

Patient management framework

Upper gastrointestinal tumour stream: pancreatic cancer

a guide to
consistent
cancer care

Patient management framework

Upper gastrointestinal tumour stream: pancreatic cancer

Acknowledgements

The Ministerial Taskforce for Cancer gratefully acknowledges the commitment of all the health professionals and consumers who gave their time and expertise to the development of the patient management frameworks

Published by Metropolitan Health and Aged Care Services Division,
Victorian Government Department of Human Services,
Melbourne Victoria Australia

May 2006

© Copyright State of Victoria, Department of Human Services, 2006.

This publication is copyright. No part may be reproduced by any process except in accordance with the provisions of the *Copyright Act 1968*.

Also published on www.health.vic.gov.au/cancer

Authorised by the Victorian Government,
50 Lonsdale Street, Melbourne.

Printed by GT Graphics Pty Ltd, 34 Stanley Street, Collingwood.

Contents

1. Introduction	1
2. Patient management frameworks	2
3. Credentialling and scope of practice	5
4. Multidisciplinary care	6
5. Supportive care	7
6. Steps in the care of patients with pancreatic cancer	9
7. Specific supportive care needs to consider for patients with pancreatic cancer	17
8. Resource list	18
9. Abbreviations	19
10. References	20

1. Introduction

Cancer is the leading cause of death in Victoria, representing 28.9 per cent of all deaths in 2002²⁶. Population ageing will significantly increase the number of new cases of cancer over the next ten years, with an estimated 10,000 more cases per annum in Victoria by 2016. In 2003, 497 Victorians were diagnosed with pancreatic cancer and in 2002, there were 486 deaths due to pancreatic cancer²⁶.

Cancer is a complex disease to diagnose and treat, and represents a significant burden to patients and their families, the health system, and the community at large. Victoria's strategic and planned approach to cancer reform includes the establishment of a Ministerial Taskforce for Cancer, and implementation of the *Fighting cancer policy*² and *A cancer services framework for Victoria*²⁷. Two significant directions of the Cancer Services Framework are the establishment of integrated cancer services in metropolitan and regional Victoria, and the development of service delivery and improvement through a tumour streams model.

Since 2004, eight integrated cancer services have been established in metropolitan and regional Victoria, based on specified geographic populations. The philosophy of an integrated cancer service is that hospitals and primary and community health services develop integrated care and defined referral pathways for the populations they serve. This requires effective collaboration between hospitals and community-based services, including general practitioners. This will promote more effective local coordination of care for cancer patients, and a more rational, evidence-based approach to cancer service planning and delivery. The Cancer Services Framework also recommended that organ or system-specific tumour streams be adopted to support the delivery and improvement of care. The reasoning behind the tumour streams is that a consistent approach to clinical management based on evidence-based practice will reduce unacceptable variations in care across the state.

2. Patient management frameworks

The Cancer Services Framework suggested some areas for improvement in the quality of care for cancer patients in Victoria. These included:

- under-treatment of patients with colorectal, lung and prostate cancer^{12,24,25}
- inadequate follow-up surveillance of patients with testicular cancer²⁸
- a high proportion of cancer patients undergoing surgery with surgeons who performed relatively few operations for colorectal cancer^{15,25}
- a high proportion of surgery for ovarian cancer having been undertaken by generalists rather than specialist surgical oncologists¹⁵.

As a consequence, the Cancer Services Framework recommended that tumour streams be developed to reduce unwanted variation in practice. In response, the Ministerial Taskforce for Cancer recommended that patient management frameworks be developed to provide a consistent statewide approach to care management in each tumour stream. The patient management frameworks are a clear description of the care pathway, identifying the critical points along that pathway and the optimal model of care required. It is important that all patients are assessed and managed appropriately throughout each stage of their journey; however, it should be noted that not all patients will progress through each step of the relevant patient management framework. This is a consequence of many factors, including disease outcomes, management decisions, and patient decisions.

2.1 Purpose of the patient management frameworks

The patient management frameworks **are a guide** to the **optimal care management** of patients in each tumour stream. They are intended to improve patient outcomes by facilitating consistent care based on evidence and best practice across the state. They set out the key requirements for the provision of optimal care which need to be considered at each step of the care pathway. In contrast to clinical practice guidelines that guide appropriate practice and decision making, the patient management frameworks provide a guide to the patient journey to ensure patients with cancer and their families receive optimal care and support.

As a guide, the patient management frameworks are to be followed subject to the health professional's independent medical judgment and the patient's preference in each individual case. They are designed to provide information to assist in decision making and organisation of service delivery.

The patient management frameworks **are not rules** and **do not carry a sense of prescription**. The patient management frameworks represent the 'what', rather than seeking to prescribe the 'how'. Recognising that services should be responsive to the needs of different patients at different phases, the patient management frameworks draw on best practice and encourage local solutions. For example, while multidisciplinary care is an essential part of treatment planning, how it is organised depends on the local situation.

In their current format, the patient management frameworks are not designed for accreditation purposes, but may be used to facilitate local benchmarking, service mapping and service development.

The patient management frameworks have been developed in collaboration with a wide range of practitioners, consumers and carers. Wherever possible, the patient management frameworks are based on current best practice, including clinical guidelines, care pathways, standards and research that exist to support optimal care at the critical points. In many cases, however, they are a statement of consensus regarding currently accepted approaches to treatment.

