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Disclaimer: Sites who participated in this exploratory study have been de-identified in this report.
1. EXECUTIVE SUMMARY

1.1 Context, Approach & Methodology

The Public and Private Cancer Care Project is part of the National Cancer Work Plan, developed by the National Cancer Expert Reference Group (NCERG) and endorsed by the Council of Australia Governments (COAG). NCERG appointed the Department of Health (the Department) to lead the project. The Department established a project Steering Committee to guide and oversee the project.

The purpose was to investigate and document enablers and barriers to effective coordination of cancer care (including effective pathways of care), across public and private settings. The aim was to inform and guide future health service planning and delivery. To identify enablers and barriers to effective treatment pathways of cancer care across public and private services the project team consulted with key stakeholders at four different sites across Australia. The sites were selected to ensure representation across jurisdictions, geographical diversity, a variety of service levels and models, and opportunities to explore management of different tumour types.

The key findings (below) reflect the personal and professional perceptions and experiences of key informants in a range of roles (including consumers, specialists and other health professionals and health service managers or administrators). Analysis and synthesis of data identified both common and unique enablers and barriers to coordinated cancer care. Narratives and vignettes were created from the evidence to describe the patient experience of cancer care at the public/private interface and critical enablers or barriers.

Generalizability of findings is limited by the scope of the project (limited to four sites and four cancer types). However the project methodology was designed to elicit service and system perspectives rather than individual opinions and analysis and synthesis of the data identified common issues and themes.

1.2 Key Findings

Individual episodes of cancer treatment generally occurred in either a public or private cancer service, however over the course of the entire cancer treatment pathway, many patients had some episodes of their cancer care across both settings.

However, one significant and overarching finding was that many patients and cancer care providers, including specialists and health professionals in both public and private settings, did not have a shared understanding of the complete cancer treatment pathway and the extent to which public and private cancer services interface.

1.2.1 Patient information transfer & clinical communication

Timely and effective clinical communication and transfer of patient information was often hindered by the absence of a common patient record and of integrated clinical information systems across public and private cancer services. Key enablers were system-level support (e.g. integrated or compatible information systems across local services) and having health professionals (usually specialists) working jointly across both public and private cancer services.

In the absence of aggregated clinical information, established professional and personal relationships between specialists and service staff were key to timely and quality patient information transfer (particularly when out of area referrals are necessary). These relationships and professional networks influenced referral, treatment and supportive care pathways both within and across public and private cancer services.

Co-location or proximity of services also supported informal transfer of patient information and coordination of patient care.
There was a general lack of shared knowledge and understanding of cancer treatment pathways and service models by patients, health professionals and service providers. Even when documented treatment pathways exist, health professionals’ awareness and implementation of them was variable. Patients generally received information about episodes of care and side effects of treatment, but were rarely given a complete picture of their expected cancer pathway, including interfaces between public and private cancer services, and the expected out-of-pocket costs.

Positions that coordinate cancer care, particularly tumour or pathway-specific, were considered a critical resource to help patients navigate their cancer treatment pathway and to understand and minimise any discontinuity at the points of interface between public and private cancer services.

1.2.2 Multidisciplinary care

Multidisciplinary team meetings (MDMs) are a critical component of treatment planning and were considered to be most effective when they operated across public and private cancer services, reviewing both public and private patients. In the context of this project, MDMs were acknowledged as an important mechanism to bring public and private health professionals together to provide peer and multidisciplinary input into treatment decisions and to assist in coordinating patient care at points of interface between public and private cancer services.

The ability of MDMs to support clinical communication and coordination of patient care across public and private services was influenced by strong clinical leadership (‘clinical champions’), consistent participation by clinicians from both public and private cancer services (dependent on information systems and support for meeting coordination) and having care coordinators or specialist cancer nurses attend.

1.2.3 Integration of supportive care

System-level approaches to distress screening, referral processes and monitoring against service indicators across integrated services were identified as key mechanisms supporting integration of supportive care.

In the absence of structured approaches, informants described informal, variable and largely ad hoc screening and referral processes for physical and psychological support at the public and/or private hospitals.

The larger tertiary public hospitals were perceived to provide a broader and ‘holistic’ range of allied health and supportive care services (a ‘one stop shop’). There was a sense that for private patients there was less coordination, given the need for individual referrals to private service providers, and that fee for service arrangements hindered access to comprehensive psychosocial care.

1.2.4 Integration of palliative care

Integration of and patient access to palliative care was influenced by the availability of palliative care services (inpatient and community-based) and the participation of palliative care physicians in MDMs.

Most of the key enablers and barriers reported by informants related to the issue of service availability, across both public and private service providers.

1.2.5 Best practice cancer care

Multidisciplinary team meetings (MDMs) were identified as a key mechanism for ensuring cancer care was consistent with best practice and enabling planning and coordination of patient pathways.

Various approaches to monitoring appropriateness and timeliness of care were reported, ranging from no formal process to clinical audits against national guidelines and assessment against key performance indicators.
Access to clinical trials was predominantly via public hospitals, with MDMs noted as a forum for increasing awareness about clinical trials and discussing eligibility of individual patients.

1.2.6 Governance & infrastructure

The key factors influencing the extent of integration and/or sharing of infrastructure between cancer services were local resources (funding and workforce availability), local patient population needs, the development of local service agreements and Commonwealth and State government cancer initiatives (e.g. the Australian Government’s Regional Cancer Centres initiative¹ or Victoria’s Integrated Cancer Services program²).

There were few instances of integrated governance and infrastructure across public and private services but some examples of service delivery partnerships or infrastructure sharing under contracts or service level agreements.

When public and private cancer services had a shared understanding of their role in a local network and the interdependencies between local services, partnership arrangements were more likely to be established and more likely to be effective in shaping the local service delivery system.

1.3 Recommendations for National Cancer Service Development

These system-level recommendations have been developed for the consideration of the National Cancer Expert Reference Group and are based on the key findings in Section 5. They should be considered in the context of the project scope and limitations, outlined in Section 3.3.

1.3.1 Integration of best practice cancer care across public & private cancer services

Recommendation 1 - Acknowledging & strengthening the role of health professional relationships & networks in coordinating care across public & private cancer services

The personal nature of healthcare delivery means that interpersonal relationships, professional networks & informal processes play an important role in facilitating a sense of a “service community”. These relationships often direct the transfer of clinical information & the coordination of patient care.

It is important that there are opportunities to bring together public & private cancer specialists & health professionals which facilitate joint training, professional development & networking. Refer to Section 5.1.1

Recommendation 2 - Strengthening care coordination & patient navigation across the public & private interface

Coordinating cancer care effectively across the public & private cancer interface, relies heavily on the capacity of health professionals to transfer information & navigate patients along the treatment pathway.

Support for coordinating roles is critical, particularly tumour-specific or pathway-specific positions, which help patients (& their families) navigate the cancer care pathway & the interfaces between public & private services. These roles are particularly important for patients with more complex care coordination needs & when part of a system-wide approach to cancer care coordination. Refer to Section 5.1.2

Recommendation 3 - Promoting national data specification, collection & reporting on quality of care, service & clinical outcomes data across public & private cancer services

Various approaches to collecting & monitoring cancer clinical data exist across public & private cancer services. These range from no formal process, through to clinical audits against national guidelines & assessment against key performance indicators. This variability across public & private cancer services, limits the ability of the cancer system as a whole to implement data driven service improvements.

Promotion of national evidence-based protocols & standardised approaches to data collection & reporting across public & private cancer services, can lead to a better understanding of health service utilisation & cancer clinical outcomes. This will also necessitate inclusion of non-cancer specific activity data systems. Refer to 5.5

Recommendation 4 - Defining best practice cancer care for the treatment pathway across public & private cancer services

Supporting & promoting evidence-based best practice cancer care is important to improving the outcomes & quality of life for people with cancer. Documented optimal cancer treatment pathways however often fail to address the issue of public & private cancer service ‘crossover’.

Strengthening a common understanding of the elements of best practice care across public & private cancer services can help standardise the quality of care provided to cancer patients. It is important that a system level approach is taken to integrating multidisciplinary care, supportive care & access to clinical trials across the entire treatment pathway (particularly when there are interfaces between public & private cancer services). Refer to Section 5.5

1.3.2 National leadership to guide a whole of cancer population approach to public & private cancer service delivery

Recommendation 5 - National guidance for shared service arrangements across public & private cancer services & different service delivery settings

Joint public & private cancer service arrangements & infrastructure is essential to define & drive improvements in cancer service delivery across the public & private interface. These arrangements can strengthen shared understanding of service roles, support a whole of cancer population view & play a key role in shaping the local cancer service system.

The development of national guidance, including key principles, will assist public & private cancer services to plan for & develop these arrangements, tailored to local population & service requirements. Refer to Section 5.6

Recommendation 6 - Facilitating co-location of public & private cancer services & shared access to clinical information

Physical co-location of cancer services with shared access to clinical information systems can facilitate efficient transfer of patient information, particularly across the public & private cancer service interface. Integrating physical & information infrastructure also supports a more seamless cancer treatment pathway for the patient.

It is important to consider appropriate co-location & shared access to clinical information systems as a key criterion in planning & establishing new public-private cancer service partnerships. This includes the use of common electronic medical records. Refer to Section 5.6
2. BACKGROUND

2.1 Cancer in Australia

Cancer is the leading cause of death in Australia.\(^3\) It 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. Cancer is estimated to be the leading cause of burden of disease in Australia, accounting for approximately 19 percent of the total disease burden in 2012.\(^5\)

Cancer incidence is increasing, due in part to the ageing population.\(^4\) Relative survival rates for cancer have increased in recent years,\(^5\) resulting in a higher number of patients needing both clinical and supportive care.

Cancer outcomes vary with remoteness, with survival being higher in major cities and lowest in remote and very remote areas.\(^6\) Poorer cancer outcomes are linked to poorer access to cancer treatment, which is also observed in remote and very remote areas. Key factors for poorer access in remote areas include a shortage of specialist treatment facilities and health care providers and a lower quality of treatment and care in non-metropolitan regions compared to metropolitan areas.\(^7\) People living in regional, rural and remote areas are also likely to have to travel for their treatment and care.

2.2 Cancer Service Delivery in Australia

The Australian health system is characterised by its mix of public and private service providers, with both sectors contributing to the financing and delivery of health services under the Medicare framework. Specialist cancer care services across Australia are also characterised by this mixed public and private approach to service delivery.

Private hospitals account for an increasing proportion of cancer care services in Australia. For example, between 2007–08 and 2011–12, the largest increases in the numbers of hospitalisations in private hospitals were for chemotherapy (by 32% to 217,246 hospitalisations).\(^8\)

In many instances, public and private hospitals and the specialist cancer services that operate within the acute hospital setting, do not operate in isolation from each other, but provide health-care services through various levels of coordination. These include contracted care arrangements, co-location and resource sharing, and private sector involvement in hospital infrastructure development for public patients.

