

GSB Consulting & Communications

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**Role Redesign Primary Care – Shared Care  
Models of Cancer Treatment and Surveillance  
Post Treatment  
Final Report**

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Prepared for Cancer Australia



25 February 2010

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## List of consultation participants

Australian College of Rural and Remote Medicine  
Australian General Practice Network  
Australian Practice Nurses Association  
Cancer Institute NSW  
Cancer Nurses Society of Australia  
Cancer Voices Australia  
Clinical Oncological Society of Australia  
Council of Remote Area Nurses of Australia  
Department of Health and Ageing (Commonwealth)  
Department of Health and Families Northern Territory  
Department of Health and Human Services Tasmania  
Department of Health South Australia  
Department of Human Services Victoria  
Medical Oncology Group of Australia  
National Breast and Ovarian Cancer Centre  
Pharmaceutical Society of Australia  
Queensland Health  
Royal Australasian College of Physicians  
Royal Australian and New Zealand College of Obstetricians and Gynaecologists  
Royal Australian College of General Practitioners  
Royal Australian College of Radiologists – Faculty of Radiation Oncologists  
Royal College of Nursing Australia  
Royal College of Surgeons  
Professor Jon Emery  
Dr Tony Hobbs  
Professor Claire Jackson  
Professor Michael Kidd  
Associate Professor Michael Jefford  
Dr Chris Pearce  
Dr Clare Willington

## Project reference group

The Role Redesign Working Group, a working group of Cancer Australia's National Strategic Forum, functioned as a reference group for the project. Their advisory role included oversight of methodology, input into key decisions and review of draft materials.

## GSB Consulting and Communications

GSB Consulting and Communications can be contacted at:  
PO Box 355  
Double Bay NSW 1360  
Tel +61-2-93278446  
casey.beros@gsbcc.com

## Glossary

For the purposes of this project, the following terms have been used with the following meanings:

- Advanced skill trained GP:** A General Practitioner who has taken training in a specific field under the auspices of the Royal Australian College of General Practitioners.
- Burden of disease:** In this report, this term is used to mean the impact of cancer on the community and individuals.
- Co-morbidity:** Where a person has more than one medical problem concurrently, e.g. heart disease and cancer or depression and cancer.
- eHealth:** The use of information and communication technologies in health care.
- Evidence-informed care:** A term which allows for clinical judgment in the application of evidence, and which acknowledges that a rigid adherence to evidence can be impractical and that often the evidence is not readily applicable.
- Holistic care:** Taking a broad view of a person's needs, from the physical and psychological to social and spiritual.
- Interdisciplinary:** Two or more clinicians from different disciplines working, learning or researching together. Is often taken to be less comprehensive but more 'equal' than multidisciplinary care or activities.
- Multidisciplinary care:** Several of the disciplines involved in cancer care coming together in some way at various stages in the cancer journey to focus on a specific patient.
- Non-government organisation (NGO):** An organisation whose governance is independent of government.
- Nurse practitioner:** A nurse trained for an extended range of independent practice, usually taking on tasks normally performed by doctors.
- Oncology nurse:** A specialist nurse in cancer care.
- Oncology:** The branch of medicine and surgery that specialises in the management of people with cancer.
- Palliative care:** Specialised care and support for people living with a terminal illness and their carers (source: Palliative Care Australia).
- Practice nurse:** A nurse working as a clinician in general practice.
- Primary care:** Usually taken to be synonymous with general practice.
- Primary health care:** This is the World Health Organization's term for care across various disciplines that occurs in the community and is often a person's first point of contact with the health care system. In the Australian context it includes all members of the care team, e.g.

community health nurses, Aboriginal Health Workers. General practice is a subset of the primary health care sector.

**Psychosexual care:** Care focused on sexual problems which might arise as a result of cancer.

**Psychosocial care:** Care focused on a person's psychological and social situation.

**Role delineation:** Defining job roles with clear boundaries.

**Rural Generalist:** A general practitioner trained in a range of procedural specialties appropriate for independent rural and remote practice under the auspices of the Australian College of Rural and Remote Medicine.

