

Northern NSW CanNET



Patient flows and referral and treatment pathways

Version: 1.0

Prepared by CanNET Project Team
for **Clinical Management Committee**



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Patient flows and referral and treatment pathways

Introduction

Northern NSW Cancer Network (CanNET) has been established to improve access to quality, clinically-effective cancer services throughout Australia, particularly for specific population groups that currently have poorer outcomes. It is one of seven demonstration cancer networks being funded by Cancer Australia. In NSW CanNET is also funded by the Cancer Institute NSW. Some key elements and principles that underpin the CanNETs being developed in Australia are:

- Active consumer involvement
- Active general practitioner involvement
- Formalised linkages between cancer services
- Enhanced communication and data systems and
- Continuous quality review and improvement
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The NSW CanNET covers cancer services provided in the geographical regions incorporating Hunter New England, Northern Sydney Central Coast and North Coast Area Health Services and include services provided in the public, private and non-government sectors.

CanNET has an ambitious project scope which has been broken up into three main streams:

- Workforce
- Patient flows
- Governance

Under the patient flow stream a significant component is the development of Referral Pathways. This discussion document aims to provide background reading defining referral pathways, discussing the experience in other places and outlines a plan for action within CanNET.

Consultation

The progress of referral pathways in CanNET will be dependent on the contribution and 'buy in' from a range of stakeholders. Consequently this discussion paper is being distributed for wide consultation to health providers (public, private, acute and primary) and consumers to gain input and feedback.

Feedback can be provided by:

- Contacting the CanNET Project officer in your Area
 - Completing the survey accessed by the link in the attached email or via the link on the CanNET website.
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Project Approach for CanNET

Treatment versus Referral Pathways

The continuum of cancer control spans prevention, screening, early detection, treatment, follow up care and palliative care. For the purposes of CanNET a referral pathway refers to section of the continuum from screening to treatment initiation. A referral pathway will focus on the timely access from the General Practitioner to the appropriate specialist.

Approach

The purpose of this project is to develop and implement a cancer patient referral pathway system across CanNET.

The aim is to provide:

- a resource document to expedite the efficient and effective referral of patients to the most appropriate specialist, with the appropriate diagnostic work up
 - to work with GP's, specialists and consumer groups to improve referral outcomes.
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Project Approach for CanNET, Continued

Which Tumours

Given the resources required to effectively implement referral pathways it is recommended that the scope of this project be limited to a select number of tumour groups.

A review of cancer mortality rates¹ for these geographic areas highlight the following as having above NSW average rates:

- skin cancer deaths are higher in these three geographic areas than the state as a whole, with North Coast being the highest
- Hunter New- England has higher mortality rates for genito-urinary cancers (including prostate).

Incidence rates in the two rural areas of CanNET reveal the same top five tumours, although in slightly different order.

Hunter New England ²	North Coast ³	North Sydney Central Coast ⁴
Breast	Melanoma	Prostate
Prostate	Prostate	Breast
Melanoma	Breast	Melanoma
Colon	Lung	Colon
Lung	Colon	Lung
54%	57%	57%

Top 5 cancers

Some cancers for example, bone and head and neck, are time critical and patient outcomes will improve where time to definitive treatment is reduced.

Anecdotally there are some geographic pockets within the CanNET region where, because of a range of factors, referrals appear to take longer than other areas. Areas named include Taree and Wyong. Reasons for the delay in referral are unknown at this stage however these will be explored in more detail individually by the project officers as the information is presented to the network.

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¹ NSW Central Cancer Registry accessed 26/09/2008

² NSW Cancer Institute. NSW Rural Cancer Services Review Statewide Summary (Draft) pg.9

³ ibid

⁴ NSW Central Cancer Registry accessed 26/09/2008

Project Approach for CanNET, Continued

Which tumours continued

Based on these data there are three options for CanNET to determine the scope of this project. In deciding which approach to take it needs to be considered that for the uptake of referral pathways to be useful GP's will need more than a limited approach. For example if we suggest to them that patient outcomes will be improved if they use referral pathways but only provide a limited number they are less likely to change practice and use them.

Options include to limit development to:

- Prostate, Melanoma, Colon and Lung tumour groups
- Bone and Head and Neck
- Prostate, Melanoma, Colon, Lung, Bone and Head and Neck
- specific geographic locations
- a defined number of tumour groups with enhanced implementation strategies for specific geographical locations.
- Exclude Breast because of the significant work and focus that has gone into breast cancer services.