2.2 Structure of the patient management frameworks

The patient management frameworks set out seven critical steps of the patient journey. The seven steps provide a consistent structure across the ten tumour streams. While the seven steps appear as a linear model, it is clear that in practice patient care does not always occur in this way but rather depends on the particular cancer, when and how the cancer is diagnosed, prognosis, management decisions, and patient decisions.

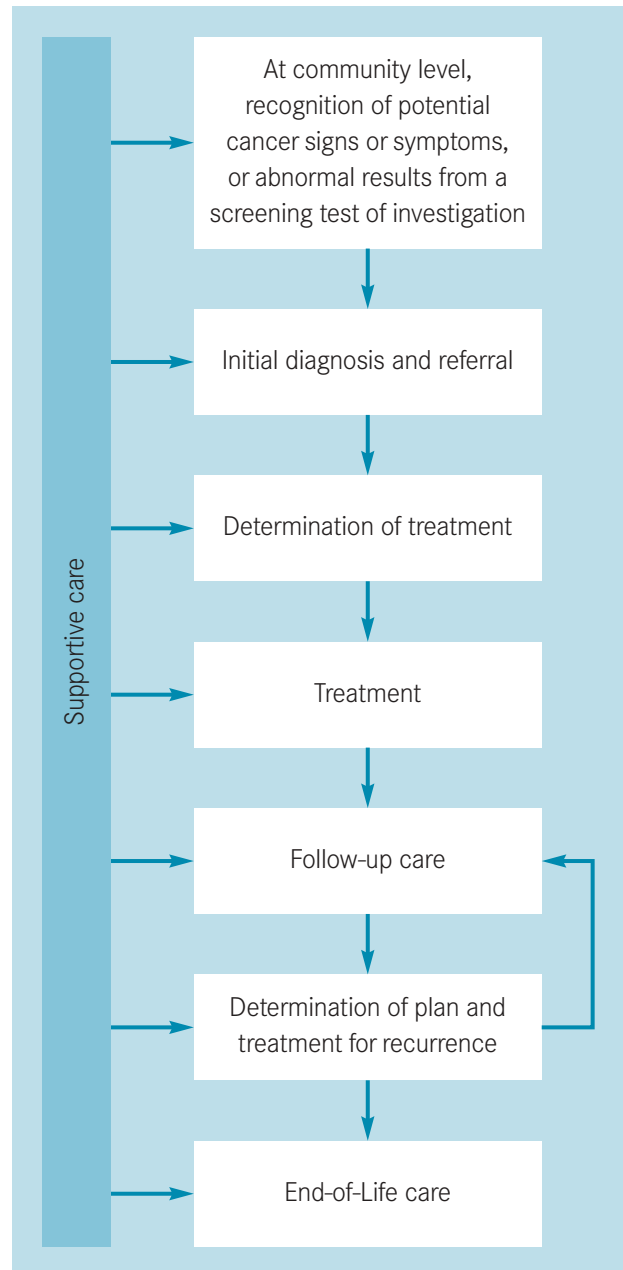
Underpinning the patient management frameworks are key principles that support all seven steps. These are:

1. patient-centred care. Patients should be involved as active participants in care planning and decision making, and wherever appropriate so should their partners, families and carers. Ultimately, any treatment decision rests with the patient or designated person. This requires information and discussion in their preferred language and sensitive to their culture

2. safe and high quality care. Cancer care is complex, involving a range of clinicians with different expertise. To ensure safe and high quality cancer care, it is important that clinicians have the technical skills and experience to carry out those aspects of cancer care they undertake and that there is institutional capacity to support such care, such as equipment, staffing and skill mix. Further detail is provided in section 3

3. multidisciplinary care. The cornerstone of best practice in cancer care is multidisciplinary treatment planning and multidisciplinary care. An effective multidisciplinary approach can result in survival benefit¹⁶, increased recruitment into clinical trials^{18,19}, detection of emotional needs of patients⁵, reduction in service duplication and improved coordination of services³. Further detail is provided in section 4

Figure 1: Steps of the patient journey



4. supportive care. People with cancer have psychological and social needs that are frequently undetected and unmet²⁰. This has the potential to result in long term distress. In the context of cancer, supportive care describes all services that may be required to support people with cancer and their carers to meet their physical, psychological, social, information and spiritual needs. Further detail is provided in section 5

5. care coordination. The cancer journey is complex and challenging, and it is not uncommon for patients to be seen by many health professionals within and across multiple health services and across different sectors. A variety of strategies are successful in improving the coordination of care. Some of these include strategies directed at the team, such as multidisciplinary team meetings, clinical protocols and case conferencing; strategies directed at the patient, such as personal patient records, appropriate information provision or case managers; and strategies directed at the health care system, such as electronic medical records, standards, performance indicators and funding models. To ensure patients experience care that is coordinated and integrated over time and settings, services need to consider the range of strategies required to facilitate care coordination.

2.3 Development of the patient management frameworks

The patient management frameworks have been developed over a 15-month period in consultation with more than 500 clinicians and consumers through workshops and written submissions. Further information on the development process can be obtained at <http://www.health.vic.gov.au/cancer/tumourstreams.htm>.

