric cancers)*
- dietitian*
- interventional endoscopist *
- radiologist/nuclear medicine *
- palliative care specialist*
- pathologist*
- gastroenterologist
- clinical trials coordinator
- GP
- occupational therapist
- physiotherapy
- psycho-oncology
- social worker.

* Core members of the MDT are expected to attend most MDT meetings either in person or remotely.

3.3.4 The optimal timing for multidisciplinary team planning

For oesophagogastric cancers, MDT discussion should occur before definitive treatment, and after tissue diagnosis and staging. The level of discussion may vary depending on both the clinical and psychosocial factors.

Timeframes for treatment planning at MDT meetings should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Oesophagogastric Cancer Working Group:

- Patients with an oesophagogastric cancer should be discussed at an MDT meeting within four weeks of GP referral.

Results of all relevant tests and imaging should be available for the MDT discussion. Information about the patient's concerns, preferences and social circumstances should also be presented at the meeting by the care coordinator or treating clinician (Department of Health 2007b).

There may also need to be a review of existing treatment plans for patients who have been discussed previously.

3.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <www.australiancancertrials.gov.au>.

3.5 Prehabilitation, support and communication

3.5.1 Prehabilitation

Cancer prehabilitation uses a multidisciplinary approach combining exercise, nutrition and psychological strategies to prepare patients for the challenges of cancer treatment, such as surgery, chemotherapy, immunotherapy and radiation therapy.

Evidence indicates that prehabilitation of newly diagnosed cancer patients prior to starting treatment can be beneficial. This may include conducting a physical and psychological assessment to establish a baseline function level, identifying impairments and providing targeted interventions to improve the patient's health, thereby reducing the incidence and severity of current and future impairments related to cancer and its treatment (Silver & Baima 2013).

Medications should be reviewed at this point to ensure optimisation and to improve adherence to medicines used for comorbid conditions.

3.5.2 Supportive care

Screening with a validated screening tool (for example, the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific needs that may arise at this time include:

- nutritional assessment and support
 - Patients requiring oral nutrition support or feeding via enteral nutrition, or patients in whom a stent has been placed, should receive support from dietitians with expertise in managing these interventions before, during and after treatment.
 - Weight loss due to GI symptoms, difficulty swallowing and decrease in appetite can be a significant issue for patients and may require referral to a dietitian before, during and after treatment. Validated malnutrition screening tools should be used at the key points in the care pathway to identify patients at risk of malnutrition.
- physical and GI symptoms such as dysphagia, pain, nausea, vomiting, mucositis, anorexia, cachexia and indigestion
- access to urgent endoscopy for removal of food bolus obstruction (if required)
- psychological and emotional distress while adjusting to the diagnosis, treatment phobias, existential concerns, stress, difficulties making treatment decisions, anxiety/depression and interpersonal problems
- financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients, and caring arrangements for other family members)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

3.5.3 Communication with the patient

The lead clinician should:

- establish if the patient has a regular or preferred GP
- discuss a timeframe for diagnosis and treatment with the patient and carer
- discuss the benefits of multidisciplinary care and make the patient aware that their health information will be available to the team for discussion at the MDT meeting
- offer individualised gastric and oesophageal cancer information that meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information and support from websites, community and national cancer services and support groups
- utilise a professionally trained interpreter when communicating with people from culturally or linguistically diverse backgrounds (NICE 2004).

3.5.4 Communication with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the patient's GP regarding the treatment plan and recommendations from MDT meetings and should notify the GP if the patient does not attend appointments
- ensure regular and timely (within a week) communication with the GP regarding the treatment plan and recommendations from MDT meetings
- gather information from the GP, including their perspective on the patient (psychological issues, social issues and comorbidities) and locally available support services
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss management of shared care
- invite the GP to participate in MDT meetings (consider using video or teleconferencing).

Step 4: Treatment

Step 4 outlines the treatment options for oesophagogastric cancers.

4.1 Treatment intent

The intent of treatment can be defined as one of the following:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

The morbidity and risks of treatment need to be balanced against the potential benefits.

The lead clinician should discuss treatment intent and prognosis with the patient and carer(s) prior to beginning treatment.

If appropriate, advance care planning should be initiated with patients at this stage as there can be multiple benefits such as ensuring a person's preferences are known and respected after the loss of decision-making capacity (AHMAC 2011).

4.2 Treatment options

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the patient. Broadly:

- Early-stage disease (stage 1/node-negative, non-bulky) may be considered for surgery alone.
- Locally advanced disease (stage II, stage III) may be considered for neoadjuvant therapy (chemotherapy or chemoradiation) followed by surgery
- Metastatic disease (stage IV) should be treated with palliative intent. Palliative oesophageal resection is not recommended.