**Pharmaceutical Benefits Scheme (PBS):** Australia's scheme for providing subsidised prescription medicines.

**Self management:** The patient taking on aspects of their own medical care.

**Shared care:** A formal arrangement in which a person with cancer is looked after in a partnership between specialists and the primary health care sector, with the aim of providing safe, high quality treatment, support, follow-up and surveillance, and provided by any member of the care team.

**Specialist care:** Care from clinicians who have been trained in and practise in a specified field.

**Specialist nurse:** A nurse trained and practising in a specific field.

**Supportive care:** Care which incorporates psychosocial and psychosexual care, and may also include specific support such as rehabilitation and social services.

## Main messages

Shared care is a crucial tool which is integral to delivering safe and effective multidisciplinary cancer care, by appropriately trained professionals as close as possible to where the person with cancer lives, allowing for fully informed choice and recognising that care close to home may be associated with sub-optimal health outcomes. There are tumours where the patient journey lends itself to shared care and some cancers where centralised, sub-specialist care is the safest, most effective option and it will be necessary to target those cancers in which shared care can be of greatest benefit.

Shared cancer care can be widely implemented now and, although shared care will be more efficient with a fully functioning eHealth system, most elements can be implemented in the short term using current resources.

As an integral component of multidisciplinary cancer care, it is therefore misleading to think of shared cancer care as any single or group of service delivery models or particularly reliant on any one set of clinicians, such as general practitioners. Shared care should be – but is not, routinely – part and parcel of comprehensive cancer care. Implementing shared cancer care does not require major role redesign of primary care services but rather, the development of the following essential components to facilitate shared care within existing primary care models:

1. Timely and systematic communication (that includes role clarity) between all shared care team members and which involves the person with cancer
2. Decision support tools, including comprehensive information packages, guidelines and algorithms, and governance systems
3. Education and training that is easy to access to encourage primary health care clinicians (including general practitioners, all primary health care nurses, allied health providers, Indigenous health workers and physician assistants) to gain advanced skills
4. Credentialing for primary healthcare providers that recognises, supports and financially rewards advanced skills, thus providing incentives and viable business models.

### About this project

GSB Consulting and Communications was commissioned by Cancer Australia to undertake a literature review and consultation process to identify role redesign options that support greater engagement of primary health care providers in cancer treatment and surveillance post treatment. The project aimed to:

- identify existing national and international shared care models in oncology and in non-oncology disciplines such as diabetes and obstetrics
- test the findings of the literature review against the experience of Australian stakeholders
- make recommendations based on the evidence derived from the study.

For the purposes of this project, shared care is purposefully arranged and planned care of people with cancer that is shared between specialist cancer clinicians and clinicians in the primary health care sector and includes role delineation, communication and referral pathways, training and clinical guidance materials and ideally, high quality patient and carer information.

## Recommendations

The literature review and consultation suggests the following shared cancer care activities should be conducted at a national level and implemented locally:

### 1. Timely and systematic communication

On a national basis, including wide consultation and building on current knowledge, in particular the work conducted by the National E-Health Transition Authority (NEHTA):

- 1.1 Identify minimum information requirements for shared care including modifiable care plans, standardised and modifiable patient information for informed consent and effective self-management.
- 1.2 Develop a standardised but locally modifiable electronic or handheld (or other effective format) cancer care plan that includes:
  - (a) Targeted information about the specific cancer and references to an additional comprehensive information source
  - (b) An evidence-informed treatment plan template that can be electronically modified depending on cancer type and the patient's ongoing needs (including data required for audit and evaluation)
  - (c) Details of the treatment team including who will do what and when (including the role of the person with cancer)
  - (d) Contact details for all treatment team members
  - (e) Evidence-informed guidance on the management of co-morbidities, supportive care and psychosexual care
  - (f) The ability to update easily as treatment progresses, thus forming a comprehensive patient record.
- 1.3 Encouraging use of the care plan:
  - (a) Develop and implement a communications strategy to establish expectations with consumers and clinicians for the use and benefits of a care plan, including addressing change management requirements to ensure that all care providers, and in particular specialists, are engaged in service delivery modification
  - (b) Identify an appropriate level of expectation of the role of people with cancer to act as a member of their own care team, giving consideration to varying levels of health literacy, competency and willingness
  - (c) Strengthen the role of the person with cancer in coordinating their own care by requiring the person who first develops the care plan to ensure the person with cancer, their carer or family, understands the role of the care plan in facilitating treatment and communication, and what they should do to guarantee the care plan is maintained on an ongoing basis
  - (d) Ensure a hard copy is provided to the person with cancer as a patient-held record and an electronic copy is provided to each treating team member (either by email or on a CD given to the patient) with instructions for adding information along the patient journey
  - (e) Allow the flexibility for clinicians to align and format the care plan with their patient notes so that double handling is minimised.