NSWOGs

It is anticipated that for this work to progress using existing structures within NSW that CanNET will work closely with the relevant Cancer Institute NSW Oncology Groups (NSWOGs) and with the relevant clinical leads in each Area who will provide the necessary high level clinical and strategic input and approval to this work.

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Project Approach for CanNET, Continued

Key Stakeholders

In addition to the NSWOGs CanNET recognizes the integral contribution of other stakeholder groups. These are detailed below.

Stakeholder	Input	Consultation Strategy
General Practitioners	<ul style="list-style-type: none"> • Their requirements • Appropriateness of approach • Support strategies 	Through Division of GP's and direct through one on one consultation and document review. Work through GP NSWOG
Consumers	<ul style="list-style-type: none"> • Their requirements • Appropriateness of approach • Support strategies 	Through Cancer Voices Australia and other consumer networks Document review
NSWOGs	<ul style="list-style-type: none"> • Key clinical input • Endorsement 	Through meetings and established communication channels
Cancer Service Providers	<ul style="list-style-type: none"> • Their requirements • Appropriateness of approach • Support strategies 	Focus groups Individual consultation Document review
Cancer Institute Projects	<ul style="list-style-type: none"> • Synergies and linkages 	Individual consultations (including projects for – Primary Health Care project, and the NSWOGs review of pt mgt frameworks)
Clinical leads and MDT leaders	<ul style="list-style-type: none"> • Clinical input, relevance and localisation • Endorsement 	Individual consultations
DACS	<ul style="list-style-type: none"> • Clinical input, relevance and localisation • Endorsement 	Individual consultations Through CMC

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Project Approach for CanNET, Continued

Support strategies

As mentioned earlier producing a referral pathway document will not produce significant change in practice. In conducting initial consultations regarding the development of this paper some interesting options were raised to support improvements in the referral systems. These and others should be explored through the consultation on this paper and appropriate options piloted and included in the implementation plan. Suggestions, which all have benefits and limitations, have included:

- Identifying medical oncologists, radiation oncologists and cancer care coordinators that are 'buddied' with particular GP practices to form relationships and provide a first point of contact in complex or uncertain cases
- Reversing the onus of patient 'readiness' from the GP to the receiving specialist
- Improving connections between centres to allow sharing of capacity – noting that the concept of standardised scheduling software is a complex and costly answer and that benefits could be realised by working at improving relationships/processes between centres in the first instance
- GP to cancer care coordinator referrals to involve the CCC at the earliest point
- Linkages with the services directory to allow one point of access for relevant information.

Achieving a balance

Key to developing referral pathways is the need to achieve a balance when setting criteria for urgent referral. If the threshold is set too high patients with a significant possibility of having cancer will be excluded. Likewise if the criteria are limited referral would be restricted to patients with the most obvious symptoms, who may be most likely to have advanced and/or incurable disease. On the other hand, if the threshold is set too low, a very large number of patients might be referred urgently causing them unnecessary anxiety and distress and services to be overwhelmed with patients not requiring care.

Audit and Review of the referral pathways

Monitoring of the referral pathways in practice will generate a valuable amount of new information which may be used to revise the pathways in the future. Evaluation of the pathways is equally important and evaluation questions may cover:

- Do GPs and specialists find the pathways useful?
- How frequently do GPs adhere to the pathways when making an urgent referral?
- Which combinations of age, symptoms, signs, etc yield the highest/lowest diagnostic ratios amongst urgently referred cases?
- What are the characteristics of patients with cancer who present as non-urgent cases?
- Have overall outcomes been improved?

Next Steps

Consultation This paper once approved by the CMC will be distributed widely for consultation and feedback. The consultation period will be officially open for three weeks, however CanNET will continue to take comment on the document beyond that.

Agreed Approach Feedback will be collated and the preferred approaches will be fed back to the CMC for a final decision on the project approach and scope / focus.

Drafting The CanNET project team will then draft referral pathways based on consultation feedback and available evidence. These will then be presented to the individual NSWOGs for input and feedback.

A consultation draft will then be developed which will be consulted on widely across the CanNET regions.

Finalisation Once feedback has been received on the consultation drafts the final documents will be developed for endorsement and approval by the NSWOGs, relevant clinical leads, MDT leaders and the CMC.

A detailed implementation plan will also be developed as part of this process.