4.2.1 Endoscopic treatments

In the oesophagus, endoscopic therapies can be used for high-grade dysplasia and select cases of early cancer as a less morbid and potentially equally effective treatment option in comparison with oesophagectomy/gastrectomy (Cancer Council Australia 2014, Uedo et al. 2012).

For oesophageal cancers, following endoscopic resection the remaining Barrett's mucosa should be eradicated (Cancer Council Australia 2014).

Endoscopic treatment is also feasible for selected high-grade dysplasia of the stomach and early gastric cancers.

4.2.2 Surgery

At present, surgical resection is considered to offer the best long-term survival chances for oesophagogastric cancers.

Palliative oesophageal resection for late-stage disease is not recommended.

The training and experience required of the surgeon are as follows:

Surgeon (Fellow of the Royal Australasian College of Surgeons (FRACS) or equivalent) with adequate training and experience in oesophagogastric surgery with institutional credentialling and agreed scope of practice within this area.

There is **strong evidence** that higher volume hospitals have better clinical outcomes for complex cancer surgery such as oesophagogastric resections (Ross et al. 2014).

There is also evidence that surgeons who undertake a higher volume of resections have better clinical outcomes for complex cancer surgery such as oesophagogastric resections (Gruen et al 2009; Killeen et al 2005). Patients undergoing radical oesophagogastric surgery should be treated at specialist centres that have integrated expertise in endoscopy, imaging, interventional radiology, surgery and histopathology and treat a high volume of these cases. Centres that do not meet the above criteria should routinely refer cases to a centre with experience in that type of case.

Hospital or treatment unit characteristics for providing safe and quality care include:

- an intensive care unit familiar with oesophagogastric surgery
- appropriate ward staff, nursing and theatre resources to manage complex surgery
- 24-hour medical staff availability
- 24-hour operating room access
- access to a specialist pathology service
- 24-hour access to interventional radiology
- fully supported by other surgical specialties
- specialist anaesthetists.

4.2.3 Chemotherapy

For locally advanced oesophageal cancer, neoadjuvant chemotherapy with or without radiotherapy followed by surgery is superior to surgery alone (NHS 2011).

For gastric cancer in Western countries, the evidence supports perioperative chemotherapy. In selected cases, patients may be offered adjuvant chemotherapy or adjuvant chemoradiotherapy.

In patients with HER2-positive advanced adenocarcinoma of the stomach, targeted therapy with trastuzumab combined with chemotherapy may be considered.

Patients with unresectable locally advanced disease, patients with resectable locally advanced disease but who are unfit for surgery, and patients with metastatic disease should be assessed for suitability for chemoradiation, palliative chemotherapy and/or targeted therapy, or other treatments such as radiotherapy or a stent.

Training, experience and treatment centre characteristics:

- Medical oncologists (Fellow of the Royal Australasian College of Physicians (FRACP) or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).
- Nurses must have adequate training in chemotherapy administration and handling and disposal of cytotoxic waste.
- Chemotherapy should be reviewed by a pharmacist with cancer services expertise, including adequate training in cytotoxic chemotherapy medication and dosing calculations according to protocols, formulations and/or preparation.
- In a setting where no medical oncologist is locally available, some components of less complex therapies may be delivered by a medical practitioner and/or nurse with training and experience with credentialling and agreed scope of practice within this area, under the guidance of a medical oncologist. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required.

Hospital or treatment unit characteristics for providing safe and quality care include:

- a clearly defined path to emergency care and advice after hours
- access to basic haematology and biochemistry testing
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including safe prescribing, preparation, dispensing, supplying, administering, storing, manufacturing, compounding and monitoring the effects of medicines (ACSQHC 2011)
- guidelines and protocols available to deliver treatment safely (including dealing with extravasation of drugs)
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not collocated.

4.2.4 Radiation therapy

Radiation therapy alone offers a benefit for symptom palliation such as dysphagia, pain and bleeding in advanced oesophagogastric cancer.

For oesophageal/oesophagogastric cancers, radiotherapy may be indicated as part of:

- neoadjuvant therapy prior to surgery
- definitive chemoradiotherapy for locally advanced disease in patients who are not able to undergo surgery (for example, medical comorbidity or patient choice)
- palliation in symptomatic individuals with metastatic disease such as dysphagia.

For gastric cancer, radiotherapy may be indicated:

- in the postoperative setting in combination with chemotherapy in selected patients who have undergone a gastrectomy for locally advanced gastric cancer
- in the palliative setting, either in combination with chemotherapy or as the sole therapy for palliation of symptoms.

Training and experience of radiation oncologist

Radiation oncologist (Fellow of the Royal Australian and New Zealand College of Radiologists (FRANZCR) or equivalent) with adequate training and experience that enables institutional credentialing and agreed scope of practice within this area (ACSQHC 2004).