Fourteen patient management frameworks have been developed, addressing the following tumour streams and tumour categories:

- breast
- central nervous system (cerebral metastases)
- central nervous system (malignant glioma)
- colorectal (colon and rectal)
- genitourinary (prostate)
- genitourinary (testis)
- gynaecological (ovarian)
- haematological (acute myeloid leukaemia)
- haematological (intermediate grade non-hodgkin's lymphoma)
- head and neck (larynx, pharynx and oral)
- lung (non-small cell)
- skin (melanoma)
- upper gastrointestinal (oesophagogastric)
- upper gastrointestinal (pancreatic).

2.4 Future review and development of the patient management frameworks

The 14 patient management frameworks that have been developed will be reviewed in December 2007. Further development of patient management frameworks relevant to the ten major tumour streams will commence in January 2007.

3. Credentialling and scope of practice

In 2004, the *National standard for credentialling and defining the scope of clinical practice*¹ was endorsed by the Australian Health Ministers. Developed by the Australian Council for Safety and Quality in Health Care, the standard provides a credentialling framework for all medical practitioners. Credentialling is a formal process for verifying qualifications, competence and performance of individual clinicians as well as defining their scope of practice within a specific health service. The process takes into account the skills and ability of the clinician as well as the capacity of the institution to support the clinician's practice.

This has particular relevance to clinicians working in the area of cancer care. Cancer care is complex for a number of reasons. These include:

- the large number and type of cancers that vary greatly in their pathology and management
- the range of clinicians with different professional expertise (medicine, nursing, allied health) that are involved in care
- the range of specialities for specific treatment modalities, such as breast or colorectal surgeons, radiation and medical oncologists, breast care nurses
- the life-threatening nature of many cancers and the serious complications and side-effects of some treatments
- the advances in technology and research that are changing best practice care at a rapid pace¹¹.

In Victoria, the complexity of cancer care poses specific challenges for health professionals working in the area of cancer. The large distances between health services and the relatively low numbers of complex cancers that will be seen at individual health services or by individual health professionals require that innovative approaches to care be developed. These include developing links between health professionals and multidisciplinary teams and initiatives such as the expansion of telemedicine, specific mentoring and upskilling programs.

For patients to have access to safe and high quality services, it is important that professionals working in the area of cancer care ensure:

- they have the necessary skills to carry out those aspects of cancer care they undertake and there is institutional capacity to support such care (for example, equipment, staffing and skill mix)
- they have clear links with a range of specialties or multidisciplinary care team required for cancer care, for the purpose of clinical advice, referral and continuing education
- they follow evidence-based practice or treatment recommendations of a multidisciplinary care team
- they undertake regular review of their performance and contribute to regular audit of their cancer care
- they are actively involved in continuing professional development
- their patients can make an informed choice about their care, including the options of referral to other professionals or specialised centres¹¹.

4. Multidisciplinary care

4.1 Achieving multidisciplinary care

Multidisciplinary care is an approach that includes both treatment planning and ongoing care. The ‘gold standard’ for multidisciplinary care is a team who meets regularly (whether in person or via teleconferencing) to prospectively plan care and treatment for all patients within a tumour group; however, it is expected that different components of multidisciplinary care will be implemented depending on the setting, the location of the team and the number and type of cancer patients being treated. While it may not always be possible to hold a multidisciplinary team meeting prior to surgery, for instance, it would be expected that some other form of multidisciplinary discussion around treatment planning take place. It is likely that regional multidisciplinary care will look different from metropolitan, while being guided by the principle that interaction between multidisciplinary team members is critical in the determination and effective implementation of the treatment plan. It is also acknowledged that patients move between the private and public sector and multidisciplinary care needs to take this into account.

4.2 Principles of multidisciplinary care²¹

The team

- There is an established multidisciplinary team comprising all core disciplines, including allied health and psychosocial health practitioners.
- The patient’s general practitioner is regarded as a team member and processes to ensure effective communication with general practitioners are implemented.
- Effective communication and referral linkages are made to all core and non-core team members.

Communication

- All core disciplines where appropriate and relevant regularly attend multidisciplinary meetings to provide input to diagnostic, treatment, supportive and palliative care planning.

- In instances where not all patients within a tumour group or groups are discussed, team protocols are developed to outline those patients who will be presented at meetings.
- Processes for communicating treatment and care plans for team members who are absent are developed and implemented.

Full therapeutic range

- All patients regardless of where they reside will have information about and access to relevant treatments and services.
- Clinical trial involvement is considered for all eligible patients who will be undergoing cancer treatment.

Quality

- Decisions, protocols and care pathways are in line with current best practice, including standards, guidelines, research and where these are not available, currently accepted approaches to treatment.
- All relevant diagnostic results, reports and pathology and radiology images are available for multidisciplinary meetings.
- Collaborative links will be formed with smaller and larger referring centres and practitioners. The result will be a network of multidisciplinary teams and practitioners across and between integrated cancer services.
- Professional development activities are supported and held for all team members.

Involvement of patient

- Patients are informed of the multidisciplinary team process.
- Patients are informed of the recommendations of the multidisciplinary discussion, provided with information about all aspects of their treatment and participate in the decision making process.
- Patients are routinely given information about and access to supportive care services.

5. Supportive care

‘Supportive care is an ‘umbrella’ term for all services, both generalist and specialist, that may be required to support people with cancer and their carers’²². It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care²².

Supportive care is required throughout the diagnostic, treatment and follow-up phases of care⁷.