The growing role of private hospitals in Australia’s health system has been supported by the Australian Government through measures such as the Private Health Insurance Rebate, and reflected in the inclusion of private hospitals in national performance monitoring initiatives such as those of the National Healthcare

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\(^7\) Deloitte Access Economics 2011. Access to Cancer Treatment in non-metropolitan areas of Australia. Amgen Australia Pty Ltd.

Agreement, and in the Performance and Accountability Framework of the National Health Reform Agreement.\textsuperscript{9,10}

The Australian Government has also invested significantly in regional cancer services through the Health and Hospitals Fund (HHF) to enable people living in regional, rural and remote areas to receive safe and appropriate care as close to home as possible. The investment in regional cancer service infrastructure requires treatment and care pathways to be integrated, coordinated and delivered across networked public and private cancer services. In addition, treatment pathways for different tumour groups in both regional and/or metropolitan settings are provided across both public and private services, highlighting the importance of understanding the enablers and barriers to effectively deliver safe and high quality treatment pathways that facilitate co-ordination of cancer care across public and private health settings.

2.3 The National Cancer Work Plan

The Public and Private Cancer Care project forms part of the National Cancer Work Plan, developed by the National Cancer Expert Reference Group (NCERG) and endorsed by the Council of Australia Governments (COAG).

The NCERG was established by the COAG in 2010. It includes senior representation from all jurisdictions, the Clinical Oncological Society of Australia, the Cancer Council Australia, Cancer Australia, as well as input from key cancer experts and consumers.

The National Cancer Work Plan focuses on improving cancer outcomes through three initiative areas:

- agreed pathways of cancer care
- efficient and effective cancer services
- implementation of evidence-based cancer treatment.

NCERG is undertaking a number of projects for each initiative area. The Public and Private Cancer Care project is of relevance to a number of these initiatives, for example, the development of tumour specific Optimal Care Pathway (OCP) guides for health services and professionals in both public and private settings.

2.4 The Public & Private Cancer Care project

The purpose of the Public and Private Cancer Care project was to investigate and document enablers and barriers to effective coordination of cancer care (including effective pathways of care), across public and private settings. The aim was to inform and guide future health service planning and delivery.

The cancer care pathway

The cancer care pathway is different for different cancer types but typically starts from the point of referral for investigation of symptoms. Key elements in the pathway are:

- appropriate referral for investigation of symptoms
- triage to fast-track diagnostic testing for high-risk patients
- diagnosis
- multidisciplinary treatment planning
- multidisciplinary coordinated care
- specialist treatment (including surgery, radiotherapy and systemic treatments)
- identification of supportive care needs and provision of appropriate support


\textsuperscript{10} NHPA (National Health Performance Authority) 2013. Sydney: NHPA. Viewed 20 January 2015.
• early access to palliative care as appropriate
• provision of rehabilitation and follow-up care following treatment
• survivorship care
• end-of-life care.

The care pathway requires input from primary care, specialist diagnostic and treatment services, nursing and allied health. These services may be provided in the public and/or private sectors and within specialist and community-based settings. Critical components across the care pathway include coordination of care and provision of appropriate information to patients and their carers to support informed decision-making.

In Victoria, tumour stream based Patient Management Frameworks (PMFs) have been developed, describing the cancer care pathway and identifying optimal models of care required at critical points on the pathway. Victoria is presently renewing the PMFs to provide optimal cancer care pathways (OCCPs) to inform the health system and support local referral pathway development, and deliver against the National Cancer Work Plan initiative on establishing best practice pathways of cancer care.

2.5 Project Management

The Department of Health (the Department) led this project on behalf of NCERG. The Department established a project Steering Committee to guide and oversee the project. Steering Committee members are listed in Appendix 7.1. The Department provided secretariat support to the Steering Committee and convened and hosted all Steering Committee meetings.

After a select tender process, the Department appointed ZEST Health Strategies to investigate and document enablers and barriers to effective coordination of cancer care, and develop recommendations for cancer service planners and healthcare providers.
3. METHODOLOGY

3.1 Definitions

There is significant variability in service delivery and funding models across the Australian health sector. Creating a binding definition for ‘a public cancer service’ versus ‘a private cancer service’ is problematic due to the complexity of mixed service provision across the public and private healthcare sectors and the complex public and private financing arrangements for services within the context of the cancer care pathway.

For the purposes of this project the following definitions were assigned, with reference to patient flow through the cancer care pathway:

- **public service**: all services and care provided to the patient across the cancer care pathway are solely provided by publicly funded services in a publicly funded site, i.e. services and service providers are primarily funded by the Government
- **private service**: all services and care provided to the patient across the cancer care pathway are solely provided by privately funded services in a privately funded site, i.e. services and service providers are not primarily funded by the Government
- **public/private partnership**: the range of services and care provided to the patient across the cancer care pathway is provided by a mixture of publicly and privately funded services delivered in partnership in a public or private site; for example, radiology services may be provided by a privately funded service in a private setting, while all other care is provided in a publicly funded service, in a public site.

3.2 Overview of Project Approach

The project was conducted in three key stages.

The overarching research methodology for this project was multiple case study design. The approach to case studies was adopted because it facilitates:

- explanation of the complex causal links in real-life service settings
- description of the real-life context in which the services are provided
- description of the services themselves
- an exploration of the situations in which there are unclear outcomes, in this case as a result of the pathways between public and private cancer services.

The cases were identified purposively, which involved selecting cases to demonstrate by comparison ‘those processes and relations that routinely come into play’. Purposive sampling is useful when studying specific organisational and

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decision-making contexts with knowledgeable experts involved,\(^{14}\) as was the case in this project.

### 3.2.1 Selection of case study sites

For the purposes of this project, a ‘site’ was considered to be a network of local public and private health services, providing comprehensive cancer care within a defined geographic area.

The case study sites were divided into metropolitan and regional and had to fit the criteria outlined in Tables 1 and 2.

#### Table 1 Criteria for selection of metropolitan sites

<table>
<thead>
<tr>
<th>Criteria Area</th>
<th>Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jurisdiction</td>
<td>• one site to be selected from South Australia</td>
</tr>
<tr>
<td></td>
<td>• one site to be selected from Victoria</td>
</tr>
<tr>
<td>Geographical location</td>
<td>• located in highly accessible area (ARIA 1)(^{15})</td>
</tr>
<tr>
<td>Service level considerations</td>
<td>• delivering a level 6 service in line with the service capability framework</td>
</tr>
<tr>
<td></td>
<td>• provide a full range of treatment &amp; care across metropolitan public &amp; private sites</td>
</tr>
<tr>
<td></td>
<td>• have active networks in place across public &amp; private clinical services &amp; providers to provide coordinated care</td>
</tr>
<tr>
<td></td>
<td>• have multidisciplinary teams in place</td>
</tr>
<tr>
<td>Tumour type</td>
<td>• provide cancer care across a minimum of two of the following tumour groups: breast, prostate, upper gastrointestinal &amp; colon</td>
</tr>
</tbody>
</table>

#### Table 2 Criteria for selection of regional sites

<table>
<thead>
<tr>
<th>Criteria Area</th>
<th>Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jurisdiction</td>
<td>• two sites to be selected from either Queensland &amp;/or Victoria</td>
</tr>
<tr>
<td>Geographical location</td>
<td>• located in a moderately accessible or remote area (ARIA 3 &amp; 4)</td>
</tr>
<tr>
<td>Service level considerations</td>
<td>• comprehensive treatment* &amp; care provided across the region via regional cancer services</td>
</tr>
<tr>
<td></td>
<td>• radiotherapy &amp;/or chemotherapy services &amp;/or surgery operated by a private provider</td>
</tr>
<tr>
<td></td>
<td>• within the region, surgery, chemotherapy &amp; radiotherapy are provided locally for high volume cancers such as breast or prostate cancer</td>
</tr>
<tr>
<td>Tumour type</td>
<td>• provide cancer care across a minimum of two of the following tumour groups: breast, prostate, upper gastrointestinal &amp; colon</td>
</tr>
</tbody>
</table>

*Defined as the provision of best-practice services and multidisciplinary care across all levels of the cancer care pathway as per Victoria Patient Management Frameworks for breast, prostate, upper gastrointestinal and colon cancers.

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Four case study sites were identified (Table 3). The included case study sites were selected because they represent a broad range of services across the criteria above. For inclusion in the project, selected case study sites were required to formally agree to participate.

### Table 3 Selection of case study sites

<table>
<thead>
<tr>
<th>Case study site</th>
<th>Geographic location</th>
<th>Tumour type</th>
<th>Tumour type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site 1</td>
<td>Regional</td>
<td>Upper gastrointestinal</td>
<td>Prostate</td>
</tr>
<tr>
<td>Site 2</td>
<td>Metropolitan</td>
<td>Upper gastrointestinal</td>
<td>Colon</td>
</tr>
<tr>
<td>Site 3</td>
<td>Metropolitan</td>
<td>Upper gastrointestinal</td>
<td>Breast</td>
</tr>
<tr>
<td>Site 4</td>
<td>Regional</td>
<td>Upper gastrointestinal</td>
<td>Prostate</td>
</tr>
</tbody>
</table>

#### 3.2.2 Selection of tumour types

Four tumour types were selected (breast, prostate, colon and upper gastrointestinal) based on consideration of volume and complexity. Some components of treatment for high volume/low complexity cancers may be provided locally across public and private services and some components of low volume/high complexity cancers are likely to involve referral out of area. For example, due to the relative low volume of upper gastrointestinal (upper GI) cancer cases and the complexity of treatment and care, it is likely that some components of treatment would be provided in larger metropolitan public services, e.g. surgery, with other components provided in local public or private services, e.g. chemotherapy and radiotherapy.

#### 3.2.3 Health service & consumer consultations

A conceptual approach to consultations and data analysis (Figure 2) was developed to reflect the multidimensional nature of cancer service delivery. This acknowledges that an individual’s perception of the public and private service interface and enablers and barriers to care coordination, are influenced by the position from which they experience the cancer care pathway, i.e. at a patient, service delivery or system level.

**Figure 2 Conceptual framework for consultations & data analysis**

Designated leads from each site were requested to identify the most appropriate staff within their service to participate in consultations. Nominated staff were then
approached by email or phone, provided with an information sheet (Appendix 7.2),
and all participants agreed to be interviewed (100% participation rate).

Pre-interview surveys were conducted with 12 key informants across the four sites to
map the cancer care pathways and identify interfaces between the public and private
services.

Telephone interviews were conducted with key stakeholders at each of the four sites
to identify enablers and barriers to effective pathways of cancer care across public
and private services (and at each level).

Telephone interviews were conducted with 38 key informants across the four sites,
including 32 service contacts (health professionals and health administrators) and 6
consumers. The primary position of interviewees is indicated in Table 4. However it is
important to note that many interviewees had multiple roles (e.g. a radiation
oncologist may also have been a clinical director with health management
responsibilities) and therefore each interviewee was able to provide multiple
perspectives, often across tumour types, treatment modalities and public and private
services.