Hospital or treatment unit characteristics for providing safe and quality care include:

- radiotherapy nurses, physicists and radiation therapists
- access to CT/MRI/PET scanning for simulation and planning
- mechanisms for coordinating chemotherapy and radiation therapy, especially where facility is not collocated
- access to allied health and advice.

4.2.5 Treatment of locally advanced inoperable disease

Patients with symptomatic locally advanced or recurrent oesophageal/oesophagogastric cancers should be assessed for chemoradiation, radiotherapy alone or systemic chemotherapy. Radiotherapy is an effective and well-tolerated modality for treating dysphagia. For patients in whom radiotherapy is not appropriate, endoscopic placement of a stent should be considered. To minimise the risk of tracheoesophageal fistula and stent migration, stent insertion ideally should not precede radiotherapy.

Patients with inoperable, locally advanced oesophagogastric/gastric cancer should be assessed for palliative chemotherapy. In some patients with gastric cancer there may be a role for surgical palliation or endoscopic stent placement for distal gastric cancer.

Timeframe for commencing treatment

Timeframes for commencing treatment should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Oesophagogastric Cancer Working Group:

- Treatment should be started within two weeks of a decision to treat by the MDT.

4.3 Palliative care

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

- Patients may be referred to palliative care at initial diagnosis.
- Patients should be referred to palliative care at the first recurrence or progression.
- Carer needs may prompt referral.

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for poor-prognosis cancers (Temel et al. 2010). Furthermore, palliative care has been associated with the improved wellbeing of carers (Higginson & Evans 2010; Hudson et al. 2015).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

For more information refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

4.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <www.australiancancertrials.gov.au>.

4.5 Complementary or alternative therapies

The lead clinician should discuss the patient's use (or intended use) of complementary or alternative therapies not prescribed by the MDT to discuss safety and efficacy and identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the patient's reason for using these therapies and the evidence base.

Most alternative therapies and some complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective.

Some complementary therapies may assist in some cases and the treating team should be open to discussing the potential benefits for the individual.

If the patient expresses an interest in using complementary therapies, the lead clinician should consider referring them to health professionals within the MDT who have a knowledge of complementary and alternative therapies (for example, a clinical pharmacist, dietitian or psychologist) to assist them to reach an informed decision.

The lead clinician should assure patients who use complementary or alternative therapies that they can still access MDT reviews (NBCC & NCCI 2003) and encourage full disclosure about therapies being used (Cancer Australia 2010).

Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <<http://canceraustralia.gov.au/publications-and-resources/position-statements>>.
- See the Clinical Oncology Society of Australia's position statement at <www.cosa.org.au/publications/position-statements.aspx>.

4.6 Support and communication

4.6.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals and/or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- referral to a dietitian for nutritional assessment and support
 - During treatment and the acute recovery phase, malnutrition is common and requires dietitian input. The benefits of enteral nutrition should also be considered at all stages of treatment and recovery.
 - Patients requiring oral nutrition support or enteral feeding, or patients in whom a stent has been placed, should receive support from dietitians with expertise in managing these interventions before, during and after treatment.
 - Weight loss due to GI symptoms, difficulty swallowing and decrease in appetite can be a significant issue for patients. Patients may require referral to a dietitian before, during and after treatment. Validated malnutrition screening tools (such as the Malnutrition Screening Tool (MST)) should be used at the key points in the care pathway to identify patients at risk of malnutrition.
- physical symptoms such as pain or dysphagia
- GI symptoms (such as nausea, vomiting, mucositis, loss of appetite, early satiety and taste changes) as a result of chemotherapy treatment, requiring optimal symptom control with medication and referral to a dietitian if dietary intake is affected
- assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications (referral to a pharmacist may be required)
- decline in mobility and/or functional status as a result of treatment (referral to an occupational therapist may be required)
- emotional and psychological issues including, but not limited to, body image concerns, fatigue, existential anxiety, treatment phobias, anxiety/depression, interpersonal problems and sexuality concerns
- potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment
- financial issues related to loss of income and additional expenses as a result of illness and/or treatment
- legal issues (such as advance care planning, appointing medical and financial powers of attorney, completing a will)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

4.6.2 Communication with the patient, carer and family

The lead clinician should:

- discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes, and provide a written plan
- provide the patient and carer with information on the possible side effects of treatment, self-management strategies and emergency contacts
- initiate a discussion regarding advance care planning with the patient and carer.

4.6.3 Communication with the general practitioner

The lead clinician should:

- discuss with the GP their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding:
 - the treatment plan, including intent and potential side effects
 - supportive and palliative care requirements
 - the patient's prognosis and their understanding of this
 - enrolment in research and/or clinical trials
 - changes in treatment or medications
 - recommendations from the MDT.

Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completion of initial treatment, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the MDT. Transition from acute to primary or community care will vary depending on the type and stage of cancer and needs to be planned. In some cases, people will require ongoing, hospital-based care.