- 1.4 For each of the activities above ensure that consideration is given to appropriate service variation in urban, rural and remote settings and specific needs of Aboriginal and Torres Strait Islander people.

## 2 Decision support tools

Develop a range of shared care tools by conducting these activities at a national level:

- 2.1 Identify and focus on cancer types, parts of the patient journey and locations where shared care in the community for people with cancer can be safe, high quality and cost effective by taking into consideration:

- i. Models of care in urban, rural and remote settings
- ii. Existing and proposed services (e.g. GP Superclinics and Regional Cancer Centres)
- iii. Rates of incidence of specific cancers
- iv. Complexity of treatment, follow-up and surveillance
- v. Access to supportive and psychosexual care
- vi. Variations between public and private settings

- 2.2 Produce a set of minimum critical specifications for shared care that can be readily and flexibly implemented by individual services and service delivery models including:

- (a) Identifying the key elements for care (including variation between cancer types)
- (b) Identifying evidence-informed shared care treatment models for each cancer type appropriate for shared cancer care
- (c) Identifying ways of increasing consumers' capacity for shared decision-making and self management and a driving role in development of the care plan and coordination of care

- 2.3 Develop a web-based system to provide access to the required information to the right people at the right time including:

- (a) A common information portal with nationally developed:
  - i. care plans
  - ii. diagnosis, treatment and care guidelines
  - iii. information and flags regarding non-clinical assistance including travel, occupational therapy etc
  - iv. treatment, monitoring and response algorithms and
  - v. specific cancer information for all parties, including clinicians and people with cancer and their families
- (b) A secure area with electronic patient histories including test results and treatment (a subset of the care plan)
- (c) A centrally located, secure data collection and analysis facility for a minimum data set for evaluation and audit of safety, quality and outcomes of shared cancer care for target cancers. The collection should be incorporated into the care plan to facilitate automatic population of specific information fields. The processed data should be made available to clinicians.
- (d) A strategy for increasing specialist take-up of electronic systems.

2.4 Develop a governance system that can be modified at a local, state and national level to ensure:

- (a) Uptake is encouraged using identified target participation rates
- (b) Quality and safety is continually improved using measurable key performance indicators, clearly identified prior to data collection, with a measurable standard.
- (c) A reporting process that:
  - i. collects and analyses issues in a timely manner
  - ii. includes timely feedback to facilitate practice modification to address analysis outcomes
  - iii. includes a process for collection, aggregation and analysis of data at a national level, with an aim over time to improve health outcomes, workforce management and cost effectiveness.

2.5 For each of the activities above ensure that consideration is given to appropriate service variation in urban, rural and remote settings and specific needs of Aboriginal and Torres Strait Islander people and other cultural groups, including language, understanding of the care journey, and timing and travel issues for those living remotely.

### **3. Education and training**

Conduct a national project, including a wide consultation with existing service providers and educational and training facilities to:

3.1 Encourage education, training and accreditation by:

- (a) Identifying the minimum education and training required on an ongoing (or periodic) basis for primary health care providers to provide evidence-informed shared care for people with the targeted cancer types
- (b) Identifying the value proposition required to get primary care providers to engage in cancer education
- (c) Identifying organisations that can provide education and training by conducting a national audit of:
  - i. Current education/training programs, providers and modalities including preparation for providing culturally appropriate care
  - ii. Existing education and information materials including:
    - treatment guidelines
    - treatment and monitoring algorithms
    - care plans, including supportive and psychosexual care
    - teamwork training and change management materials
    - information about each targeted cancer type
    - patient history records including electronic and hardcopy templates
    - self management materials including decision support tools
- (d) Identifying gaps between existing information and minimum requirements
- (e) Developing information to fill gaps identified at 3(d) ensuring appropriate language for target users and consistency of key messages

- (f) Assisting education and training facilities to implement comprehensive programs using existing and enhanced materials.