Table 4 Primary role of interviewees

<table>
<thead>
<tr>
<th>Primary role</th>
<th>Number of interviewees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgeon</td>
<td>5</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>3</td>
</tr>
<tr>
<td>Medical oncologist</td>
<td>3</td>
</tr>
<tr>
<td>Nurse</td>
<td>5</td>
</tr>
<tr>
<td>MDT Coordinator or Cancer Care Coordinator</td>
<td>8</td>
</tr>
<tr>
<td>Allied health professional</td>
<td>5</td>
</tr>
<tr>
<td>Health service manager/administrator</td>
<td>3</td>
</tr>
<tr>
<td>Consumer</td>
<td>6</td>
</tr>
</tbody>
</table>

A key informant interview guide was developed to inform the interviews, all interviews
were audio recorded, and interviewers took detailed notes that were transcribed into
a data capture table (with reference to audio recordings as required). An overview of
the consultation process is provided in Figure 3.

Figure 3 Key steps in health service & consumer consultation
3.2.4 Synthesis & Reporting

An analysis framework (Figure 4) was developed to guide analysis and synthesis of data from pre-interview surveys and key informant interviews with a focus on key aspects of the interface between the public and private services.

A thematic analysis of the pre-interview survey and interview data was conducted to identify key themes and both common and unique barriers and enablers to coordinated care.

Figure 4 Thematic analysis framework

A validity workshop was held on 29 October 2014 with members of the project Steering Committee and participants from each of the sites involved in the consultation. The purpose was to present and discuss key findings and to enable expert interpretation and input into development of recommendations.

3.3 Scope & Limitations

The project was focused on the enablers and barriers to coordinated cancer care across public and private cancer services. Many of the issues identified may also be applicable to cancer care generally in which case the critical question applied was ‘How does this impact on the public/private interface?’

The scope of the project did not allow consultation on the assessment of symptoms in the primary care setting or the referral process to specialist services. The project also excluded primary care on either side of the treatment pathway.

There are a number of limitations to the findings and their generalizability due to the scope of the project (limited to four sites and four cancer types). Findings cannot necessarily be extrapolated beyond the sites involved and cancer types included. The methodology however did enable identification of common issues and themes.

At the time of this report, there was no universal treatment pathway for a patient (even by cancer type). The collated information in this report is based on information from consultations. The information primarily reflects the personal and professional perceptions and experiences of interviewees, however the selection of a range of informants in key roles was designed to elicit service and system perspectives rather than individual opinions.
At some sites interviews did not cover the full range of personnel representing medical and nursing staff and service management across the public and private services.

Six consumers were interviewed, covering patient experience or knowledge of services at each of the case study sites. The consumers had a variety of experiences and roles: some as patients, while others had consumer representative roles with health services.
4. SITE CASE STUDIES

Four case study sites were identified for inclusion in the project, as per the criteria outlined in Section 3.2.1. The sites represented a broad range of service delivery models across different tumour types and settings (metropolitan and regional).

A general description of each is provided below, with detailed site profiles (including service profiles, public and private interfaces, enablers and barriers and example cancer care pathways) outlined in the appendices.

4.1 Site 1: Regional Location

The regional site includes co-located public and private hospitals in a regional town, with a service population of 225,000. The hospitals and cancer services are part of a regional Integrated Cancer Service, a state Government Department of Health initiative to improve integration of cancer care by coordinating health services in specific geographic areas.

For a detailed outline see Appendix 7.3

4.2 Site 2: Metropolitan Location

The metropolitan site includes co-located public and private hospitals and a comprehensive cancer wellness centre. Its service population is 1.29 million people. The hospitals and wellness centre are part of a metropolitan Integrated Cancer Service, a state Government Department of Health initiative to improve integration of cancer care by coordinating health services in specific geographic areas.

For a detailed outline see Appendix 7.4

4.3 Site 3: Metropolitan Location

The site incorporates a public and a private hospital, which are located adjacent to each other. There is a private radiotherapy centre, which is contracted to provide public services and is co-located with the private hospital. These services are in a metropolitan area with a service population of 350,000.

Note that the private hospital from this site, did not participate in the project.

For a detailed outline see Appendix 7.5

4.4 Site 4: Regional Location

The site is located in a regional area of the state with a local service population of approximately 240,000. Cancer services are provided at a public Cancer Care Centre (adjacent to the main public hospital campus), private hospital (some surgical and minimal medical oncology services) and a co-located private radiotherapy service contracted to provide public services. All patients referred for radiotherapy (locally) are treated as public patients under an agreement between the state health department and the private radiotherapy service.

For a detailed outline see Appendix 7.6
5. KEY FINDINGS

5.1 Patient Information Transfer & Clinical Communication

Timely and effective clinical communication and transfer of patient information was hindered by the absence of a common patient record or integrated clinical information systems across public and private cancer services.

Established professional and personal relationships between specialists and service staff were key to timely and quality patient information transfer (particularly when out of area referrals were necessary). Co-location or proximity of services also supported informal transfer of patient information and coordination of patient care.

There was a general lack of shared knowledge and understanding of cancer treatment pathways and service models by both patients and health professionals. Where documented treatment pathways existed, health professionals’ awareness and implementation of the pathways varied.

Patients generally received information about episodes of care and side effects of treatment, but were rarely given a complete picture of their expected cancer pathway, including interfaces between public and private cancer services, and the expected out-of-pocket costs.

Key enablers

- System-level integration and approaches to information transfer and coordination across services.
- Established professional relationships across services and between specialists, facilitating information sharing and ongoing communication about patients.
- Specialists having joint appointments or admitting rights at both public and private cancer services.
- Multidisciplinary meetings (MDMs) with real time access to patient clinical records.
- Defined health professional roles (e.g. cancer care coordinator, cancer nurse, MDT coordinator) to coordinate care and assist patients (and their families) to navigate the treatment pathway and interfaces between public and private cancer services.

Key barriers

- No common patient record.
- Fragmented information systems both within and across cancer services.
- Absence, lack of awareness or ad hoc application of documented cancer care pathways.
- Inaccessibility to cancer patients’ clinical information following presentation to emergency department after hours.
- Patient information ‘loss’ following a referral out of area.
- Cancer services working in isolation without knowledge of the whole cancer pathway and of all services.

5.1.1 Integrated clinical information systems & accessibility to patient records

One of the key barriers to communication about, and coordination of, a patient’s cancer care was the absence of integrated clinical information systems across public and private cancer services. The inability to create and/or access a common patient record meant the various specialists and health professionals involved in a patient’s care did not have a comprehensive view of the patient’s clinical information or history on which to base treatment decisions and coordinate care. The existence of multiple information systems that don’t communicate with each other prevents aggregation of clinical information as the patient moves along the cancer pathway.
“Sometimes I’ve been [the] meat in the sandwich between the [private] surgeon [and the public hospital] where she said ‘They’re not sending copies of your file reports to me’. But then you go back to the public cancer doctors and they say ‘Oh she is able to log on to the system herself and see it’. And you sort of think, oh, this is a process issue that you guys need to sort out.”
– Consumer

Informants reported significant segmentation of information by treatment modality, often housed in separate information systems e.g. private rooms, outpatient clinics, and private radiology. While there was some shared access to pathology and/or radiology across services at some sites it was not consistent or always reliable (illustrated in Figure 5). A common barrier to electronic information transfer or sharing was the presence of IT firewalls in public facilities. This prevented transfer to or access by health professionals outside the public system, which impacted service provision and participation in MDMs by private clinicians and GPs.

Figure 5 Illustration of fragmented clinical information systems across public & private cancer services

“If I have a patient referred from the public sector (and who has had their radiology there), when they turn up in my private room for a first consult, I can’t review their radiology and I have to then take their details back to the public hospital, find a computer, log on, look at these separately and then give the patient a phone call.”
– Surgeon

As a result of fragmented information systems, information sharing across services was described as generally manual and ‘clunky’, involving scanning paper based forms and letters. It was time-consuming and inefficient for each clinician or service provider to collate a comprehensive clinical picture of the patient. Many jurisdictions are in the process of piloting electronic and patient-held medical records. However, at the time of consultation, most clinical information at the study sites was recorded and transferred between specialists via referral letter or summary letter of treatment (paper based and manual) for both public and private patients.

“A typical patient I see has about five or six different investigations undertaken and sees about three or four different clinicians – all in the space of about a week to ten days. The public sector as it’s currently configured simply can’t handle this.”
– Oesophago-gastric surgeon

Not having timely access to patient clinical information was a particular barrier to quality and continuity of care when a patient (especially if treated privately) presented to a public hospital emergency department (ED) after hours or on a weekend, often with adverse effects of chemotherapy treatment.
“The patient may have chemo in the [private] day surgery and then become unwell and turn up at [public] ED after hours and there is no information in [their] system about the patient or the treatment – it impacts on the coordination and plan for the patient. Additionally the consultant won’t have admitting rights to [the public] hospital which means that the care is transferred to another specialist. This is not ideal for the patient.” – Oncologist

Several consumers reported their experience of presentations at an ED and the frustration, delays and duplication (e.g. repeating tests or imaging) caused by the inability of staff to access their full clinical records.

Hence a key enabler of efficient clinical communication between health professionals was system-level integration and mechanisms for information transfer and coordination across services.

**Specialists working across services**

Oncologists with privileges across multiple services reported less problems with clinical information transfer as they had remote access in their treating rooms. This was described as a ‘work-around’ solution rather than a process or system for services to share information. Most health professionals as well as the MDM coordinators or administrative staff charged with collating patient clinical data, reported challenges in accessing medical records, pathology results, imaging and records from private rooms.

**Health professional relationships and networks**

In the absence of common records and systems enabling clinical information sharing, health professionals often relied on professional relationships, particularly between public and private specialists, and the resourcefulness of individuals in MDM and care coordination roles.

Strong and respectful relationships between health professionals permitted ad hoc consultation and exchange of clinical information as required. Oncologists reported often having a phone or face-to-face conversation with another specialist about a patient’s treatment or transfer between services – an ad hoc and undocumented, but efficient, process.

MDM coordinators physically collected and collated faxed or scanned paper-based notes, films and results from CDs or USB sticks, work they described as time-consuming but essential to enable MDMs and treatment planning.

**Referral out of area**

When a patient was transferred out of area for care, information was generally transferred from hospital to hospital via a transfer/discharge summary and the patient took a copy of their notes and often a disc of diagnostic results. The quality of the information transferred through this manual process depended primarily on the referring doctor. The possibility of information ‘loss’ was high, particularly when the patient returned to their local service.

Sharing of clinical information after a private patient was recruited to a clinical trial depended on the referring doctor having a relationship with health professionals at the public hospital.

Similarly, out of area referrals relied on strong relationships with metropolitan or tertiary hospital specialists. Relationships were often developed through training or discipline specific networks and facilitated both formal networks for referral and informal routes of coordinating patient treatment and care.
5.1.2 Coordination & navigation of patients for cancer care across private & public services

Shared understanding of the cancer care pathways

Patients, health professionals and service providers described a lack of knowledge and understanding of the overall cancer pathway and service model.