Evaluation Program level evaluation will be incorporated into the overarching evaluation for NSW CanNET. Specific evaluation measures can be discussed as part of the implementation plan.

Sustainability Once the impact of the referral pathways is known it is expected that the NSWOGs will take ongoing governance of the pathways. The Cancer Institute can then work with the NSWOGs to agree an approach for the statewide roll out and ongoing maintenance.

Background

Cancer Projections

Projections estimate that in NSW there will be 380,000 people diagnosed with cancer over the next ten years and with deaths numbering 130,000. This represents a 31% increase in cancer from the rates we have seen over the last decade⁵. Cancer represents approximately 19% of the total State's disease burden⁶.

The NSW Cancer Plan 2007-2010⁷ highlights the need to develop smarter and more efficient service delivery models to better equip the health services to cope with the expected increasing burden on cancer treatment and care, identifying improved access to cancer services through business improvement and through redesigning clinical models of care.

In the CanNET region the numbers show equally significant growth over the next decade. A recent review of rural areas in NSW (excludes North Sydney Central Coast) shows the following projections of new cases.

	2006	2011	2016
Hunter New England AHS	4846	5533	6317
North Coast AHS	3,266	3,863	4,549

Table 1: Cancer Projections for New Cases⁸

In addition people affected with cancer are now living longer with many requiring ongoing follow up and some requiring complex support.

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⁵ NSW Cancer Plan 2007-2010, p27-28

⁶ NSW Cancer Plan 2007-2010 Discussion Paper, p.20.

⁷ NSW Cancer Plan 2007 – 2010, p 63

⁸ NSW Cancer Institute. 2007 NSW Rural Cancer Services Review Statewide Summary pg.9

Background, Continued

Links with Strategic Directions

The NSW Cancer Plan and A New Direction for NSW, State Health Plan towards 2010 highlight the importance of the provision of patient centred care, equity of access, quality services and outcomes, IT integration, partnerships and collaboration and improving the quality of life of cancer patients and their carers.

The National Service Improvement Framework⁹ lists critical intervention points for improved cancer care including:

- Improved access to treatment services for all Australians, particularly those living in regional, rural and remote areas and Aboriginal and Torres Strait Islander people.

This is reflected in the NSW Cancer Plans 2004-2006 and 2007-2010 and subsequently the Area Cancer plans.

⁹ National Service Improvement Framework for Cancer p7.

Referral Pathways

Cancer Care Cancer control is complex and involves many interactions between service providers and the clients. Delays, duplications and gaps are often characteristics of the complex process and cancer control is no different. There are many opportunities for delays and barriers to optimal treatment¹⁰.

Definition A referral pathway with respect to cancer is defined¹¹ as:

A series of steps, including clinical intervention to be taken by health care providers in response to people newly diagnosed with cancer or with recurrent or progressive disease. Its aim is to ensure more appropriate referral to specialist cancer services, including the multidisciplinary team.

A referral pathway is a process as much as a product or tool. Ideally it is developed via a comprehensive and inclusive approach between cancer services and relevant health agencies to establish relationships and a shared understanding and agreed ways of working together to better address the cancer care needs of a defined population.

Benefits of Pathways

The advantage of a clear referral process is that it will help to:

- ensure that patients are supported from the initial stage of their cancer journey
 - facilitate appropriate referral from primary to secondary care for pts a GP suspects may have cancer
 - enables the rapid assessment of patients likely to have cancer
 - contribute to reduced waiting times from GP to specialist appointment
 - reduce patient anxiety that occurs during the wait for appointment information
 - minimise labour intensive tasks involved with the appointments process through review and streamlining processes
 - improve communication of appointment arrangements to referring doctors
 - support coordination of care across the continuum
 - build on the referral to tumour specific Multidisciplinary Teams
 - assist to minimise duplication of the assessment process.
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¹⁰ National Service Improvement Framework for Cancer

¹¹ CanNET glossary

Referral Pathways, Continued

Limitations of Referral Pathways

We know that documents alone will not change practice. While referral pathways will provide a useful resource they will ultimately rely on the cooperation and uptake by both the GP sector and changes by receiving (specialist) services. Achieving consensus from all key stakeholder groups may also be challenging, particularly in those areas where the evidence is less clear.

Practical strategies designed to make it easy for both the referrer and receiver to improve services will be required to achieve real change in referral behaviour. Options for these strategies are discussed later in this paper.