In the context of cancer, supportive care needs include:

- physical needs (for example, pain, fatigue)
- psychological needs (for example, anxiety, distress)
- social needs (for example, practical supports, carer needs)
- information needs (for example, regarding diagnosis, prognosis, types of treatment)
- spiritual needs (for example, addressing hopelessness, despair).

5.1 Providers of supportive care

Supportive care is provided by generalist and specialist health services as well as community services.

All members of the multidisciplinary team, including general practitioner, surgeon, radiation oncologist, medical oncologist, nurse, social worker and other allied health staff, have a role in the provision of supportive care. In addition, community capacity to support people with cancer makes an important contribution to supportive care. This includes support from family, friends, support groups, volunteers and other community-based organisations.

As a specialist service, palliative care may provide many of the elements of supportive care; however, palliative care also includes specific areas of expertise that may be required, such as unresolved symptoms, and complex psychosocial, end-of-life and bereavement issues²².

5.2 Achieving supportive care

An important step in the provision of supportive care services is to identify, by routine and systematic questioning of the patient and family, views on issues they require help with for optimal health and quality of life outcomes⁹. Reassessment of their needs is not a ‘once only’ incident because a person’s needs change along the disease trajectory¹⁰.

A routine and systematic approach to identifying supportive care needs will help to identify people who are at higher risk of psychological or social distress. This identification provides the opportunity for further referral for assessment that is specific to their needs and recognises the individual factors that may place them at increased risk of psychological morbidity. Such factors include characteristics of the individual, such as age and marital status, and characteristics of the disease, such as time of diagnosis or recurrence, stage of disease and prognosis²⁰.

A detailed assessment will help to identify those patients who require more specific one-to-one intervention and follow-up.

5.3 Establishing a supportive care model

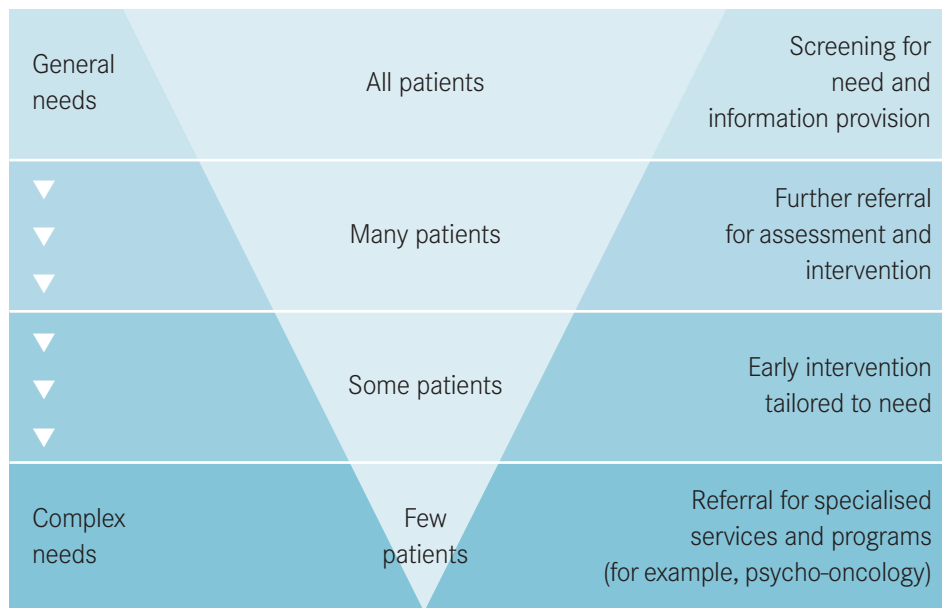
A supportive care model should recognise the variety and the level of intervention required at each phase and be specific to the individual. Such a model (see Figure 2) targets the type and level of intervention required to meet patients' supportive care needs. While there needs to be provision of general information to all patients, only a few patients will require specialised intervention.

As supportive care is provided by a range of services, it is important the following are considered in ensuring cancer patients have access to supportive care:

- processes that assist the identification of patient, family and carer supportive care needs
- clear referral pathways to specialised supportive care services
- adequate staff training in identifying and responding to supportive care needs
- promotion of supportive care as an important element of cancer service delivery.

Figure 2: Supportive care model

(Adapted from Fitch⁷. Reproduced with kind permission of Peter MacCallum Cancer Centre).



6. Steps in the care of patients with pancreatic cancer

This section sets out the steps along the treatment pathway and the optimal care required. Not all patients will follow every step of the pathway. This will depend on the stage of the cancer at diagnosis and the patient's decisions about his or her care.

Step 1:

At community level, recognition of potential cancer signs or symptoms, or abnormal results from a screening test or investigation

This step identifies screening programs, the types of people who may be at higher than average risk of developing cancer, and the types of symptoms that require further investigation by the general practitioner.

1.1 Screening

- There are no formal screening programs for pancreatic cancer.

1.2 Those at higher risk

- People with the following are at higher risk:
 - family history of pancreatic cancer. This is rare and forms a small proportion of all cases of pancreatic cancer
 - chronic pancreatitis.

1.3 Signs and symptoms that should lead to general practitioner consultation

- Patients commonly present with non-specific symptoms. Persistent symptoms require further investigation. These may include:
 - jaundice
 - epigastric and back pain (often debilitating pain and diagnosis delayed)
 - pancreatic insufficiency—digestive problems
 - symptoms of gastric outlet obstruction
 - paraneoplastic syndromes (for example, superficial thrombophlebitis)
 - weight loss and diabetes.