“In the words of my urologist I slipped through the net. It was my understanding the radiation oncologist thought I was going back to the urologist, and the urologist didn't know I was going back to the radiation oncologist so [there was] some breakdown in communication. And I experienced this every week, every day, between GPs and consulting specialists in all fields. They have so much work to do and in a world of speciality if you get something minor many GPs refer to specialists so there is an increase in activity, in information flow, and so an opportunity for information to get lost.” – Consumer (regional)

At some sites, formal and documented cancer pathways were not established or awareness of them was low. This contributed to variable health professional understanding of the appropriate pathway and potential interfaces between public and private services. At one regional site a cancer pathway was described as “organic and not well understood even by the local staff”, with poorly defined processes for patient handover even between co-located services in the local region. A private service provider reported having “no idea what happens to [their] patients when they go across to the public service”, with most of the information coming from patients themselves.

“There is always going to be a bit of an ‘us and them’ mentality when it comes to private and public sector. We do things differently and there is a lack of understanding on how each other works.” – Registered Nurse

Consumers interviewed described frustration at the limited information sharing between services. Consumers reported having to undergo tests and imaging multiple times, with some reporting that the medical staff ordered identical tests because they had preferred providers. The rationale for this was poorly understood by consumers.

Co-location or proximate services – sense of a service “community”

Co-location and proximity of services supported ease of transfer of information (particularly where medical staff had privileges across both sites). It also increased the opportunities for specialists to have face-to-face conversations, and for hospital-to-hospital transfer of notes. The defined geographic area of the regional integrated cancer services in one state, and resulting personal and professional relationships between staff across services, supported a “community focus” and commitment to efficient care coordination. The integrated cancer service provided a system level view of the cancer service across both public and private services and was a hub for information for services, health professionals and community including service directory, pathways, model of care and information for patients and their family.

Care coordinators

Defined care coordination roles (e.g. cancer care coordinator, cancer nurse, MDT coordinator) were identified as key to coordinating and helping patients navigate their cancer care. Most of the positions identified were public hospital based, but it was suggested that their role could often extend to navigating patient care across the public and private interface.

“As long as the connections have been made all goes well; if you miss a step then it doesn’t go smoothly.” – Social Worker

These positions were described as “key to supporting the specialists”, and were often involved in complex patient care coordination, particularly if the role was focused on a particular tumour stream.
In one state the two upper GI specialist cancer nurses were acknowledged as having key roles in coordinating care (often involving medical teams across the public and private sectors) and also ‘problem solving’ along the cancer care pathway. In the other three sites there were no tumour-specific roles to support coordination of patients with upper GI cancer.

The availability of specialist support roles varied according to tumour type. For example, at one regional site, a man with prostate cancer may be supported by up to three different staff:

- a cancer resource nurse (providing information regarding treatment, coordinating transport, supportive care screening and referral, and navigation for both public and private patients travelling for cancer treatment)
- a prostate nurse (coordinating care across the treatment pathway for both public and private patients)
- a continence nurse (coordinating the post-surgical pathway for private patients).

5.1.3 Patient understanding of the cancer care pathway & out-of-pocket costs

The absence of documented pathways that acknowledge the interface between public and private cancer services hindered coordination and provision of information to patients about their potential care pathway.

The absence of a ‘complete view’ of the cancer care pathway

Patients generally did not receive a copy of the treatment plan or a summary of the proposed pathway of care. Most patients were informed of the treatment plan at a consultation with their oncologist (if a private patient) or by a specialist or registrar in the outpatient clinic (if a public patient). They received additional information from key personnel along the treatment pathway, e.g. chemotherapy nurses commonly gave patients information regarding side effects. Informants described information packs that were given to patients, and support and resources available from hospital services and community-based organisations. However, information about the treatment pathway and interface between public and private services appeared to be lacking.

Often patients were unaware of the model of service provision, e.g. that all patients (public and private) access radiation oncology through a private provider. Some informants suggested that if the service was co-located and “fairly seamless to the patient” it was not necessary to be explicit about the public/private interface as the patient’s immediate concerns were focused on treatment options and prognosis. Others felt patients should be fully informed about their care pathway.

“There is a need for patients to know who is providing their care, to know that there is a transition plan in place and to be aware of what stage their treatment is at.” – Prostate cancer nurse

Continuity of patient care across public & private cancer services

Concerns around continuity of care were one of the most commonly cited by the consumers interviewed. Patients who chose to ‘go private’ often did so because of a desire to see the same specialist and nursing staff across their cancer treatment. Health professionals however, often reported that seeing a single specialist throughout the treatment pathway could limit comprehensiveness of care, compared to that provided by a larger multidisciplinary team.

There was a sense that once a patient had selected or been referred to a specialist in a public or private cancer service, the specialist’s or service staff’s sense of ‘ownership’ of the patient determined the cancer pathway, and therefore choice of all treatment options by location might not be discussed with the patient.

“The surgeon was in a private hospital the following week and she said I’m doing four operations and you’re being operated on and that was pretty much...”
the end of the story. … With hindsight it would have been nice to have had it
done through the public system but because it was between Christmas and
New Year there wasn’t much of a choice … there was no decision, I was just
told. … It was quick and for the type of tumour it probably needed that quick
action.”– Consumer (regional)

Consumers also reported sensing competition between public and private services to
patients.

“It might be better in the city where they might work better together but not in
[regional centres]. Both services are there to support their own needs and the
private guys want their dollars and the public people want their turnover of
patients to support their needs.”– Consumer (regional)

Episodic & ad hoc information about costs

Provision of information about out-of-pocket costs was reportedly ad hoc and
informal, despite indications that some of the biggest unexpected costs occurred
where there was a public/private partnership model. Cost implications of private
imaging and pathology were often poorly explained or not disclosed in advance.

Patients were often given information in advance about the costs of particular
episodes of care (sequentially), however they were rarely given an indication of total
costs across their whole treatment pathway. Specialists seemed to have limited
awareness of cost implications and, according to consumers, often viewed it as
someone else’s responsibility (e.g. hospital admission staff) to inform the patient.

Financial consent was more consistently obtained when a patient chose to be a
private patient in a private hospital (particularly if uninsured) or the out-of-pocket
costs of treatment were expected to be significant (although what constitutes
‘significant’ was not well defined). However, private specialists reportedly had
different practices about disclosing and discussing their fees in advance of treatment.

“Patients are not informed about costs well; patient feedback highlights the
difficulty, particularly in the private, and knowing where there are gaps [which
is the] responsibility of the clinicians.”– Strategic Manager (Integrated Cancer
Service)

Consumers also noted that being informed of costs was not the only issue; patients
may need time to prepare financially and referral to services providing financial
assistance.

Vignette: Public/private cancer service partnership model (Site 4)

The potential benefits of a public/private partnership model of delivering cancer
services were highlighted at the regional site.

Until 2010 radiotherapy was not available locally to public patients in this regional
town. Patients requiring radiotherapy had to travel to the nearest regional tertiary
hospital (approximately four hours’ drive) or to metropolitan hospitals (involving a two
hour flight or two days drive).

In recognition of the impact on the cancer outcomes and quality of life of regional
patients, the state health department established a service agreement with a private
service provider to deliver radiation therapy to patients at the Medicare schedule fee,
ensuring no out-of-pocket costs.

The cancer centre within the local public hospital and the private service provider,
undertook joint service planning before the service was established, including
developing referral pathways and raising community awareness about the availability
of radiotherapy services locally.

Co-location of the radiotherapy service within the public hospital, supports a
seamless experience from the patient perspective. The radiation oncology team
includes radiation oncologists, radiation therapists, nurses, medical physicists and
administration staff. There is also a team of allied health service providers, including dieticians, speech pathologists, physiotherapists, occupational therapists, social workers and psychologists, providing rehabilitation and psychosocial support services through the public hospital, at no cost to public or private patients.

Radiation oncologists are ‘shared’ across both the public hospital and private radiotherapy service (contracted 50 percent to each), strengthening service relationships and clinical communication and enhancing continuity of care for the patient. The impact of the co-location of the private service and the public cancer centre is strengthened through some shared electronic access to patient notes across services.

5.2 Multidisciplinary Care

Multidisciplinary team meetings (MDMs) are a critical component of patient treatment planning. In the context of this project, MDMs were acknowledged as a critical mechanism in bringing public and private health professionals together and coordinating patient care at points of interface between public and private services.

The ability of MDMs to support clinical communication and coordination of patient care across public and private services depended on:

- clinical leadership (‘clinical champions’)
- participation by clinicians across the public and private services (dependent on information systems and support for meeting coordination)
- having care coordinators or specialist cancer nurses attend.

Not all patients were reviewed at an MDM. This was due to a number of reasons, including there being no MDM for their tumour type, private patient cases not being routinely presented, or the high volume of cases and restricted meeting frequency limiting the number of patients that can feasibly be presented and reviewed.

MDMs were most effective in supporting coordination and integration of cancer care when they operated across services for all public and private patients.

Key enablers

- Clinical champions and consistent involvement of clinicians and staff working across both public and private cancer services.
- Well-coordinated meetings, physical location to hold the meeting, and information systems (e.g. videoconferencing, electronic clinical data sharing) enable active participation by all interested stakeholders.
- Participation of cancer care/pathway coordinators to navigate patient care and manage information transfer across the public and private interface.

Key barriers

- No tumour-specific MDM for patients with a particular cancer type.
- Non or inconsistent participation by clinicians key to treatment decision-making.
- Case review occurring at a single point in time (e.g. no potential to address changing needs).
- High volume of patients and time constraints restrict the number of cases that can be presented.

International and Australian evidence has established that cancer patients whose care is considered by a multidisciplinary team (MDT) receive higher quality care in line with best practice standards.16,17,18


Multidisciplinary team meetings (MDMs) are a critical component of patient treatment planning. Support for MDMs was consistent among health professionals of all disciplines and across both public and private services at each of the case study sites. Participants valued the opportunity to obtain peer review and advice from multiple specialists, nurses and allied and palliative care specialists.

MDMs were acknowledged as a critical mechanism in bringing public and private health professionals together and identifying gaps or barriers to optimal care coordination and effective interfaces between public and private services. Informants highlighted the dual purposes of MDMs – for individual patient treatment planning and referrals, and an opportunity to discuss hospital or system-wide processes to improve patient care. In addition to supporting consistent practices across both sectors, the MDM was a considered a supportive teaching environment for health professionals.

“The value of an MDT is not just in the clinical review of complex patients but in streamlining the broader approaches to patient care and in refining our hospital systems and processes.” – Medical oncologist

“[We meet in a] physical venue which is appropriate for both private and public MDM discussions, so everyone gets invested in the process and there’s good attendance. The meetings are well organised and supported by the [Integrated Cancer Services management], rather than clinicians trying to cobble it together, including record keeping, systems and technology and dedicated resources.” – Oncologist

The great majority of patients (with the tumour types investigated) transition between public and private services at some point during their cancer treatment pathway. Where a patient enters their treatment pathway reportedly influenced whether their case was considered at an MDM. At some sites, only the private patients of specialists that worked across both public and private hospitals were presented at MDMs. For example, while all women with breast cancer having surgery in the public hospital at one metropolitan site were discussed pre- and post-operatively at the breast MDM, presentation of private patients was driven by the individual treating specialist and was therefore more ad hoc.