In summary the limitations of referral pathways from the GP point of view¹² may include:

- the use of guidelines predictive power as a marker for cancer diagnosis is low
- causes unnecessary worry
- places pressure on hospital clinics/ diagnostics
- GPs feel swamped by literature
- current guidelines / referral protocols need to be simplified
- GPs exhibit poor compliance with following guidelines / protocols.¹³ A practical strategy may be to encourage Practice Nurse checks of referral requirements if patient meets urgent referral guidelines.
- information overload - GPs feel swamped by literature and need a universal, simplified and readily accessible resource for being an effective information interface for their patients.¹⁴

Australian Referral Pathways in Cancer - Victoria

A recommendation from the 2003 *Cancer Services Framework for Victoria* suggested *that* tumour streams be developed to reduce unwanted variation in practice. Subsequently Patient Management Frameworks covering each tumour stream were developed to provide a consistent statewide approach to care management in each tumour stream. The patient management frameworks¹⁵ are a clear description of the care pathway, identifying the critical points including referral from the general practitioner to specialist.

The patient management frameworks have been developed in collaboration with a wide range of practitioners, consumers and carers. In many cases, however, they are a statement of consensus regarding currently accepted approaches to treatment.

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¹² Presentation from Dr Andy Croaker – HNE learning session 2 (8 October 2008)

¹³ Sladden MJ, Thomson AN: How do general practitioners manage rectal bleeding? *Aust Fam Physician* 27(1-2):78-82 1998.

¹⁴ Jiwa M, Halkett G, Aoun S, Arnet H, Smith M, Pilkington M and McMullen C. Factors influencing the speed of cancer diagnosis in rural Western Australia: a General Practice perspective. *BMC Fam Pract* 8:27 May 2007.

¹⁵ <http://www.health.vic.gov.au/cancer/pmfnew.htm>

Referral Pathways, Continued

Local Referral pathways

Hunter New England (HNE) has begun work looking at minimal diagnostic work ups for the Lung and Colon tumour types. The lung referral pathway is now in final draft (see Appendix 1). HNE has also committed to developing a generic patient pathway as part of their *08-09 Cancer Services Operational Plan*.

International Referral Pathways in Cancer

Ireland and Scotland have developed comprehensive cancer referral pathways and the links to these can be found in the footnotes below.

The Scottish referral guidelines¹⁶ for suspected cancer were first published in 2002. The revised guidelines, published in February 2007 have been produced by an Expert Group following wide consultation, review of evidence and the findings of audits undertaken since publication of the first guidelines. The guidelines cover twelve tumour groups. For each tumour group the guidelines include information on:

- key points about the characteristics of patients with the relevant cancers
- guidelines for urgent referral.

As with the initial referral guidelines, the aim of the second edition guidelines is to facilitate appropriate referral between primary and secondary care for patients whom a GP suspects may have cancer. The guidelines should help GPs to identify those patients who are most likely to have cancer and who therefore require urgent assessment by a specialist. Equally the guidelines may assist GPs to identify patients who are unlikely to have cancer and who may require observation in a primary care setting or non-urgent referral to a hospital.

Irish cancer referral pathways¹⁷ have been developed in response to recommendations from general practitioners. The following recommendations to improve early detection of cancer were suggested:

- agreed referral criteria and clinical guidelines in particular to agree criteria for screening
- clear communication links/ information including public awareness campaigns
- increase in the number of rapid access cancer clinics and improvement access to investigative radiology for GPs.

Other examples of the development of referral pathways include those developed by NICE¹⁸, England and the British Columbian Cancer Agency¹⁹, Canada.

¹⁶ <http://www.pathways.scot.nhs.uk/>

¹⁷ <http://www.icgp.ie/go/archive/AB67F232-D5AB-5C10-71B7BE59FBDF1899.html>

¹⁸ <http://www.nice.org.uk/guidance/index.jsp?action=byTopic&o=7165&set=true>

¹⁹ <http://www.bccancer.bc.ca/HPI/FPON/GuidelinesandProtocols.htm>

Current need

GP Issues

General Practitioners (GP) are crucial in screening, early detection and early intervention for cancer. However any one GP will not necessarily see large volumes of any one particular type of cancer²⁰ and can find it difficult to know what to do and who to refer to. It is estimated that each GP working in Australia encounters, on average, four new serious cancer cases and one and a half cancer deaths each year. At any one time, the average Australian GP would have around sixteen patients in their care who have cancer.²¹ Cancer is therefore not a common health problem in general practice.