1.4 Timeframe for general practitioner consultation

- Jaundice requires urgent consultation.
- Other symptoms, including persistent, progressive or new epigastric or back pain, require review within two weeks.

Step 2: Initial diagnosis and referral

This step details the process for establishing the diagnosis and appropriate referral. The types of investigations undertaken by the general practitioner and specialist (surgeon or gastroenterologist) depend on many factors, such as the patient's desires, access to particular tests or access to specialists. Decisions on investigations require discussion and agreement between the general practitioner, specialist and patient. There are a number of options. If the diagnosis can be confirmed with initial tests, then referral to an appropriate oncologist is optimal. If the diagnosis is suspected, then referral to a specialist for further investigation may occur prior to referral to an appropriate oncologist.

2.1 General practitioner

- Where undiagnosed abdominal pain, back pain or weight loss is present:
 - consider abdominal CT scan
 - undertake staging tests after consultation with the multidisciplinary team
 - early referral is indicated, usually prior to a definitive diagnosis being made.
- Where jaundice is present, the following should be performed:
 - liver function tests
 - abdominal ultrasound
 - CT where appropriate.

2.2 Referral

- Pancreatic cancer can be complex to diagnose and assess, and several referral pathways are possible before referral to the treating (lead) clinician and multidisciplinary team. Pathways include:
 - referral to surgeon or gastroenterologist with experience in pancreatic cancer, before further referral to multidisciplinary team setting for treatment planning
 - further referral to a hepatopancreaticobiliary surgeon, medical oncologist and radiation oncologist with expertise in pancreatic cancer, either before or at multidisciplinary team discussion, may be required.
- Specialists should provide timely communication to the general practitioner about the consultation, and should notify the general practitioner if the patient does not attend.

2.3 Staging

- The following should occur prior to multidisciplinary treatment planning:
 - CT scanning
 - MRI
 - PET if available
 - endoscopic ultrasound if available.
- Staging is the cornerstone of treatment planning. Synoptic reporting is encouraged where operative resection has occurred and pathological staging is available.

Step 3: Determination of treatment

This step identifies the members of the multidisciplinary team who need to be involved in initial treatment planning for this type of cancer. While the treatment and patient needs vary considerably depending on the extent of the cancer, the guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.

3.1 Multidisciplinary team

- The multidisciplinary team comprises (in alphabetical order):
 - dietitian
 - endoscopist (expertise in endoscopic retrograde cholangiopancreatography +/- endoscopic ultrasound)
 - general practitioner
 - medical oncologist (expertise in gastrointestinal oncology)
 - nurse
 - pathologist (expertise in gastrointestinal pathology)
 - radiation oncologist (expertise in gastrointestinal radiation therapy)
 - radiologist (expertise in hepatopancreaticobiliary interventional procedures)
 - social worker
 - surgeon (expertise in hepatopancreaticobiliary surgery)
- with access to:
 - allied health services where appropriate
 - palliative care services where appropriate
 - psycho-oncology services where appropriate (psychologist/psychiatrist).
- The lead role is taken by the initial clinician who has assessed the patient.

3.2 Multidisciplinary planning

- Contrary to the situation with most cancers, definitive tissue diagnosis prior to multidisciplinary planning is not recommended.
- Multidisciplinary assessment should be after initial staging but before definitive treatment.
- The primary specialist who makes the referral to the multidisciplinary team is responsible for the patient until care is passed to another practitioner.

3.3 Next steps in starting treatment

- The initial or lead clinician should be responsible for ensuring implementation of the treatment program.
- The lead clinician should ensure there is adequate discussion with the patient (and family) of the diagnosis and recommended treatment, including rationale and aim, likely effects, possible outcomes, other treatment options, and psychosocial supports for the patient and family.
- There should be timely communication to the general practitioner about the agreed treatment plan.
- Progression of care within the multidisciplinary team should be coordinated, ensuring the patient, general practitioner and multidisciplinary team members are clear on their responsibilities for coordination of care.

Step 4: Treatment

This step is concerned with the scope of clinical practice to deliver quality and safe practice. Scope of practice reflects both the expertise and experience of the individual as well as the organisational capability for the provision of safe, high quality cancer services¹. Pancreatic cancer management is complex and the development of teams with sufficient caseload to build expertise and experience is encouraged.

4A: Surgery

4A.1 Patients who may benefit from surgery

Surgery is indicated for:

- patients with resectable localised pancreatic disease
- patients receiving palliation of unresectable pancreatic cancer.

4A.2 Training and experience of surgeon

- Hepatopancreaticobiliary surgeon (FRACS or equivalent) with adequate training and experience in pancreatic surgery that enables institutional credentialling and agreed scope of practice within this area¹
- Surgeon (FRACS or equivalent) with adequate training and experience in palliative pancreatic surgery that enables institutional credentialling and agreed scope of practice within this area¹

4A.3 Hospital or treatment unit characteristics

Staff

Staffing includes:

- nurses experienced in oesophagogastric surgery
- surgeon as specified in 4A.2
- anaesthetic services.

Facilities

The following are available:

- intensive care unit for major surgery and a high dependency unit for palliative surgery
- pathology services: frozen section reporting, margins reporting
- interventional radiology capable of managing development of biliary obstruction and complications of surgery.