Some informants in the regional sites suggested that the exclusion of private cases from MDM review meant private hospital staff may have more limited understanding of the MDM processes and were less likely to be aware of interfaces between public and private settings.

Enablers of effective meetings & sharing of treatment plans

MDMs were considered to be most effective in supporting coordination and integration of cancer care when they operated at a population level across services for all public and private patients (or subsets of patients).

The effectiveness of MDMs was reported to be influenced by the leadership or support of clinical champions (in both public and private services), securing ‘buy in’ from all key multidisciplinary team members and having a dedicated meeting coordinator and/or administrative support. Engagement of health professionals working across public and private hospitals ensured consistency and streamlining of the treatment pathway and the opportunity to identify points of interface between services at which patients (or patient information) might get lost.

Active participation by all MDT members and other key health professionals was influenced by IT systems enabling access to patient data during the MDM.


At one regional site, a locally-developed information system (in use across the regional integrated cancer service) permitted real time data entry and access during meetings to pathology and radiology digital information systems (to support staging and treatment planning). A treatment plan was generated that was integrated into the patient record in both the public and private hospitals.

"[The keys are] good administration, good relationships, digital technology and shared diagnostic information systems; and the process is driven by ... and self-regulated by the doctors." – Urologist

In one state, video conferencing facilities enabled team members in regional centres to participate in the upper GI MDM. However, the health service IT firewall prevented access to patient clinical information for participants not at a public health service site. The firewall was a practical barrier to the involvement of specialists from private cancer services and to GP involvement in the MDMs.

The benefits of having care coordinators or specialist cancer nurses participate in MDMs were reiterated by all sites. Attendance at the meeting enabled these key patient support roles to inform patients about the treatment pathway and coordinate treatment and supportive care, particularly at the interfaces between public and private services. At one regional site, for example, the prostate nurse attends prostate cancer MDMs and was identified as the "glue" between the different services.

Limitations of MDMs & barriers to effectiveness

The primary barrier to multidisciplinary planning and coordination of cancer care consistently reported by informants was the absence of an MDM. For example, in one regional site a urology MDM is presently "on hold".

Non- or inconsistent participation by key specialists and other health professionals in MDMs created inconsistency in processes and systems that supported clinical decision-making, and meant some patients were denied multidisciplinary review and potentially the option to consider different treatment pathways.

The volume of patients and the time it takes to provide treatment planning prohibits multidisciplinary team discussion for all patients. The prostate MDM at one regional site reportedly reviewed about 20 percent of all new prostate cancer patients, with oncologists identifying the more complex and advanced cancers in greatest need of multidisciplinary discussion and treatment planning. By contrast, the lower volume and high complexity of most upper GI cancer cases meant the upper GI MDMs at most sites reviewed the majority of patients (public and private).

In some sites regular case conferencing meetings enabled multidisciplinary discussion of some of the patients not reviewed by the MDMs or with changing needs. At one regional site there were weekly case conferencing meetings to discuss all patients in the system undergoing radiation therapy (public or private). These conferences involve oncologists and radiation oncologists (public), with outcomes documented in medical records and discussed with the patient to plan care and address supportive care needs.

In most cases a patient’s MDM review occurred at a single point in time, meaning there were limited opportunities to discuss patient needs as they changed over time. Referral to the MDM may also occur after the patient has already had surgery (surgeons often determine the timing of when patients are referred to an MDM). This can reduce the ability for multidisciplinary treatment planning at the point of diagnosis. This highlights the importance of other mechanisms, outside of the MDM, to monitor patient needs across the cancer pathway.

GP involvement in MDMs was uncommon, although many health professionals indicated the desire to have greater involvement of GPs in the MDM process. Generally GPs were sent a letter outlining the high level treatment plan or a
discussion summary sheet circulated after the MDM, however it was reported these were often not received by the GP until several weeks after treatment had commenced.

**Vignette: State-wide Upper GI MDM (Site 3)**

One state-wide upper GI cancer multidisciplinary team (MDT) approach highlights some of the critical enablers of a well-organised, multidisciplinary process for treatment planning and care coordination.

The low volume and high complexity of upper GI cancer cases, and support for consolidation of surgery in large tertiary hospitals, facilitated clear referral pathways and strong integration of public and private cancer services across the state.

The enthusiasm of a clinical champion (surgeon) and participation of key senior specialists from both public and private cancer services were identified as critical factors in the effectiveness of the state-wide upper GI MDM. Administrative support and practical considerations, like rotating clinical chairs for the meetings, ensure sustainability and “buy in” from participants.

Other enablers included having the support of a meeting coordinator and the dissemination of a summary of outcomes and treatment plans (including to patients' GPs) soon after the meeting.

A practical barrier to involvement of health professionals outside public hospitals (e.g. private specialists and GPs) is an IT firewall implemented across the state health department. This was partly addressed by the use of videoconferencing at five regional public hospitals or health services, to enable specialists and staff outside the metropolitan region to participate (and view records) from those sites.

The MDT has established targets for case review, aiming to have all patients with cancer of the stomach or oesophagus referred to an MDM. A 2013 audit found the MDM reviewed 220 cases that year – accounting for over 90 per cent of oesophageal cancer patients, and about 60 to 65 per cent of patients with gastric cancer. The state’s upper GI cancer care pathway specifies the time from diagnosis to development of a treatment plan should not exceed 2 weeks.

### 5.3 Integration of Supportive Care

System-level approaches to distress screening, referral processes and monitoring against service indicators across integrated services were identified as key mechanisms supporting integration of supportive care.

In the absence of structured approaches, informants described informal, variable and largely ad hoc screening and referral processes for physical and psychological support at the public and/or private hospitals.

The larger tertiary public hospitals were perceived to provide a broader and ‘holistic’ range of allied health and supportive care services (a ‘one stop shop’). There was a sense that for private patients there was less coordination, given the need for individual referrals to private service providers, and that fee for service arrangements hindered access to comprehensive psychosocial care.

**Key enablers**

- Guidelines for distress screening and referral to psychosocial support.
- Performance monitoring and feedback to services on effectiveness of screening for supportive care.
- Access to allied health and psychosocial care services for both public and private patients.
- Well-established personal and professional relationships between public and private allied health service staff.
• A dedicated cancer care coordinator (or similar role) informing and helping patients access available supportive care services.
Key barriers

- Lack of formal approach or consistent approach to assessment/screening and referral to supportive care services – both by individual medical/nursing staff and between services within a site.
- Lack of acute and community-based allied health and psychosocial support services.
- Absence of ongoing or recurrent funding to maintain services and meet changing or increasing demand.

Investigation of approaches to supportive care integration into the public and private cancer care pathway revealed a distinct difference between sites.

At the public services within one state, there is a coordinated approach to screening patients (both public and private) for distress. This state has developed a state-wide approach to distress screening (delivered through regional integrated cancer services) with tools for both public and private services to standardise referral processes. A wide range of allied health and supportive care services are available at both public and private cancer services. Screening rates were monitored and reported to the Integrated Cancer Service management at regular governance meetings, with feedback to services on the effectiveness of integration of supportive care. Well-established relationships between the public and private allied health services supported patient transfer and continuity of supportive care.

At the other sites management of supportive care screening, assessment and referral and availability of services was reportedly more variable and often ad hoc across public and private services. Referral to appropriate rehabilitation services, allied health or psychosocial care was largely dependent on the attention and knowledge of specialists or, more commonly, care coordinators, social workers or cancer nurses.

“Integration and referral for supportive care is not a formal process and probably needs improvement.” – Upper GI surgeon

“Ensuring the right questions are asked by nursing or medical staff determines whether the patients are referred for supportive care needs.” – Social worker

Informants at one of the regional sites noted the absence of a systematic approach to screening or assessment of patients’ supportive care needs (in the public and private hospitals) and a lack of acute and community-based services. Referrals were made by individual specialists or the patient’s GP “informally or opportunistically”.

“Patients are not really aware of the possible complications of their treatment and the impact on their quality of life and even when they are, there is little that can be done because they don’t always have access to or meet the eligibility criteria for services.” – Prostate cancer nurse

A key finding from the consultations was that fee for service arrangements did not facilitate comprehensive access to supportive care services. There was a perception that supportive care was more limited in the private system and referral and care was more variable because of the absence of systems and protocols and the requirement for individual referral to privately-provided services. Informants (including health professionals and consumers) reported that the large tertiary public facilities provided more ‘holistic’ psychosocial care (a ‘one stop shop’ service) through access to a more comprehensive range of allied health and supportive care services.

“In the private system you get private rooms and a private surgeon – but you may never see a breast care nurse.” – Registered nurse

This was not universal however, with the private service at the one of the regional sites providing supportive care services through a Wellness Centre, covered under private health insurance.
Informants highlighted the challenges in screening for and integrating supportive care when acute and community-based services were absent or stretched beyond capacity.

In one state informants highlighted the current unavailability of public lymphoedema treatment for women after breast cancer treatment, due to funding issues and difficulties securing a clinic space, and the challenges in accessing supportive care for patients in regional areas. In another state site interviewees noted the limited services to meet the needs of men after prostate cancer treatment, and the likely increase in demand for physiotherapy, sexual health, continence and psychosocial care given the current transition to local urology services in the region.

5.4 Integration of Palliative Care

Integration of and patient access to palliative care was primarily influenced by the availability of palliative care services (inpatient and community-based) and the participation of palliative care physicians in MDMs.

Most of the key enablers and barriers reported by informants related to this issue of service availability, across both public and private service providers.

Key enablers

- Referral systems and processes to identify patient needs and facilitate referral
- Palliative care physician attending MDMs – enabling early identification of patients and seamless referral.
- Awareness of and links to both public and private community-based service providers (given limited hospital inpatient capacity).

Key barriers

- Unavailability of palliative care specialists in some regions.
- No consistent approach to identification/assessment and referral of patients to palliative care.
- Insufficient palliative care services (hospital and community-based) to meet needs.
- Perception from the private services that palliative care is not well funded by private health insurance.

Informants at each of the case study sites were asked about approaches to palliative care integration into the public and private cancer care pathway including assessment of need, processes and roles.

At most sites palliative care physicians and services were available at both public and private hospitals (both inpatient and outpatient).

The main influence on timeliness of access to hospital palliative care services was service capacity. Informants acknowledged the important role of community hospices and palliative care providers given the limited capacity of hospital-based services. In one site’s region the waiting time for one of the few palliative care beds in the hospital or community-based care (described as “severely lacking”) was reportedly three months.

At one site informants described the provision of palliative care to hospital inpatients as “relative seamless”. Palliative care physicians attended MDMs, which served as a referral point. In the private hospital patients were referred to a private palliative care physician. The private service also reportedly accepts public patients without private health insurance.

Key barriers identified most commonly were the insufficient range of services to meet diverse palliative care needs and limited service capacity (both hospital and community-based), and the unavailability of palliative care specialists in some regions, which inhibited integration of palliative care into the cancer care pathway.
5.5 Best Practice Cancer Care

Multidisciplinary team meetings (MDMs) were identified as a key mechanism for ensuring cancer care was consistent with best practice and enabling planning and coordination of patient pathways.