Referral patterns from GP's are governed by multiple factors including:

- previous experience with the cancer type
- relationships with specialist
- location
- awareness of local, regional and tertiary services
- access to appropriate service directories.

There is a lack of systems to alert GP's to the required investigations relevant to the presenting problem. This may result in over ordering or under ordering. Delays in seeing a specialist may also result in investigations being outdated by the time the patient sees the specialist, requiring repeat testing further delaying definitive treatment and increasing the cost of care.

Many GPs may not perceive that they have a need for ongoing cancer education and training when it poses a relatively insignificant problem in their practice. The same may prove true in the need for referral pathways.

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²⁰ As above

²¹ National Cancer Control Initiative (NCCI b). (2003). The Primary care Perspective on Cancer – An introductory Discussion. Melbourne: National Cancer Control Initiative.

Referral Pathways, Continued

Patient Issues Patients who receive a diagnosis of cancer or suspected cancer are often in shock. They rely heavily on the General Practitioner in terms of the immediate next steps. More and more these days patients also access the internet to provide them with a more comprehensive range of material (some of questionable rigor).

Patients want and deserve to be given accurate information about their options. This includes the range of specialists or services they could be referred to, however being referred out of town can come at a significant cost to patients who may have to fund travel, accommodation and care relief in their absence.

The Cancer Professional Development Framework²² identifies patients need as:

- have cancer found as early as possible, if early treatment is beneficial
- have enough information to decide whether to participate (if eligible) in population screening programs
- be able to access population screening and diagnostic services
- be confident that population screening and diagnostic services are providing high quality care
- understand their test results
- if they are diagnosed with cancer, to be told appropriately and provided with support.

Service Issues Services are struggling to meet increased demand. In order to be able to best meet the projected increases in demand services, are and need to, review their processes to ensure they are operating in the most efficient and effective manner.

The presence of waiting lists in many services further adds to the workload for staff and delays for clients. More efficient scheduling systems, better preparation and triaging of clients and improved follow up arrangements will all improve patient flow and timeliness. A referral pathway is one component that may lead to improved efficiencies.

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²² Cancer Professional Development Framework 2008 (Draft)

Referral Pathways, Continued

Specialist Issues Specialists are frustrated with the at times length delays it takes patients to see them and when they see them without sufficient work up to allow them to make a definitive diagnosis or appropriately stage the disease. Specialists are time poor, however there may be some scope for specialists to review their practices to determine whether they are spending their time where they best add value. There may be the potential for them to 'divest' some of their tasks to other members of the cancer team or their practice to allow them to be more responsive to new diagnoses and complex cases, where their scarce expertise may be better utilised.

Current Referral Patterns It is difficult to map existing referral patterns because of the multiple causative factors. Attempts to do so to date have proved fruitless as they tend to depict the highly varied referral patterns that have grown over time. Data are difficult to collate as there is no one source. Data are being collected through various mechanisms across the network including out of area flows and postcode related data. These data will assist to inform current referral pathways and provide useful baseline data to evaluate the effectiveness of any improvement strategies.

Waiting times Comprehensive waiting time data is available on the NHS website.²³ This website provides information on the waiting times of patients with suspected cancer and those subsequently diagnosed with cancer at NHS Trusts in England. Waiting times are set at a maximum of one month wait from an urgent referral for suspected cancer to the beginning of treatment and two weeks from diagnosis to first outpatient appointment.

Similar waiting time targets are described for NSW cancer services however the data are not as readily available. Data gathered to date shows that the most significant delays occur when waiting to see a medical oncologist. Target data for the HNE Area identifies a waiting time of 14 days for a medical oncologist. The actual data²⁴ across four services was 18, 28, 34 and 35 days wait for a medical oncologist.

Randomized controlled trials of breast²⁵ and colorectal cancer²⁶ screening suggest delayed cancer detection has significant effects on mortality. GPs and the Area Health Service need greater collaboration to minimise delays.

²³ <http://www.performance.doh.gov.uk/cancerwaits/2005/q3/index.html>

²⁴ Extract from HNE Balanced Scorecard.

²⁵ Nystrom L, Rutqvist LE, Wall S et al. Breast cancer screening with mammography: overview of Swedish randomized trials. *Lancet* 341: 973-978. 1993.

²⁶ Towler B, Irwig L, Glasziou P, et al. A systematic review of the effects of screening for colorectal cancer using the fecal occult blood test, Hemoccult. *BMJ* 317: 559-565 1998.