4B: Radiotherapy

4B.1 Patients who may benefit from radiotherapy

Radiotherapy may be indicated:

- with or without chemotherapy, for patients with locally advanced but not resectable disease
- as part of adjuvant chemoradiotherapy
- for patients receiving palliative care.

4B.2 Training and experience of radiation oncologist

- Radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice in the treatment of upper gastrointestinal malignancy¹

4B.3 Hospital or treatment unit characteristics**Staff**

Staffing includes:

- nurses
- radiation oncologist as specified in 4B.2
- radiation oncology medical physicist
- radiation therapist.

Facilities

The following are available:

- dual modality LINACS
- CT planning facilities
- treatment planning system.

4C: Drug therapy**4C.1 Patients who may benefit from drug therapy**

Patients who may benefit include:

- those requiring adjuvant therapy to resected pancreatic cancer
- those with unresectable pancreatic cancer
- those with locally advanced disease
- those receiving palliative care.

4C.2 Training and experience of medical oncologist

- Medical oncologist (FRACP or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice in the treatment of upper gastrointestinal malignancy¹

4C.3 Hospital or treatment unit characteristics**Staff**

Staffing includes:

- medical oncologist as specified in 4C.2
- nurses with adequate training in chemotherapy administration, handling and disposal of cytotoxic waste
- If chemotherapy is prepared on site, then a pharmacist with adequate training in chemotherapy medications, including dosing calculations according to protocols, formulations and/or preparation is required.
- Some components of less complex therapies may be delivered in a setting where no medical oncologist is locally available, by another medical practitioner with training and experience that enables credentialling and agreed scope of practice within this area. 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.

Facilities

- The facility has a clearly defined path to emergency care and advice after hours.
- The facility is able to care for neutropenic patients.
- There is access to haematology testing.
- Cytotoxic drugs are prepared in a pharmacy with appropriate facilities.
- Occupational health and safety guidelines are followed in relation to handling of cytotoxic drugs, including preparation, waste procedures and spill kits²⁹.
- Guidelines and protocols, in the case of extravasation of drugs are available and understood.
- Palliative care service is available and integrated into the treatment, because most patients with pancreatic cancer will not be cured of their disease.

Step 5: Follow-up care

This step includes monitoring of the status of the disease (including detection of metastatic disease) and management of symptoms that arise following the initial treatment. A clear follow-up plan needs to be established to avoid excessive follow-up by multiple specialists. Follow-up may vary depending on the intent of the initial treatment.

5.1 Plan for follow-up

- At discharge, the multidisciplinary team needs to make a specific plan for follow-up care, including appointments and surveillance for:
 - clinical follow-up
 - radiological follow-up (minimal role).

5.2 Persons involved in follow-up care

- Not all disciplines need to be involved in longer term follow-up. The multidisciplinary team, in consultation with the general practitioner decides on the lead clinician who will coordinate follow-up.
- Responsibility for follow-up investigations needs to be agreed between the designated lead clinician, the general practitioner and the patient, with an agreed plan documented, including notification to the general practitioner or multidisciplinary team member if the patient does not attend.
- The general practitioner has a key role in coordination of follow-up.
- The palliative care service may have a role in follow-up.

Step 6:

Determination of plan and treatment for recurrence

This step covers treatment for recurrence. The intent may be disease control and, in most situations, palliative. Clinical evaluation and patient decision making will determine the focus of the treatment.

6.1 Investigative tests

- The following investigations may be indicated:
 - CT scan
 - tumour markers
 - endoscopy.

6.2 Multidisciplinary team

- The lead clinician has responsibility for managing treatment for recurrence.
- Management should be discussed with the multidisciplinary team.
- General practitioner and palliative care service participation is essential.

6.3 Treatments that a patient is most likely to have for recurrence

Treatment will depend on the location and extent of the recurrence, and on previous management. Treatment may include surgery (local recurrence leading to gastrointestinal or biliary obstruction), radiotherapy (localised symptomatic recurrences), and drug therapy (may have a role for systemic metastases and in association with radiotherapy). In addition, symptom relief may require specialised interventions (for example, coeliac nerve blocks).

Step 7: End-of-life care

This step is concerned with quality of life for the patient and his or her family through care that addresses physical, psychological, emotional and spiritual needs. For the family and carers, this may include bereavement support.

7.1 Multidisciplinary team

- The multidisciplinary team should include (in alphabetical order):
 - allied health staff as appropriate
 - general practitioner
 - medical oncologist
 - nurses
 - palliative care service—relevant team members
 - pastoral care services—relevant team members.

7.2 Services that may be required

- Palliative care service: community-based and inpatient
- Home and community care
- Community nursing
- Allied health: dietitian, occupational therapy, pastoral care, physiotherapy

7. Specific supportive care needs to consider for patients with pancreatic cancer

The supportive care needs of patients with intermediate pancreatic cancer will vary in severity and complexity along the disease trajectory. Identifying and assessing the supportive care needs of people with pancreatic cancer involves a general assessment of the physical, psychological, social, information and spiritual needs as detailed in section 5. In addition to these general needs, all members of the multidisciplinary team should be aware of the particular needs related to pancreatic cancer detailed below which may require intervention from specific members of the multidisciplinary team.