#### **4. Credentialing, funding and remuneration**

Conduct a national project, including a wide consultation with existing service providers, to:

- 4.1 Develop a system for credentialing care providers and facilities by identifying:
  - i. the minimum skill set required to provide specific components of shared cancer care that are safe, high quality and cost effective
  - ii. education or training goals that can act as key performance indicators or assessment tools of competency in advanced skills
  - iii. minimum requirements of the care environment (e.g. chemotherapy safety)
- 4.2 Develop and recommend funding mechanisms (e.g. the applicability of existing Enhanced Patient Care items, funded care packages, and MBS item numbers for cancer related care by credentialed clinicians, including nurse practitioners and other non-medical providers with specific credentials) to support shared care based on the advanced skill credentials of the provider and giving consideration to:
  - (a) issues between acute and community care settings
  - (b) state border issues (e.g. patient accommodation and travel schemes)
  - (c) variations in care in metropolitan, regional, rural and remote settings
  - (d) workforce issues
  - (e) appropriate care planning and referral mechanisms, and
  - (f) consultation times needed for cancer patients.
- 4.3 Develop and recommend changes to the Pharmaceutical Benefits Scheme (PBS) to allow appropriately credentialed clinicians (including non-oncologists with specific credentials) to prescribe long-term, high-dose opiates and chemotherapy agents.

## 1. Background and purpose of project

GSB Consulting and Communications was commissioned by Cancer Australia to undertake a literature review and consultation process to identify role redesign options that support greater engagement of primary health care providers in cancer treatment and surveillance post treatment.

Role redesign in this context is tightly linked to models of care and their design, with a specific focus on people living in regional, rural and remote Australia.

More specifically, the project aimed to:

- identify existing national and international shared care models in oncology and in non-oncology disciplines such as diabetes and obstetrics, to determine:
  - the barriers and facilitators to adopting these shared care models at consumer, provider and system levels
  - the degree to which these shared care models could be adapted to suit Australian health systems and settings
  - new and redesigned roles that primary care could perform
  - successful change management processes that would support a shared care or other appropriate model
  - methods for monitoring and assessing the success of role redesign programs
  - the impact of these shared care models at the consumer, provider and system level including cost, possible funding mechanisms, patient safety, health outcomes and the social impact on family/carers
  - quality assurance frameworks to support good patient outcomes.
- test the findings of the literature review against the experience of Australian stakeholders
- make recommendations based on the evidence derived from the study.

### 1.1 Definition of shared care for this project

For the purposes of this project, shared care is purposefully arranged and planned care of people with cancer that is shared between specialist cancer clinicians and clinicians in the primary health care sector and includes role delineation, communication and referral pathways, training and clinical guidance materials and ideally, high quality patient and carer information.

There may be further possibilities for role redesign within specialty cancer centres, but the scope of this project is limited to role design involving the primary health care sector.

### 1.2 Objectives of shared care

The objectives of shared care are to:

- Improve health outcomes and quality of life for people with, or who have survived, cancer by increasing timely access to evidence-informed shared care that is clinically appropriate, effective, cost effective and culturally sensitive across the holistic care continuum, as close to home as safely possible for both patients and the workforce

- Decrease inappropriate service variation by providing clinical guidance, ongoing education and credentialing, and by creating and maintaining a facility for data collection, monitoring and assessment
- Provide supporting care that empowers people with cancer and their families by increasing their ability to self-manage in the community and considering holistic needs that extend beyond clinical needs
- Improve access to care by ensuring that systems are in place to support interdisciplinary care and role delineation so that use of specific services is matched to the specific needs of the person with cancer (e.g. care plans that clearly define who will do what and when, that are well coordinated, communicated and understood by all care team members including the person with cancer, and giving consideration to all service providers including NGOs and community services, appropriate responses to monitoring and symptom management, referral pathways and guidelines)
- Improve continuity and timeliness of care for complications, side effects and psychosocial care
- Improve access to shared care that is sustainable in the long term by addressing resourcing requirements including financial and workforce issues and by promoting the benefits of shared care for all parties.

## 2. Methods

The project involved three stages:

1. Literature review and early consultations with key experts
2. Main round of consultation (by telephone survey)
3. Final round of consultation (by email).