5.1 Survivorship

Oesophagogastric cancers have a poor prognosis, and five-year survival rates are relatively low compared with other cancers. In Australia, five-year survival is 16 and 27 per cent for people diagnosed with oesophageal and gastric cancer, respectively (AIHW 2014). International research shows there is an important need to focus on helping cancer survivors cope with life beyond their acute treatment. Cancer survivors experience particular issues, often different from patients having active treatment for cancer.

Many cancer survivors experience persisting side effects at the end of treatment. Emotional and psychological issues include distress, anxiety, depression, cognitive changes and fear of cancer recurrence. Late effects may occur months or years later and are dependent on the type of cancer treatment. Survivors may experience altered relationships and may encounter practical issues, including difficulties with return to work or study, and financial hardship.

Survivors generally need to see a doctor for regular followup, often for five or more years after cancer treatment finishes. The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes four essential components of survivorship care (Hewitt et al. 2006):

- the prevention of recurrent and new cancers, as well as late effects
- surveillance for cancer spread, recurrence or second cancers; and screening and assessment for medical and psychosocial late effects
- interventions to deal with the consequences of cancer and cancer treatments (including management of symptoms, distress and practical issues)
- coordination of care between all providers to ensure the patient's needs are met.

All patients should be educated in managing their own health needs (NCSI 2015).

5.2 Post-treatment care planning

5.2.1 Treatment summary

Upon completion of initial treatment, the patient, the patient's nominated carer (as appropriate), and GP should receive a treatment summary outlining:

- the diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

5.2.2 Follow-up care

Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues), as well as individual clinical and supportive care needs. It is important that post-treatment care is evidence-based and consistent with guidelines.

Responsibility for follow-up care should be agreed between the lead clinician, the patient's GP, relevant members of the MDT and the patient, with an agreed plan documented that outlines:

- what medical follow-up is required (surveillance for cancer spread, recurrence or secondary cancers, screening and assessment for medical and psychosocial effects)
- care plans from other health professionals to manage the consequences of cancer and treatment
- a process for rapid re-entry to specialist medical services for suspected recurrence.

In particular circumstances, follow-up care can safely and effectively be provided:

- in the primary care setting
- by other suitably trained staff (for example, nurse-led follow-up)
- in a non-face-to-face setting (for example, by telehealth).

The options for follow-up care should be discussed at the completion of the primary treatment.

A patient's follow-up schedule will be planned based on their individual circumstances. Investigations should be determined on a case-by-case basis.

There is currently no high-level evidence on which to base advice about medical follow-up after treatment for upper GI cancers. A general guide is:

- Asymptomatic patients require three-monthly follow-up, including a comprehensive history and physical examination, for two years, followed by a six-monthly assessment until five years post-surgery or as long as is deemed appropriate.
- Following endoscopic therapy, patients will require endoscopic surveillance tailored to their individual circumstances.
- Investigations should only be undertaken if clinically indicated.
- A physical examination and nutrition assessment by an experienced dietitian should take place at intervals of three to six months for two years, and then six-monthly until five years post-treatment.

Ongoing nutritional counselling and support from a dietitian may be required, and information on how to access nutritional services should be provided to the patient and/or caregiver. Access to a range of other health professions may be required including physiotherapy, occupational therapy, nursing social work, genetic counselling and psychology.

5.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <www.australiancancertrials.gov.au>.

5.4 Support and communication

5.4.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals and/or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- nutritional assessment and support
 - Malnutrition post-treatment due to ongoing treatment side effects (including weight loss, reduced oral intake and cachexia) is common and requires monitoring and nutrition intervention by a dietitian.
 - Patients requiring oral nutrition support or enteral feeding, or patients in whom a stent has been placed, should receive support from dietitians with expertise in managing these interventions before, during and after treatment.
 - GI symptoms (including vomiting, mucositis, reflux and early satiety), difficulty swallowing and decrease in appetite can be a significant issue for patients. Patients may require referral to a dietitian before, during and after treatment. Validated malnutrition screening tools (for example, the MST) should be used at the key points in the care pathway to identify patients at risk of malnutrition.
- physical symptoms such as dysphagia or pain
- decline in mobility and/or functional status as a result of treatment (referral to an occupational therapist may be required)
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns
- a need for increased community supports as the patient recovers from treatment
- financial and employment issues (such as loss of income and assistance with returning to work, and the cost of treatment, travel and accommodation)
- legal issues (such as advance care planning, appointing medical and financial powers of attorney, completing a will)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway, from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

5.4.3 Palliative care

The lead clinician should ensure patients receive a timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

- Patients may be referred to palliative care at initial diagnosis.
- Patients should be referred to palliative care at the first recurrence or progression.
- Carer needs may prompt referral.