Physical needs

- Weight loss, cachexia and changes in appetite⁴ can be improved for some people through nutritional support, such as pancreatic enzymes and possibly lipid supplements. The majority of patients will require referral to a dietitian²³.
- Diabetes mellitus⁸ management may require medical, nurse specialist and dietitian involvement.
- Diarrhoea/steatorrhoea⁴ and constipation¹³ may require review by a continence nurse, dietitian, and medical specialist.
- Because abdominal ascites may occur, abdominal symptoms need monitoring and assessment¹³.
- Coeliac plexus pain and poorly localised visceral pain possibly referred to cutaneous sites may require referral to a pain service⁶. Other techniques, such as relaxation therapy, distraction and massage may have short term effects in relieving pain¹⁷.

Psychological needs

Anxiety

- Increased feelings of anxiety related to poor prognosis, if diagnosed at an advanced stage, require regular monitoring. Patients should be screened to identify those at high risk of anxiety or depression at each visit. Strategies such as information provision, relaxation techniques, meditation¹⁷ and a referral to a palliative care service, psychologist or psychiatrist as required may be helpful.

Depression

- The incidence of both anxiety and depression is high for people diagnosed with pancreatic cancer³⁰. Regular screening for depression and anxiety specifically for these patients and possible referral to a psychologist or psychiatrist may be required.

Practical/social needs

- The additional costs related to meal preparation, aids to assist with cooking, and enteral feeding may be significant. Referral to a social worker for further assessment and identification of appropriate funding support may be required.

Information needs

- It is estimated that 10 per cent to 20 per cent of pancreatic cancers are hereditary or have a familial link⁶. Referral to a familial cancer centre if the clinician is unsure of management or the person is at high risk of familial cancer (family history of cancer in first- and second-degree relatives) may be appropriate.
- Further specific information is available from The Cancer Council Victoria web site <http://www.cancervic.org.au/cancer1/patients/pancreas/pancreas.htm> and the United States' National Cancer Institute web site <http://www.cancer.gov/cancertopics/wyntk/pancreas/page1>.

8. Resource list

For patients, families and carers

1. The Cancer Council Victoria

1 Rathdowne Street
Carlton 3053

Telephone: 03 9635 5000
Facsimile: 03 9635 5270
Email: enquiries@cancervic.org.au
Web site: <http://www.cancer.org.au>

For information on cancer, its treatment and side effects, support services, medical terminology, and research

2. Cancer Helpline (operated by The Cancer Council Victoria)

Telephone: 13 11 20
Hours: Monday to Friday, 8.30 am–5.30 pm

For telephone peer support from people who have had cancer experiences or for information on more than 120 cancer support groups across Victoria

3. The Cancer Council Australia

<http://www.cancer.org.au>

Fact sheets:

Lifestyle: www.cancer.org.au/lifestyle
Early detection: www.cancer.org.au/earlydetection
Post diagnosis: www.cancer.org.au/diagnosis

For health professionals

4. National Health and Medical Research Council

<http://www.nhmrc.gov.au/publications/subjects/cancer.htm>

For downloading clinical practice guidelines for cancer prevention and treatment

5. The Cancer Council Australia

Fact sheets for health professionals providing advice to patients:

<http://www.cancer.org.au/factsheets>

One-page fact sheets to help general practitioners and other health professionals advise their patients about cancer prevention, screening and diagnosis. These can also be downloaded from the patient education browser in the latest version (2.86) of the general practice software package, Medical Director.

Cancer resources for primary health care professionals:
www.cancer.org.au/primarycare

Directory of cancer resources to support general practitioners and other health professionals. Developed by the General Practice Committee of The Cancer Council Australia, the directory provides a single point of access to state, territory and national cancer resources.

6. Clinical trials

A national, online register of clinical trials being undertaken in Australia, the Australian Clinical Trials Registry, is available at <http://www.actr.org.au>. The Australian Clinical Trials Registry includes trials from the full spectrum of therapeutic areas, trials of pharmaceuticals, surgical procedures, preventive measures, lifestyle, devices, treatment and rehabilitation strategies and complementary therapies.

9. Abbreviations

CT	computed tomography
FRACP	Fellow of Royal Australasian College of Physicians
FRACS	Fellow of Royal Australasian College of Surgeons
FRANZCR	Fellow of Royal Australian and New Zealand College of Radiologists
LINAC	linear accelerator