### 2.1 Literature review

For the literature review, sources were identified using an Internet-based search (including PubMed and Cochrane) and by contacting key experts and organisations in Australia and target countries to identify relevant evaluations and reports.

Search terms included: shared care, coordinated care, primary care, general practitioner, GP oncologist, role redesign, community care, community based care, rural, regional, remote, cancer care, cancer survivors, cancer surveillance, follow up, outreach, extension.

The literature search focused initially on cancer, but extended to shared care models in diabetes, mental health, chronic and complex illness, addiction medicine, and obstetrics. Countries of interest were those with health care systems similar to Australia, i.e. New Zealand, Canada, United Kingdom, Netherlands, Denmark, Finland and to some extent the United States. Priority was given to systematic reviews, randomised controlled trials and comparative studies. Selected reviews, qualitative studies and reports were included if they were relatively recent, and had practical relevance for the Australian health care system. In total, 35 studies were reviewed.

## **2.2 Limitations of the literature review**

Few high-quality studies of shared care interventions were identified, and many models in operation have not been rigorously evaluated. Limitations include:

- many studies were of short duration
- most of the shared care interventions were complex and heterogeneous, and involved a variety of health conditions and health care systems
- health outcomes measurement was variable in quality and it was often difficult to determine whether lack of effect was real
- most studies did not evaluate important service design factors such as costs, payment models, governance and change management.

Despite these limitations, there was considerable agreement on the barriers and facilitators to shared care, and to a lesser extent, on the impact of shared care arrangements.

## **2.3 Consultations**

The findings of the literature review were used to develop a Draft Findings Report, which also included three proposed models of shared care for Australia. The Draft Findings Report was provided to consultation participants prior to the first round of consultation (by telephone survey).

Responses to the first round of consultation were then incorporated into a Revised Findings Report, which was provided to consultation participants during the final round of consultation (by email).

Copies of the Draft Findings Report and Revised Findings Report are attached as Appendices A and B. Questions asked during the telephone survey are listed in Appendix C.

The list of organisations and individuals invited to participate in the consultation was developed in collaboration with Cancer Australia and the project reference group.

All invited organisations and individuals agreed to participate in the consultation.

### 3. Findings

Section 4.1 below summarises the outcomes of shared care identified from the literature review. Section 4.2 lists the key features of seven existing models of shared care operating in Australia and internationally. Sections 4.3 and 4.4 identify the core elements of shared care and barriers to shared care, as described in the literature review and refined through the consultation. Further findings from the consultation are in section 4.5.

#### 3.1 Impacts of shared care identified in the literature

##### 3.1.1 Health and patient outcomes

A Cochrane Review of effectiveness of shared care in chronic disease management [1] found there was insufficient evidence to demonstrate benefits from shared care, apart from improved prescribing, although methodological shortcomings may partially account for this. The authors commented that it was often difficult to determine whether genuine collaboration between the primary and specialty care had taken place. None of the studies involved cancer patients.

A Cochrane Review of specialist outreach clinics in primary care and rural hospital settings (one study involved breast cancer patients) [2] found they provided greater benefit where they were part of complex multifaceted interventions involving collaboration with primary care, education or other services. Benefits included improved health outcomes, more efficient guideline-consistent care, and less use of inpatient services. On the other hand, simple 'shifted outpatients' styles of specialist outreach clinics, improved access but not health outcomes.

A systematic review comparing the effectiveness and cost-effectiveness of primary versus secondary care follow-up of cancer patients [3] found equivalence for patient wellbeing, recurrence rate, survival, recurrence-related serious clinical events, diagnostic delay and patient satisfaction. GP-led breast cancer follow-up was cheaper than hospital follow-up. However, reviewers noted that in general the quality of the data was poor, allowing no firm conclusions.

Another systematic review conducted by the same researchers [4] analysed qualitative studies examining patients' and healthcare professionals' views about cancer follow-up. It found that patients' main concern is recurrent disease, and that patients find regular specialist follow-up, the expertise of specialists, and quick access to tests reassuring. However, it also found patients have unmet information needs and that continuity of care, unhurried consultations and psychosocial support are sometimes lacking in secondary care. GPs were thought to be unwilling and to have insufficient time and expertise to conduct follow-up.