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for poor-prognosis cancers (Temel et al. 2010). Furthermore, palliative care has been associated with the improved wellbeing of carers (Higginson & Evans 2010; Hudson et al. 2015).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

For more information, refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

5.4.4 Communication with the patient, carer and family

The lead clinician should:

- explain the treatment summary and follow-up care plan
- provide information on the signs and symptoms of recurrent disease
- provide information on secondary prevention and healthy living.

5.4.5 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the GP regarding:

- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- the patient's progress
- recommendations from the MDT
- any shared care arrangements
- a process for rapid re-entry to medical services for patients with suspected recurrence.

Step 6: Managing recurrent, residual, or metastatic disease

Step 6 is concerned with managing recurrent or residual local and metastatic disease. If oesophagogastric cancer recurrence is detected, the patient should be discussed at the MDT to explore the possibility of further management.

6.1 Signs and symptoms of recurrent, residual or metastatic disease

Treatment of recurrent, residual or metastatic oesophagogastric cancers is rarely curative and metastatic oesophagogastric cancer is usually associated with a poor prognosis. For the majority of patients, treatment is often given with palliative rather than curative intent.

6.2 Multidisciplinary team

Even though the majority of patients with oesophageal and gastric cancer are not curable, the MDT can still play an important role in discussing appropriate management. In those patients with recurrent or residual disease there should be timely referral to the original MDT (where possible) and thereby quick access to specialist input into care.

Active involvement by the patient's GP and review by a specialist palliative care team is essential. Responsibility for follow-up care should be agreed between the specialist MDT and GP, with an agreed plan outlining whether the lead clinician role should be transferred to the GP or specialist palliative care.

6.3 Treatment

If oesophagogastric cancer recurrence is detected, the patient should be restaged and discussed at the MDT to explore the possibility of further management.

Treatment will depend on the location and extent of disease, previous management and the patient's preferences.

Potential therapies include radiotherapy (for localised recurrence), chemotherapy (for systemic disease), combined chemo-radiation and endoscopic stenting as a palliative option.

Participation in research and/or clinical trials should be encouraged where available and appropriate.

6.4 Palliative care

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

- Patients may be referred to palliative care at initial diagnosis.
- Patients should be referred to palliative care at the first recurrence or progression.
- Carer needs may prompt referral.

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for poor-prognosis cancers (Temel et al. 2010). Furthermore, palliative care has been associated with the improved wellbeing of carers (Higginson & Evans 2010; Hudson et al. 2015).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

Begin discussions with the patient and carer about their preferred place of death.

For more information refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

6.5 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <www.australiancancertrials.gov.au>.

6.6 Support and communication

6.6.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals and/or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- dietician referral for nutrition assessment and management/support to maintain quality of life and assist with managing symptoms
- surgical intervention for palliation of symptoms of advanced gastric cancer
- active treatment for dysphagia – radiotherapy or a stent may be required for advanced oesophageal cancer
- physical and GI symptoms such as dysphagia, pain, nausea, vomiting, mucositis, anorexia, cachexia and indigestion
- access to urgent endoscopy for removal of food bolus obstruction (if required)
- acute events such as catastrophic haemorrhage, perforation or obstruction
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- decline in mobility and/or functional status as a result of recurrent disease and treatments (referral to an occupational therapist may be required)
- increased practical and emotional support needs for families and carers, including help with family communication, teamwork and care coordination where these prove difficult for families
- emotional and psychological distress resulting from fear of death, complications of chemotherapy, existential concerns, anticipatory grief, communicating wishes to loved ones, interpersonal problems and sexuality concerns
- financial issues as a result of disease recurrence (such as early access to superannuation and insurance)
- legal issues (such as advance care planning, appointing medical and financial powers of attorney, developing a will)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

6.6.2 Rehabilitation

Rehabilitation may be required at any point of the care pathway, from preparing for treatment through to disease-free survival and palliative care. Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

6.6.3 Communication with the patient, carer and family

The lead clinician should ensure there is adequate discussion with the patient and carer about the diagnosis and recommended treatment, including the intent of treatment and its possible outcomes, likely adverse effects and supportive care options available for both the patient and their family/carer.

Step 7: End-of-life care

End-of-life care is appropriate when the patient's symptoms are increasing and functional status is declining. Step 7 is concerned with maintaining the patient's quality of life and addressing their health and supportive care needs as they approach the end of life, as well as the needs of their family and carer. Consideration of appropriate venues of care is essential. The principles of a palliative approach to care need to be shared by the team when making decisions with the patient and their family.

7.1 Multidisciplinary palliative care

If not already involved, referral to palliative care should be considered at this stage (including nursing, pastoral care, palliative medicine specialist backup, inpatient palliative bed access as required, social work and bereavement counselling) with GP engagement.

If not already in place, the patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

The multidisciplinary palliative care team may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or spiritual advisor
- bereavement counsellor
- therapist (for example, music or art).

The team might also recommend accessing:

- home- and community-based care
- specialist community palliative care workers
- community nursing.