10. References

1. Australian Council for Safety and Quality in Health Care, 2004, *Standard for credentialling and defining the scope of clinical practice*, ACSQHC, viewed 3 February 2006, <http://www.safetyandquality.org/credenti.pdf>.
2. Australian Labor Party, 2002, 'Fighting Cancer', *Australian Labor Party*, viewed 3 February 2006, http://www.vic.alp.org.au/dl/fighting_cancer.pdf.
3. Barr, O, 1997, 'Interdisciplinary teamwork: consideration of the challenges', *British Journal of Nursing*, Volume 6, no. 17, pp. 1005–1010.
4. Bowles, MJ & Benjamin, IS 2001, 'ABC of the upper gastrointestinal tract: cancer of the stomach and pancreas', *British Medical Journal*, Volume 323 pp. 1413–1416.
5. Butow, PN, Brown, RF, Cogar, S, Tattersall, MHN & Dunn, S, 2002, 'Oncologists reactions to cancer patients verbal cues', *Psycho-oncology*, Volume 11, pp. 47–58.
6. DeVita, VT, Hellman, S & Rosenberg, SA (Eds) 2000, *Cancer: principles and practice of oncology*, 7th edn., Lippincott, Williams and Wilkins, Philadelphia.
7. Fitch, M 2000, 'Supportive care for cancer patients', *Hospital Quarterly*, Volume 3, no. 4, pp. 39–46.
8. Fitzsimmons, D, George, S, Payne, S & Johnson, CD 1999, 'Differences in perception of quality of life issues between health professionals and patients with pancreatic cancer', *Psycho-Oncology*, Volume 8, no. 2, pp. 135–43.
9. Foot, G & Sanson-Fisher, R, 1995, 'Measuring the unmet needs of people living with cancer', *Cancer Forum*, Volume 19, no. 2, pp. 131–135.
10. Holland, J, 2002, 'History of psycho-oncology: overcoming attitudinal and conceptual barriers', *Psychosomatic Medicine*, Volume 64, no. 2, pp. 206–221.
11. Frommer, M, Heinke, M & Barton, M, 2005, The credentialling of cancer clinicians in Australia, *The Cancer Council Australia and the Australian Cancer Network*, Sydney, NSW, Australia.
12. Frydenberg, M, Giles, GG, Mameghan, H, Thursfield, VJ, Millar, J, Wheelahan, JB, Bolton DM, & Syme, RR, 2000, 'Prostate cancer in Victoria in 1993: patterns of reported management', *Medical Journal of Australia*, Volume 172, pp. 270–274.
13. Groenwald, SL, Frogge, MH, Goodman, M & Yarbro, CH 1997, 'Cancer nursing principles and practice', 4th edn., Jones and Bartlett Publishers, London.
14. Grossi, M, Quinn, MA, Thursfield, VJ, Francis, PA, Rome, RM, Planner, RS & Giles, GG, 2002, 'Ovarian cancer: patterns of care in Victoria during 1993–1995', *Medical Journal of Australia*, Volume 177, pp. 11–16.
15. Hill, DJ, Jamrozik, K, White, V, Collins, J, Boyages, J, Shugg, D, Pruden, M, Giles, GG & Byrne, MJ, 2000, 'Surgical management of breast cancer in Victoria in 1995', *Anti-Cancer Council of Victoria*, Melbourne.
16. Junor, EJ, Hole, DJ & Gillis, CR, 1994, 'Management of ovarian cancer: referral to a multidisciplinary team matters', *British Journal of Cancer*, Volume 70, pp. 363–370.
17. Kearney, N & Richardson, A, 2006, *Nursing patients with cancer: principles and practice*, Elsevier Limited, Edinburgh.
18. Magee, LR, Laroche, CM & Gilligan, D, 2001, 'Clinical trials in lung cancer: evidence that a programmed investigation unit and a multidisciplinary clinic may improve recruitment', Letter, *Clinical Oncology (Royal College of Radiologists)*, Volume 13, no. 4, pp. 310–311.
19. McVie, JG, 1996, 'Current areas of treatment'. *Seminars in Oncology*, Volume 23, (Supplement 1), pp. 1–3.
20. National Breast Cancer Centre and National Cancer Control Initiative, 2003, 'Clinical practice for the psychosocial care of adults with cancer', *National Breast Cancer Centre*, Camperdown, Australia.
21. National Breast Cancer Centre, 2005, 'Multidisciplinary meetings for cancer care: a guide for health providers', *National Breast Cancer Centre*, Camperdown, Australia.
22. National Institute for Clinical Excellence, 2004, *Guidance on Cancer Services—Improving Supportive and Palliative Care for Adults with Cancer. The Manual*, National Health Service, London, United Kingdom.
23. Pancreatic Section of the British Society of Gastroenterology 2005, 'Guidelines for the management of patients with pancreatic cancer periampullary and ampullary carcinomas', *Gut*, Volume 54, (Supplement 5), pp. 1–16.
24. Richardson, GE, Thursfield, VJ & Giles, GG, for the Anti-Cancer Council of Victoria Lung Cancer Study Group, 2000, 'Reported management of lung cancer in Victoria in 1993: comparison with best practice', *Medical Journal of Australia*, Volume 172, pp. 321–324.
25. Spigelman, AD & McGrath, DR, 2002, *The National Colorectal Cancer Care Survey*. Australian Clinical Practice in 2000, National Cancer Control Initiative, Melbourne.
26. The Cancer Council Victoria, 2004, 'Canstat no. 41', *The Cancer Council of Victoria*, viewed 14 April 2006, http://www.cancervic.org.au/cancer1/facts/pdfs/canstats/canstat_41_cancer_vic_2003.pdf.
27. The Collaboration for Cancer Outcomes Research and Evaluation, 2003, 'A Cancer Services Framework for Victoria', *CORE*, Melbourne.
28. Toner, GC, Neerhut, GJ, Schwarz, MA, Thursfield, VJ, Sandeman, TF, Giles, GG & Snow RM, for the Urology Study Committee of the Victorian Co-operative Oncology Group, 2001, 'The management of testicular cancer in Victoria, 1988–1993', *Medical Journal of Australia*, Volume 174, pp. 328–331.
29. Worksafe Victoria, 2003, *Handling cytotoxic drugs in the workplace*, Melbourne: Victorian Workcover Authority, Melbourne.
30. Zabora, J, Brintzenhofesoc, K, Curbow, B, Hooker, C & Piantadosi, S, 2001, 'The prevalence of psychological distress by cancer site', *Psycho-Oncology*, Volume 10, no. 1, pp. 19–28.