Various approaches to monitoring appropriateness and timeliness of care were reported, ranging from no formal process to clinical audits against national guidelines and assessment against key performance indicators.

Access to clinical trials was predominantly via public hospitals, with MDMs noted as a forum for increasing awareness about clinical trials and discussing eligibility of individual patients.

Key enablers

- MDMs, as a mechanism for planning delivery of care according to clinical best practice and promoting relevant clinical trials.
- Awareness and application of evidence based protocols (e.g. clinical practice guidelines, treatment pathways, eviQ).
- Clinical audit, key performance indicators and review of outcomes.
- Trials coordinated by national cancer clinical trials groups with local investigators, infrastructure and administrative support.
- Training networks for health professionals across both public and private cancer services.

Key barriers

- Lack of knowledge, or inconsistent application, of processes and protocols within or across treating teams.
- Absence of mechanisms or aggregated information to monitor timeliness of care delivery across public/private services.
- Delays between GP referral and specialist investigation.
- Lack of capacity, infrastructure, dedicated resourcing and/or patient volume to support clinical best practice.

Key measures of best practice cancer care that were considered in the context of the interface between public and private cancer services included:

- processes to ensure that cancer care is delivered according to clinical best practice across public and private services (including timeliness and appropriateness of care)
- capacity building and training to support the workforce in the delivery of best-practice cancer care across public and private cancer services
- access and referral to clinical trials across public and private services.

Consistency with clinical best practice

Multidisciplinary team meetings (MDMs) were identified as a key mechanism for ensuring cancer care was consistent with best practice and enabling planning and coordination of patient pathways (as discussed in Section 5.2).

Informants highlighted the importance of promoting existing mechanisms and resources to facilitate best practice care, including clinical practice guidelines and the eviQ cancer treatment protocols. It was suggested that regional and rural ‘roadshows’ could increase awareness of evidence-based resources that should be referenced in care pathways, and utilisation of national data (e.g. MyHospitals data) for benchmarking and setting local service key performance indicators (KPIs).
Monitoring appropriate and timely care

At the case study sites there were varied approaches to and mechanisms for monitoring appropriateness and timeliness of care, including the use of:

- clinical audits, e.g. waiting times against national guidelines
- outcomes reviews, including patient satisfaction surveys (against KPIs at some sites)
- relative utilisation rates.

It was suggested that quality assurance systems and processes in private services were largely ‘internally-driven’ (or self-imposed) whereas those used by public hospitals were more likely to be part of system-wide approaches. At one of the metropolitan sites, the private radiotherapy service provider reported undertaking regular audits of waiting times, reviewed by a quality and safety committee against national guidelines. In addition to national and international treatment guidelines, the service has developed local protocols. In one state key performance indicators and clinical outcomes measures were established at the Integrated Cancer Service level for the whole service population.

Access and referral to clinical trials

Access to cancer clinical trials in the participating sites, was generally via the public hospitals.

MDMs also provided a forum for increasing awareness about clinical trials that were open or planned in hospitals both within and outside the region and determining eligibility of particular patients.

Trial support and coordination by national cancer clinical trials groups was identified as a key enabler of local participation. Informants at one regional site suggested there were few trials recruiting local patients because infrastructure was lacking at the public hospital and patients were not being informed about trials. The exception was a multi-site trial coordinated by the Trans Tasman Radiation Oncology Group (TROG) with a local principal investigator.

One regional site had established referral systems in place with metropolitan clinical trials units to facilitate access to clinical trials for regional patients.

Oncologists indicated a preference not to replicate trial infrastructure or coordination in the private sector, given most trials active in public settings were open to and able to support private patients.
Barriers to best practice

There was some evidence that timeliness and appropriateness of care is adversely impacted when knowledge or application of evidence-based processes and protocols differed within and/or across treating teams. This includes different treating teams across public and private cancer services.

In one of the metropolitan sites, timelines for referral to diagnosis, and diagnosis to treatment, are specified in the state-wide cancer care pathways. A reported barrier to meeting these timelines was lack of awareness of referral processes or of local factors influencing access to specialists, e.g. a new registrar making an incorrect referral, or a GP referring to a busy gastroenterologist with no indication of the urgency of the case.

The capacity of specialists was commonly identified as an issue impacting on timeliness of patients accessing treatment. In one of the regional sites for example, while state health policies permit referral out of area to other public services, the nearest tertiary public hospital to the regional site is several hours drive away so this is not practical for most patients.

Monitoring timeliness of care was also reported as being particularly difficult when care was provided by multiple public and private cancer services, and information was not aggregated and stored in a shared clinical information system.

5.6 Governance & Infrastructure

There were few instances of integrated governance and infrastructure across public and private services but some examples of service delivery partnerships or infrastructure sharing under contracts or formal agreements.

Having a shared vision and purpose, and strong personal and professional relationships between service providers, particularly clinicians, are key enablers of clinical service integration or effective delivery of public and private cancer services.

Key enablers
- Formal service level agreements or contracts for service delivery.
- A shared vision, purpose and recognition of interdependence of local services.
- Mechanisms to support best practice, such as standards, guidelines and/or care pathways.
- Joint processes for review and monitoring of service performance.

Key barriers
- Separate management and funding structures across public and private services.
- IT firewalls.

Consultation with informants at the sites and key project stakeholders identified little evidence of formal integration of public and private cancer services (including shared infrastructure), however some local arrangements are in place.

Service level agreements or contracts were the key mechanism formalising delivery of public and private service partnerships. At the case study sites, these were usually between the state Department of Health (or local health service district/area) and a private service provider, and mostly for radiation therapy. At one of the metropolitan sites, a service level agreement between the public and private services enabled surgeons to use extra theatre capacity at the private hospital for public patients, when required.

Most informants were unable to identify shared facilities or infrastructure. Even when aware of public/private partnerships for service delivery, health professionals were often unaware of the specific conditions or terms, e.g. capped patient arrangements. At one of the regional sites most of the coordination of care across services occurs “through networking”. Informants reported that while there is a formal state health
process for referring public patients to the private radiotherapy service it was not considered useful or practical.

Informants suggested a shared vision and purpose was more important than agreements or contracts in facilitating integrated governance and infrastructure sharing. When services had a shared understanding of their role and their interdependency with other services (across public and private settings) joint governance arrangements were more likely to be established and more likely to be effective in coordinating patient care.

Again, personal and professional relationships between service providers, particularly health professionals, were identified as a key enabler to the integration of clinical services across public and private sites.

As one informant noted, the successful relationship between services at one of the regional sites was the “result of 20 years of hard work”, with health professionals “continuing to work at it”. While there was a formal MOU in place between the public and private hospitals it was not specific to oncology patients, and hence successful integration of cancer services was largely supported by the Integrated Cancer Service mechanisms rather than hospital-level mechanisms.

**Vignette: Joint governance arrangements (Site 1)**

At the regional site, the integration of cancer services is enabled by a system-level view and approach to coordination of cancer treatment pathways.

As part of an Integrated Cancer Service (ICS), the strategic directions and governance of the public and private cancer services in this region are defined by geography and boundaries. This “provides clarity and cohesion” and a mechanism for service providers to develop novel solutions to local issues or barriers impacting on service delivery across public and private services, rather than viewing services in isolation.

The ICS Governance Committee includes representatives of service executives, health professionals and consumers from both public and private services. The committee is advised and supported by an ICS executive, consumer reference group, lead clinicians group, primary care reference group and data working group.

For both the tumour groups investigated at this site (upper GI and prostate), there are multidisciplinary team meetings (MDMs) at which both public and private patient cases are reviewed. Coordinated MDMs for both public and private patients supports a population view, led by specialists, which provides a cohesive regional ‘upper GI cancer service’ and ‘urogenital cancer service’.

To support the MDMs in facilitating best practice and optimal patient care coordination across the services, the ICS provides administrative support for meeting coordinating and a locally-developed information system that permits real time data entry and development of a treatment plan, subsequently incorporated into both public and private hospital records.

> “The importance is that both sides understand the synergistic nature of how we behave … In a metro service publics don’t really care about privates and vice versa too much, as they can function in their own network. Whereas when you are in a rural location, like we are, without one the other will fall over …

> “As [the public hospital has] radiotherapy and we rely on them to provide this service it’s a synergistic arrangement: [both public and private hospitals are] serving a local community and know who they are providing services to.” – Hospital Executive

Other mechanisms to support best practice across the ICS include management of state funded positions (e.g. prostate cancer specialist nurse) to support care coordination and patient navigation across public and private services, and
implementation of state-wide protocols for distress screening and referral to supportive care. Screening rates are monitored and reported to the ICS Governance Committee, with feedback to services on effectiveness of the integration of supportive care. The committee also reviews other service monitoring including quality of care and patient outcome data (survival rates, outcomes by clinician, waiting times and utilisation of chemotherapy and radiotherapy) and the results of patient experience surveys.
6. OTHER FINDINGS

A number of issues considered to be beyond the scope of this project were identified in the consultations. These largely relate to the primary care sector and are listed here for consideration.

- Key informants highlighted the importance of strong relationships and engagement between primary care providers, particularly GPs, and cancer services. Within specialist cancer services, there was some uncertainty about the appropriateness of assessment of symptoms in the primary care sector and of the initial referral to specialists.

- The key determinants of the referral pathway from assessment of symptoms in the primary care sector to specialists was also raised. These were described as largely historical, ad hoc and influenced by whether patients had private health insurance and their GP’s relationships with particular specialists.

- High turnover of GPs, particularly in the regional sites was seen as a key barrier to coordination of patient care along the treatment pathway. This turnover led to local primary care providers having limited knowledge of local cancer services and pathways and presented challenges to the establishment of ongoing professional relationships and networks.

- Some key informants discussed the role of regional cancer services in strengthening the integration between public and private cancer services and actively shaping local cancer service systems. Defining the expectations of regional cancer services in this context, may be important.

- The volume-outcome relationship in cancer surgery19 was described by some informants as influencing referral practices and treatment pathways. This was often determined informally between specialists, to ensure surgery for complex/high risk cancers was undertaken in higher volume services/units. While this issue has been briefly referenced in this report, further consideration of this issue may be required.

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7.  APPENDICES

7.1  Steering Group Membership

- Associate Professor Rosemary Knight (Commonwealth)
- Professor Helen Zorbas (Cancer Australia)
- Ms Colleen Jen (QLD)
- Ms Shelly Rushton (NSW)
- Mr Adam Chapman (VIC)
- Professor Dorothy Keefe (SA)
- Associate Professor Violet Platt (WA)
- Ms Terri Price (QLD)
- Ms Denise Lamb (ACT)

Department of Health

- Ms Phillipa Lowrey, Director, Cancer Services
- Ms Cristy Henderson, Assistant Director, Cancer Services
- Ms Natalie Bortolotto, Cancer Services Section
7.2 Information Sheet

Public and Private Cancer Care Pathway Project

The project aims to document effective pathways of care for cancer patients whose care involves both public and private healthcare services. Consultations will be undertaken at two regional sites and two metropolitan sites. At each site the consultations will focus on care pathways for two of the following tumours - breast, upper gastro-intestinal, prostate and colon.