Consideration of an appropriate place of care and preferred place of death is essential.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

For more information refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

7.2 Research and clinical trials

Participation in research and clinical trials should be encouraged where available and appropriate.

For more information visit <www.australiancancertrials.gov.au>.

7.3 Support and communication

7.3.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals and/or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues identified in the **appendix**, specific issues that may arise at this time include:

- comfort measures to manage nutritional and hydration needs
- physical and GI symptoms such as dysphagia, pain, nausea, vomiting, mucositis, anorexia, cachexia and indigestion
- acute events such as catastrophic haemorrhage, perforation or obstruction
- decline in mobility and/or functional status impacting on the patient's discharge destination (referral to an occupational therapist may be required)
- emotional and psychological distress from anticipatory grief, fear of death, anxiety/depression, interpersonal problems and anticipatory bereavement support for the patient as well as their carer and family
- practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the patient
- legal issues relevant to people with advanced disease such as accessing superannuation early, advance care planning, powers of attorney and completing a will
- information for patients and families about arranging a funeral
- specific spiritual needs that may benefit from the involvement of pastoral care
- bereavement support for family and friends
- specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs.

7.3.2 Communication with the patient, carer and family

The lead clinician should:

- provide clear, simple and appropriate information to patients and their carers about possible acute events and ensure 24-hour access to support
- be open to and encourage discussion about the expected disease course, with due consideration to personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the patient and carer with the contact details of a palliative care service.

7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care and transition planning to ensure the patient's needs and goals are addressed in the appropriate environment. The patient's GP should be kept fully informed and involved in major developments in the patient's illness trajectory.

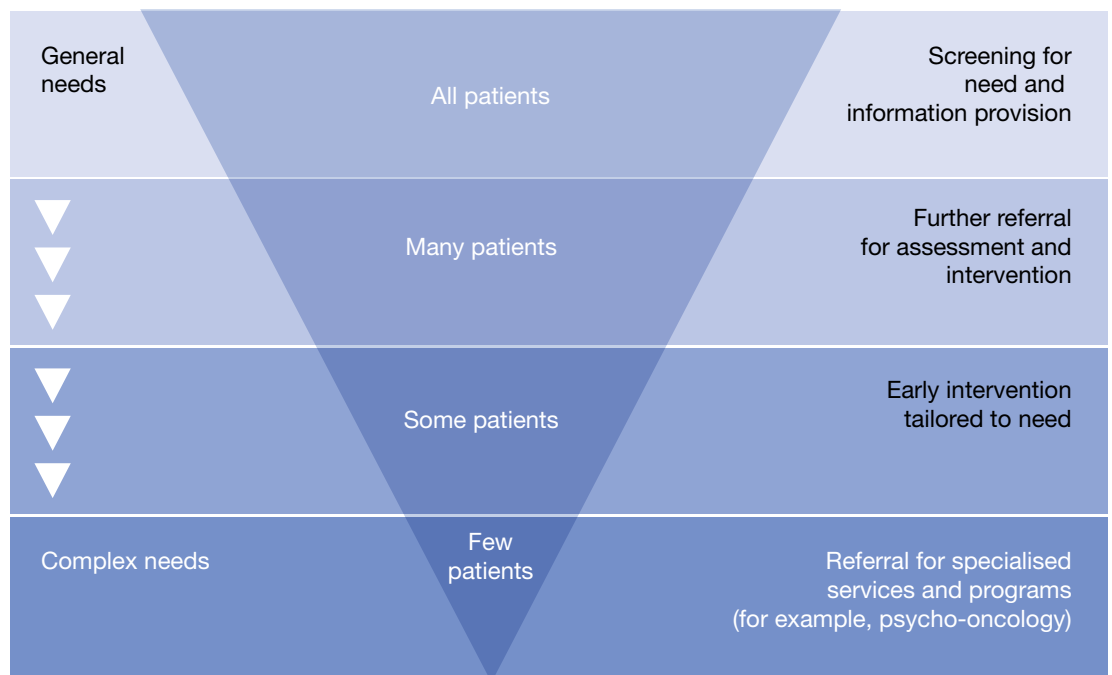
Appendix: Supportive care

Supportive care in cancer refers to the following five domains:

- physical domain, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation (NBCC & NCCI 2003)
- psychological domain, which includes a range of issues related to the person's mental health and personal relationships (NBCC & NCCI 2003)
- social domain, which includes a range of social and practical issues that will impact on the individual and family such as the need for emotional support, maintaining social networks and financial concerns (NICE 2004)
- information domain, which includes access to information about cancer and its treatment, support services and the health system overall (NBCC & NCCI 2003)
- spiritual domain, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns (NICE 2004).

Fitch's (2000) model of supportive care (Figure 1) recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual. The model targets the type and level of intervention required to meet patients' supportive care needs.

Figure 1: The tiered approach



While all patients require general information, some will require specialised intervention. Common indicators in patients with oesophagogastric cancers that may require referral to appropriate health professionals and/or organisations include the following.

Physical needs

- Provide nutritional assessment and support:
 - During treatment and the acute recovery phase, malnutrition is common and requires dietitian input. The benefits of enteral nutrition should also be considered at all stages of treatment and recovery.
 - Patients requiring oral nutrition support or enteral feeding, or patients in whom a stent has been placed, should receive support from dietitians with expertise in managing these interventions before, during and after treatment.
 - Weight loss due to GI symptoms, difficulty swallowing and decrease in appetite can be a significant issue for patients and may require referral to a dietitian before, during and after treatment. Validated malnutrition screening tools should be used at the key points in the care pathway to identify patients at risk of malnutrition.
- Many patients need help to manage physical symptoms such as dysphagia and pain.
- Gastrointestinal symptoms (such as nausea, vomiting, mucositis, loss of appetite) as a result of chemotherapy treatment often require optimal symptom control with medication and referral to a dietitian if dietary intake is affected.
- As the majority of people with oesophagogastric cancers are elderly, the rapid deterioration of their self-care is likely and this may require early consideration of hospice care placement.
- Reduced sexual interest and sexual dysfunction may require referral to medical specialists. Sensitive discussion and referral to a clinician skilled in this area may be appropriate.
- Alteration of cognitive functioning in patients treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information.
- Referral to a pharmacist may be useful for people managing multiple medications.
- Although treatments have improved, nausea and vomiting are still serious side effects of cancer therapy. Some patients are bothered more by nausea than by vomiting. Managing both is important for improving quality of life.

Psychological needs

- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, gay, bisexual, transgender, and intersex (LGBTI) communities) a cancer diagnosis can come with additional psycho-social complexities. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some people may have disabling symptoms and may benefit from referral to psychology services.
- Distress and depression can be just as common in carers and family members including children.
- Consider a referral to a psychologist, psychiatrist or social worker if the patient is:
 - displaying emotional cues such as tearfulness, distress, avoidance or withdrawal
 - preoccupied with or dwelling on thoughts about cancer and death
 - displaying fears about the treatment process and/or the changed goals of their treatment
 - worried about loss associated with their daily function, dependence on others and loss of dignity
 - becoming isolated from family and friends and withdrawing from company and activities that they previously enjoyed
 - feeling hopeless and helpless about the impact that cancer is having on their life and the disruption to their life plans
 - struggling with communicating to family and loved ones about the implications of their cancer diagnosis and treatment
 - experiencing changes in sexual intimacy, libido and function
 - struggling with the diagnosis of metastatic or advanced disease
 - having difficulties with quitting drug and alcohol use
 - having difficulties transitioning to palliative care.

Fertility preservation

- Consider the need for sperm storage or egg banking before treatment. Referral to fertility counselling may be appropriate.

Social/practical needs

- A diagnosis of cancer can have significant financial, social and practical impacts on patients, carers and families as outlined above.
- Consider referral to a peer support group.
- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.

Spiritual needs

- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.
- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.

Populations with special needs

Elderly people with cancer (70 years or older)

Given that the average age of people diagnosed with an oesophagogastric cancer is 69 years, the majority of people with oesophagogastric cancers are elderly and may therefore experience a rapid deterioration. Their ability to self-care means it is likely that they may require early consideration of hospice care placement.

Planning and delivery of appropriate cancer care for elderly people presents a number of challenges. Improved communication between the fields of oncology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as implications of cognitive impairment on suitability of treatment and consent (Steer et al. 2009).

A national interdisciplinary workshop convened by the Clinical Oncology Society of Australia recommended that people over the age of 70 undergo some form of geriatric assessment, in line with international guidelines (COSA 2013). Assessment can be used to determine life expectancy and treatment tolerance as well as identifying conditions that might interfere with treatment including:

- function
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional status
- social supports.

Aboriginal and Torres Strait Islander communities

The burden of cancer is higher in the Australian Indigenous population (AIHW 2014). Survival also significantly decreases as remoteness increases, unlike the survival rates of non-Indigenous Australians. Aboriginal and Torres Strait Islander people in Australia have high rates of certain lifestyle risk factors including tobacco smoking, higher alcohol consumption, poor diet and low levels of physical activity (Cancer Australia 2013). The high prevalence of these risk factors is believed to be a significant contributing factor to the patterns of cancer incidence and mortality rates in this population group (Robotin et al. 2008).