By way of background, the National Cancer Expert Reference Group was established by the Council of Australian Governments in 2010 to lead work on the most effective cancer diagnosis, treatment and referral protocols, and includes representatives of all jurisdictions.

The Department of Health is leading the Public and Private Cancer Care Project on behalf of NCERG and has engaged a consultant, ZEST Health Strategies (ZEST), to:

- investigate and document the enablers and barriers to effective, safe and high quality treatment pathways that facilitate coordination of cancer care across public and private health settings, and
- develop recommendations for cancer service planners and healthcare providers.

Consultations will involve a one-hour telephone interview with 6 key informants from your service in August 2014 and brief pre-interview online survey.

During the consultations, ZEST will seek information on issues such as:

- patient information transfer between public/private sectors
- multidisciplinary treatment planning meetings
- provision of supportive care
- communication among health professionals
- provision of best practice care
- access and timeliness of care.

Following the consultations, ZEST will develop de-identified vignettes describing the features of service delivery that facilitate good coordination of care across the selected public and private services; and those features that act as potential barriers.

The project steering committee and some key informants from the consultations will be invited to a meeting in late October 2014 to review the vignettes. ZEST will then develop a report to the steering committee including recommendations for future cancer services design. The report will be provided to NCERG and all services that participated in the consultations.

Your agreement to participating in the consultation process is greatly appreciated and is important for the success of the project.
7.3 Regional Site Case Study (Site 1)

This site encompasses co-located public and private hospitals in a regional town, with a service population of 225,000. The hospitals and cancer services are part of a regional Integrated Cancer Service, a state Government Department of Health initiative to improve integration of cancer care by coordinating health services in specific geographic areas. The site profile includes:

- privately-provided cancer services include oncology and haematology day surgery (inpatient and outpatient), including private outreach services to public and private patients in nearby towns, PET and allied health services
- public cancer treatment and allied health services provided at the public hospital, and a level 1 ICU
- a co-located public radiotherapy centre and integrated chemotherapy and allied health services (for public and private patients)
- various supportive care and wellness services for patients available at both public and private services
- accommodation for regional (public and private), managed by the private hospital, funded by the hospital and community fundraising
- public inpatient palliative care for public and private patients

Two tumour types were examined at this site - upper gastrointestinal (upper GI) and prostate cancer. A summary of the service profiles at this site, for each of these cancer types, is provided in Table 5.

**Table 5 Summary of regional site profile (Site 1)**

<table>
<thead>
<tr>
<th>Location: Regional - Population: 225,000</th>
<th>Services: Public hospital, Private hospital, Wellness/Wellbeing centres, Co-located; part of Integrated Cancer Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service</td>
<td>Upper GI</td>
</tr>
<tr>
<td>MDM</td>
<td>Public/private</td>
</tr>
<tr>
<td>Diagnosis &amp; referral</td>
<td>Endoscopy at public &amp; private</td>
</tr>
<tr>
<td>Planning &amp; staging</td>
<td>Thoracic &amp; CT scan at public &amp; private</td>
</tr>
<tr>
<td>Surgery</td>
<td>Public &amp; private (ICU - public)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Public &amp; private</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Public</td>
</tr>
<tr>
<td>Supportive care</td>
<td>Management of physical effects at public &amp; private sites; psychosocial support primarily at public site</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Provided at public (inpatient) &amp; community service</td>
</tr>
</tbody>
</table>
Cancer care pathways

While individual cancer care pathways vary, the most common interfaces between the public and private services at this site occur for:

- treatment planning by MDM (involving public and private specialists and staff)
- private patients requiring radiation therapy (delivered at public radiotherapy centre)
- private patients having complex surgery requiring Level 1 ICU, who are transferred to the public hospital post-operatively, then back to the private hospital
- private patients presenting at the public hospital emergency department after hours (public ED)
- private patients who are referred to or access supportive care services at public hospital or wellness centre.

Site-specific enablers and barriers

Key enablers to coordinated care across public and private service interfaces at this site include:

- system-wide and population view by tumour stream, with co-location of services, specialists with appointments at both public and private hospitals, and commitment to coordination built on personal and professional relationships
- effective MDMs, supported by a coordinated information system and treatment plans generated for notes for both public and private patients
- system-wide support as part of an Integrated Cancer Service, including information systems and personnel supporting transfer of patient information
- electronic access across sites to pathology and radiology results and established referral systems.

Key barriers at this site include:

- absence of common patient medical record
- the presence of ‘stand-alone’ private services not integrated with the regional cancer network
- patients not fully informed about whole cancer care pathway, the service models or out-of-pocket costs of some services
- patients referred out of the region for services unnecessarily, including some private radiotherapy referral to metropolitan private services.
**Example of the upper GI cancer care pathway**

While cancer care pathways vary, an example of a common upper GI cancer care pathway at this site is provided (Figure 6) for illustration purposes.

**Figure 6 Example cancer care pathway for upper GI cancer at the regional site**

Joe is a 68-year-old man who lives in a large regional town. Last year he visited his GP with upper GI symptoms: difficulty swallowing, nausea and vomiting and weight loss. After confirming Joe has private health insurance, his GP referred him to a general surgeon specialising in upper GI surgery at the nearby private hospital. An endoscopy and biopsy at the private hospital confirmed Joe’s diagnosis of oesophageal cancer.

The surgeon presents Joe’s case at the monthly upper GI multidisciplinary team meeting (MDM). The team includes medical and radiation oncologists, pathologist, radiologist and palliative care physician. After discussion, including consideration of clinical trials, the team develops a treatment plan. A summary is included in Joe’s patient notes (at the public and private hospitals). Joe’s surgeon talks him through the treatment plan and possible side effects, and gives him printed information from the Cancer Council.

Joe has surgery in the private hospital, but is transferred to the public hospital’s intensive care unit for ICU care. Post operatively his recovery is in the private hospital. He is referred for rehabilitation (covered by his private health insurance) at the wellbeing centre at the private hospital.

Joe returns to the private hospital for chemotherapy. At his first appointment a nurse gives him printed information from eviQ about his chemotherapy cycle and possible side effects. At cycle two he is screened for distress. He is at low risk so is not referred to psychosocial care but is given some information about support services and programs.

As per his treatment plan, Joe is referred by his medical oncologist for radiotherapy, delivered at the public hospital. During his radiotherapy treatment cycle he is assessed for supportive care needs (as all patients are).
Joe finds the transition between services to be pretty smooth, but there are points when he isn’t sure what is happening next. His surgeon’s practice manager gives him a letter detailing all the surgery costs, but he is surprised by the out-of-pocket costs of his diagnostic tests, which he doesn’t feel he was informed of at the time.
### 7.4 Metropolitan Site Case Study (Site 2)

The metropolitan site includes co-located public and private hospitals and a comprehensive cancer wellness centre. Its service population is 1.29 million people. The hospitals and wellness centre are part of a metropolitan Integrated Cancer Service, a State Government Department of Health initiative to improve integration of cancer care by coordinating health services in specific geographic areas. The site profile includes:

- a public teaching hospital that offers a comprehensive range of cancer services
- a co-located private hospital offering a comprehensive range of surgical and oncology services
- radiotherapy services available solely at the public hospital
- a clinical trials centre located within the public hospital
- supportive care and wellness services are offered through a dedicated service in the public hospital
- a limited number of supportive care services are provided at the private hospital
- a public inpatient palliative care unit within the public hospital
- community palliative care services that operate out of a separate location.

Two tumour types were examined at this site - upper gastrointestinal (upper GI) and colon cancer. A summary of the service profiles at this site, for each of these cancer types, is provided in Table 6.

#### Table 6 Summary of metropolitan site profile (Site 2)

<table>
<thead>
<tr>
<th>Location: Metropolitan - Population: 1,290,000</th>
<th>Services: Public hospital, Private hospital, Private supportive care service, Wellness centre (public), Co-located; part of Integrated Cancer Service</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Service</strong></td>
<td><strong>Upper GI</strong></td>
</tr>
<tr>
<td>MDM</td>
<td>Public (for public &amp; private patients)</td>
</tr>
<tr>
<td>Diagnosis &amp; referral</td>
<td>Endoscopy at public &amp; private (preference for imaging in the public)</td>
</tr>
<tr>
<td>Planning &amp; staging</td>
<td>Thoracic &amp; upper CT at public &amp; private; PET at public</td>
</tr>
<tr>
<td>Surgery</td>
<td>Public &amp; private</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Public &amp; private</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Public</td>
</tr>
<tr>
<td>Supportive care</td>
<td>Management of physical effects at public site; psychosocial &amp; practical support provided at public site</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Primarily provided at public</td>
</tr>
<tr>
<td>Other</td>
<td>Upper GI care coordinator</td>
</tr>
</tbody>
</table>
Cancer care pathways

While individual cancer care pathways vary, the most common interfaces between the public and private services at this site occur for:

- treatment planning by MDM (involving public and private specialists and staff)
- private patients requiring radiation therapy (delivered only at public radiotherapy centre)
- private patients presenting at the public hospital emergency department after hours
- private patient participation in clinical trials (coordinated through the public hospital)
- private patients who are referred to or access supportive care services at public hospital or wellness centre.

Site-specific enablers and barriers

Key enablers to coordinated care across public and private service interfaces at this site include:

- MDMs for each tumour group, attended by public and private clinicians and health professionals with administrative support
- co-location of services, and appointment of specialists at both the private and the public hospitals – making them focal points for communication and referral between services

Key barriers at this site include:

- absence of common records or shared clinical information systems
- private hospital staff not having electronic access to public patient records or MDM summaries
- inability to access private oncology service records when a private patient presents at public hospital ED after hours.

Example of the colon cancer care pathway

While cancer care pathways vary, an example of a common colon cancer care pathway at this site is provided (Figure 7) for illustration.
The following describes how a patient may experience this pathway:

**A patient's pathway for colon cancer**

David was 62 years old when diagnosed with colon cancer. After reporting significant bowel symptoms David's GP referred him to a colorectal surgeon at a large private hospital, as David has private health insurance and requested referral to a private specialist.

After diagnosis was confirmed by colonoscopy (at the private hospital), David's surgeon presented his case at the colorectal MDM, attended by public and private clinicians and health professionals. She chose to present before surgery (about half of the colon cancer cases are presented after the patient has had surgery). The MDM coordinator sent a printed record of the discussion outcomes and recommended treatment plan to the surgeon, which she has scanned and added to the patient’s record held in her rooms.

While David was recovering after surgery (in the private hospital) a nurse assessed his supportive care needs and recommended services provided at the public hospital, which he declined.

David had chemotherapy in the private hospital. One weekend after his second cycle of treatment David became unwell and his wife took him to the public hospital emergency department. After waiting several hours, David was admitted for observation overnight. The ED staff could access some of his private hospital records using data sharing arrangements, but not the medical oncology records as the oncologist’s rooms were closed. David’s medical oncologist saw him the next morning while attending his public patients and arranged a transfer (by ambulance) to the private hospital. After he is discharged David's oncologist refers him for radiotherapy at the public hospital as there is no private radiotherapy service.
7.5 Metropolitan Site Case Study (Site 3)

The site incorporates co-located public and private hospitals and a private radiotherapy centre in a metropolitan area with a service population of 350,000.

The site profile includes:

- a public hospital that offers a comprehensive range of cancer services
- a private hospital located offering a range of surgical and oncology services
- radiotherapy services available through private provider (co-located within the private hospital) and under contract to provide public service
- supportive care and wellness services are offered through the public hospital
- a public inpatient palliative care unit within the public hospital
- community palliative care services that operate out of a separate location.

Two tumour types were examined at this site - upper gastrointestinal (upper GI) and breast cancer. A summary of the service profiles at this site, for each of these cancer types, is provided in Table 7.

Table 7 Summary of metropolitan site profile (Site 3) Location: Metropolitan - Population: 350,000 Services: Public hospital. Private hospital*, Private radiotherapy, Co-located

<table>
<thead>
<tr>
<th>Service</th>
<th>Upper GI</th>
<th>Breast</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDM</td>
<td>State-wide, based at public (for public &amp; private patients)</td>
<td>State-wide, based at public (for public &amp; private patients)</td>
</tr>
<tr>
<td>Diagnosis &amp; referral</td>
<td>Endoscopy at public &amp; private</td>
<td>Breast screen referrals to surgeon at either public or private</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Core or punch biopsy at public &amp; private</td>
</tr>
<tr>
<td>Planning &amp; staging</td>
<td>Thoracic &amp; upper CT scan at public &amp; private</td>
<td>CXR +/- bone scan at public &amp; private</td>
</tr>
<tr>
<td></td>
<td>PET at public</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>Public &amp; private</td>
<td>Public &amp; private</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Public &amp; private</td>
<td>Public &amp; private</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Private (agreement for public patients)</td>
<td>Private (agreement for public patients)</td>
</tr>
<tr>
<td>Supportive care</td>
<td>Management of physical effects at public site; psychosocial &amp; practical</td>
<td>Physiotherapy services based at public site; lymphoedema services &amp; support for cognitive impairment at private site; body image, fertility &amp; pregnancy, &amp; sexuality services at public &amp; private sites</td>
</tr>
<tr>
<td></td>
<td>support provided at public site – coordinated by pathway coordinator</td>
<td></td>
</tr>
<tr>
<td>Palliative care</td>
<td>Public &amp; private</td>
<td>Public &amp; private</td>
</tr>
<tr>
<td>Other</td>
<td>Pathway coordinator at public site</td>
<td>Breast Cancer Nurse (public)</td>
</tr>
</tbody>
</table>

* Note that the private hospital did not participate in this project and so service profile is based on publicly available information.
Cancer care pathways

While individual cancer care pathways vary, the most common interfaces between the public and private services at this site occur for:

- treatment planning by state-wide upper GI MDM (for public and some private patients)
- public patients referred to private service for radiotherapy (private provider contracted for public service)
- in some limited cases, public patients having surgery at the private hospital (under an agreement allowing use of extra theatre capacity)

Site-specific enablers & barriers

Key enablers to coordinated care across public and private service interfaces at this site include:

- state-wide MDMs for treatment planning (for all upper GI patients); breast MDM for all public and some private breast cancer patients that foster clinical communication and relationships between specialists and health professionals
- MDMs that include clinicians who work across both private and public services
- an MDT coordinator who disseminates treatment plans, supports patient information transfer and channel referrals across both systems
- some shared clinical information systems, e.g. private radiotherapy service has electronic access to public radiology and pathology and private radiology (but not patient case notes)
- Breast Cancer Nurse at public hospital to support patients (and their families) navigate the pathway and access support services.

Key barriers at this site include:

- no common patient record or integrated clinical information systems
- public health system IT firewall prevents transfer of patient records from the public hospital to private services, and restricts participation of MDT members outside the public hospital as it prohibits external access to clinical records

Example of the breast cancer care pathway

While cancer care pathways vary, an example of a common breast cancer care pathway at this site is provided (Figure 8) for illustration.

Figure 8 Example cancer care pathway for breast cancer at the metropolitan site
The following describes how a patient may experience this pathway:

**A patient’s pathway for breast cancer**

Jen is a 55 year old woman who is referred by her GP for further assessment after an abnormal mammogram result. Jen has private health insurance, but elects to see a breast surgeon at the large public tertiary hospital. The surgeon requests diagnostic pathology and radiology tests at the public hospital (at no cost to Jen).

The breast surgeon presents Jen’s case at the next MDM, operating at the public hospital. Meeting outcomes and treatment summaries are recorded electronically by the MDM coordinator and circulated to the treating team (and copied to Jen’s GP) within a week of the meeting.

The Breast Care Nurse at the public hospital explains the treatment plan developed by the MDM to Jen and gives her written information about the recommended therapies, likely side effects and available support services.

Due to theatre capacity issues in the public hospital, Jen has surgery in the private hospital theatres across the road (she is told the public hospital uses the theatres sometimes, but had to ask a few people before someone could confirm there won’t be any additional costs to her). She then begins radiotherapy, provided by a private service on the same site, but at no cost for public patients. She is frustrated by having to provide information about her medical history and surgery again, as the radiotherapy service couldn’t access her records.

Jen sees the Breast Care Nurse at the public hospital a few more times during her treatment. The nurse gives her information about support groups and some private and community-based services to help manage her lymphoedema (as the public lymphoedema services are limited).
7.6 Regional Site Case Study (Site 4)

The site is located in a regional area of the state with a local service population of approximately 240,000. Cancer services are provided at a public cancer centre (adjacent to the main public hospital campus, a co-located private radiotherapy service contracted to provide public services, and a private hospital (with limited surgical and medical oncology services). All public patients referred for radiotherapy (locally) are treated as public patients under an agreement between state health services and the private radiotherapy service. The site profile includes:

- private cancer services includes day oncology unit
- public cancer treatment and allied health services provided at the public hospital, and an ICU
- a co-located private radiotherapy centre (for public and private patients)
- various supportive care and wellness services for patients available at the public service
- inpatient palliative care at public and private services

Two tumour types were examined at this site - upper gastrointestinal (upper GI) and prostate cancer. A summary of the service profiles at this site, for each of these cancer types, is provided in Table 8.

Table 8 Summary of regional site profile (Site 4)  
Location: Regional - Population: 240,000 Services: Public hospital, Private hospital, Private radiotherapy, Co-located

<table>
<thead>
<tr>
<th>Service</th>
<th>Upper GI</th>
<th>Prostate</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDM</td>
<td>Public (via teleconference out of area)</td>
<td>Public (currently on hold)</td>
</tr>
<tr>
<td>Diagnosis &amp; referral</td>
<td>Endoscopy at public and private</td>
<td>Biopsy at public &amp; private</td>
</tr>
<tr>
<td>Planning &amp; staging</td>
<td>Thoracic &amp; upper CT scan at public &amp; private</td>
<td>DRE assessment &amp; CT scan at public &amp; private</td>
</tr>
<tr>
<td></td>
<td>PET out of area (public/private)</td>
<td>MRI (if needed) at public</td>
</tr>
<tr>
<td>Surgery</td>
<td>Out of area (public/private)</td>
<td>Public &amp; private (+ out of area)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Public &amp; private</td>
<td>Public &amp; private</td>
</tr>
<tr>
<td></td>
<td>Tertiary referral out of area</td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Private (agreement for public patients)</td>
<td>Private (agreement for public patients)</td>
</tr>
<tr>
<td></td>
<td>Tertiary referral out of area</td>
<td></td>
</tr>
<tr>
<td>Supportive care</td>
<td>Management of physical effects &amp; psychosocial support at public site</td>
<td>Management of physical effects provided at public site; some psychosocial, fertility &amp; sexuality services provided at public site</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Public &amp; private</td>
<td>Public &amp; private</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>Prostate Cancer Specialist Nurse (public)</td>
</tr>
</tbody>
</table>
Cancer care pathways

While individual cancer care pathways vary, the most common interfaces between the public and private services at this site occur for:

- all public patients referred for local radiation therapy, attend a private radiotherapy centre (under contract with Queensland Health to provide public service)
- private patients may be referred to public hospital for MRI
- public patients may have diagnostic testing by private provider (given waiting times for some public services)
- private patients may present at the public hospital emergency department after hours

Site-specific enablers & barriers

Key enablers to coordinated care across public and private service interfaces at this site include:

- service agreement between the state Health Department and private radiation therapy provider, providing access for public patients to high quality radiotherapy services locally at no out-of-pocket cost
- co-location of public cancer centre and private radiotherapy provider allowing relatively ‘seamless’ patient flow
- shared appointment of radiation oncologists across public cancer centre and private service, facilitating patient coordination and information transfer
- a prostate cancer specialist nurse, who explains the cancer care pathway and supports patients (and their families) in navigating it

Key barriers at this site include:

- lack of a system wide view of cancer service planning and delivery between public and private services
- lack of formally defined processes for patient transfer between public and private services
- no integration of clinical information systems across services or regions – particularly important given all upper GI and most prostate cancer patients have surgery, and often diagnostic testing and/or other therapies, out of area, and hence potential for patient information loss
- limited capacity of rehabilitation and psychosocial supportive care services at the public and private services
- flow on impacts of local cancer service expansion e.g. increase demand for allied health and supportive care services resulting from the expansion of a local urology service.
Example of the prostate cancer care pathway

While cancer care pathways vary, an example of a common prostate cancer care pathway at this site is provided (Figure 9) for illustration.

Figure 9 Example cancer care pathway for prostate cancer at the regional site

The following describes how a patient may experience this pathway.

A patient's pathway for prostate cancer

Farmer Bob is 60 years old and has been experiencing pain when urinating for about six months when his wife convinced him to see their local GP. As Bob doesn’t have private health insurance, his GP referred him to a urologist at the public hospital in the regional city, about an hour’s drive from his property.

At his first appointment with the urologist, Bob is scheduled for a series of diagnostic tests, including a biopsy. Because not all the necessary equipment is available in the region Bob has to travel to the city. Bob is treated as a public patient so there are no treatment-related costs, but the patient travel and accommodation allowance does not cover the full costs of his travel.

Bob returns to the regional cancer centre and the urologist undertakes Bob’s prostatectomy at the local hospital, under supervision of a consultant from a metropolitan tertiary hospital. Bob is one of the first patients to have prostate surgery locally; as 90 per cent of patients are referred to the city or the nearest regional tertiary hospital for their surgery.

The urology multidisciplinary meeting that was operating in the public service is currently on hold, so Bob’s urologist phones a radiation oncologist colleague to discuss the case and decides on combined radiotherapy and chemotherapy. He asks the local prostate cancer specialist nurse to meet Bob and discuss his treatment plan, transport and supportive care needs.

Bob sees a radiation oncologist in the public hospital outpatient clinic who also works at the co-located private radiation oncology service where Bob has his radiotherapy (at no cost to him).

The prostate cancer nurse talks to Bob about possible side effects of treatment and gives him the contact details for the sexual health services at the public hospital (and advises him about the limited services and possible waiting times).