In caring for Aboriginal and Torres Strait Islander people diagnosed with cancer, the current gap in survivorship is a significant issue. The following approaches are recommended to improve survivorship outcomes (Cancer Australia 2013):

- Raise awareness of risk factors and deliver key cancer messages.
- Develop evidence-based information and resources for the community and health professionals.
- Provide training for Aboriginal and Torres Strait Islander health workers and develop training resources.
- Increase the understanding of barriers to care and support.
- Encourage and fund research.
- Improve knowledge within the community to act on cancer risk and symptoms.
- Improve capacity of Aboriginal and Torres Strait Islander health workers to provide cancer care and support to their communities.
- Improve system responsiveness to cultural needs.
- Improve our knowledge through targeted priority research.
- Improve our understanding of gaps through data monitoring.

Culturally and linguistically diverse (CALD) communities

For people from CALD backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In many languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis. In addition to different cultural beliefs, when English language skills are limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for patients. A professionally trained interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those born overseas, and particular attention should be paid to supporting these patients (Department of Health 2009).

Resource list

For patients, families and carers

Australian Cancer Survivorship Centre

General and tumour-specific information primarily focused on the post-treatment survivorship phase.

- Telephone: (03) 9656 5207
- <www.petermac.org/cancersurvivorship>

beyondblue

Information on depression, anxiety and related disorders, available treatment and support services.

- Telephone: 1300 22 4636
- <www.beyondblue.org.au>

Cancer Australia

Information on cancer prevention, screening, diagnosis, treatment and supportive care for Australians affected by cancer, and their families and carers.

- Telephone: 1800 624 973
- <www.canceraustralia.gov.au>

Cancer Council (operated by Cancer Council Victoria)

A confidential telephone support service for people affected by cancer that provides information on treatment, cancer support groups and other community resources.

- Telephone: 13 11 20
(Monday to Friday, 8.30 am – 5.30 pm)
- <www.cancervic.org.au>

Care Search: Palliative Care Knowledge Network

Information for patients and carers on living with illness, practical advice on how to care, and finding services.

- Telephone: (08) 7221 8233
- <www.caresearch.com.au>

For health professionals

Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are recruiting new participants.

- <www.australiancancertrials.gov.au>

Cancer Australia

Information including guidelines, cancer guides, reports, fact sheets, DVDs, posters and pamphlets.

- <www.canceraustralia.gov.au>

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority.

- <www.cancer.org.au>

eviQ

Clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment.

- <www.eviq.org.au>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment.

- <www.nhmrc.gov.au>

For detailed information on treatment guidelines refer to:

- NHS (2011) guidelines for the management of oesophageal and gastric cancer at <<http://www.medscape.com/viewarticle/751024>>
- European Society for Medical Oncology (2013) clinical practice guidelines for oesophageal cancer at <http://annonc.oxfordjournals.org/content/24/suppl_6/vi51.full.pdf>.

Glossary

Advance care planning – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

Alternative therapies – treatments that are used in place of conventional medical treatment, often in the hope they will provide a cure.

Care coordinator – the health professional nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and where care is primarily located.

Complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life, and help people deal with the side effects of cancer.

End-of-life care – a distinct phase of palliative care, appropriate when a patient's symptoms are increasing and functional status is declining despite anti-cancer therapy.

General/primary medical practitioner – the practitioner to whom the patient first presents with symptoms. This may be the general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

Lead clinician – the clinician who is responsible for managing patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Multidisciplinary care – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each patient (Department of Health 2007b).

Multidisciplinary team – comprises the core disciplines integral to providing good care. The team is flexible in approach, reflects the patient's clinical and psychosocial needs and has processes to facilitate good communication.

Optimal care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.

Palliative care – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

Patient management framework – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal care pathways are updated versions of these models, being developed by the Victorian Government from 2013.

Prehabilitation – one or more interventions performed in a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the patient undergoes treatment and beyond.

Primary specialist – the person who makes the referral to the multidisciplinary team (for example, specialist physician, surgeon, oncologist, palliative care specialist). This person will also make referrals for treatment and will be responsible for oversight of follow-up care.

Rehabilitation – comprises multidisciplinary efforts to allow the patient to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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Governance – project steering committee representation

Ballarat Health Services
Cancer Australia
Cancer Council Victoria, Strategy and Support
Consumer representatives
Department of Health and Human Services, Cancer Strategy and Development
Grampians Integrated Cancer Service
Monash University
North Eastern Melbourne Integrated Cancer Service
Peter MacCallum Cancer Centre
Royal Hobart Hospital
Western Health

Medical colleges and peak organisations invited to provide feedback

Allied Health Professions Australia
Australian Association of Nuclear Medicine Specialists
Australian and New Zealand Gastric and Oesophageal Surgery Association
Australian and New Zealand Society of Palliative Care
Australian Chapter of Palliative Medicine, Royal Australasian College of Physicians
Australian College of Nursing
Australian Institute of Radiography
Australian Medical Association
Australian Psychological Society
Gastroenterological Society of Australia
Interventional Radiology Society of Australasia
Interventional Radiology Society of Australasia
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