These results suggest that while patient preferences must be taken into account, there is a potential role for GPs and/or nurses in follow-up and supportive care.

In addition, the following impacts may be cautiously concluded from individual studies (while bearing in mind the short duration of many studies and the lack of longitudinal research on shared care):

- Health outcomes, where measured, can be equal to or better than usual care, as long as there is adequate clinician training, ongoing support, shared protocols, and

communications systems [5-15]. An Australian randomised trial comparing general practice and surgical-based follow-up for people with colon cancer found no differences in quality of life, anxiety, depression or patient satisfaction, and while surgeons and GPs followed different patterns of investigation, there were similar results for recurrence, time to detection and death rates [16].

- Several studies found an improvement in patient satisfaction with shared care [5;8;12;15;17;18], though bias is possible in these results since patients who agreed to participate might have been those more receptive to GP care.
- GP confidence and/or satisfaction with specialist collaboration tends to improve with shared care [7;19;20].
- Some studies report an improvement in continuity of care [5;21].
- Shared care has the potential to reduce unmet supportive care needs [21].
- In the case of survivorship care, it has been noted that survivors of childhood cancers sometimes have issues with the transition to adult hospital-based follow-up, in which case shared care may improve compliance with follow-up and detection of late effects [22].

### **3.1.2 Financial outcomes**

Few studies have measured costs and cost-effectiveness and they vary in costs taken into account.

Simon et al 2001, studying shared care for depression in the US, reported substantial increases in treatment effectiveness for moderate increases in costs, and an acceptable return on investment.

Davies et al 2007, studying rheumatoid arthritis in the UK, found that shared care was likely to be more cost effective than aggressive treatment delivered in hospital in 60 to 90 per cent of cases, and aggressive treatment in hospital showed no benefit for health outcomes.

The Inala model of complex diabetes care in Queensland (advanced skills GP, diabetes educator and visiting endocrinologist) claims to have achieved better outcomes for a fraction of the cost of hospital based multidisciplinary outpatient care (paper submitted to *Diabetologia*).

Six of the 20 studies included in the Cochrane Review of shared care [1] compared the cost of shared care to costs in the control group. Of these, four indicated shared care was more expensive and two reported cost savings. However, there was variation in costs allocated to each sector depending on the health system in which the study took place. The two studies that reported direct patient costs (including costs such as travel) found that these were significantly lower in shared care compared to usual care.

### **3.1.3 Consumer choice and involvement**

Some studies noted that shared care arrangements are not suitable for all people. Those who had a negative experience with their GP at the time of cancer diagnosis, for example, were unwilling to see the GP for follow up [5]. Flexibility and patient choice needs to be maintained.

The Cochrane Review of shared care [1] noted that many shared care models failed to involve consumers in designing or introducing shared care services, and did not evaluate patient and provider experiences.

### **3.1.4 Clinician choice and involvement**

Clinician preferences may also affect the success or failure of shared care services. In many studies involving GPs, a proportion of GPs declined to participate. Some GPs may be reluctant to refer their patient for surveillance to a nurse or even another GP, and some specialists may be reluctant to refer to the primary sector.

However, several studies have found that the majority of GPs are willing to participate in cancer care and clinician involvement in designing care arrangements could also facilitate shared care models.

## **3.2 Existing Australian and international models of shared care**

The literature review found that there is significant variation in models of shared care in Australia and internationally – across specialties (and within cancer, across tumour streams); across geographic areas; across the private and public sectors; and even at a jurisdictional and local level. Existing models with key elements relevant to the Australian setting are described below.

### **3.2.1 Scotland – NHS Tayside Diabetes Managed Clinical Network**

This is an internationally renowned integrated pathway for people with diabetes living in the catchment of Dundee in Scotland. They set clear targets, involve patients in the planning and implementation and devolve as much as possible to general practice. A semi-automated patient held record is part of the system as is extensive training and education and investment in increased access to podiatry and eye screening.

They launched a Local Enhanced Service for Diabetes in January 2008, which aims to support patients who do not require specialist intervention to be looked after in general practice. The program has had remarkable outcomes for people with diabetes.

Scotland also has Managed Clinical Networks in cancer. These are mostly focused on improvement of secondary and tertiary services but they are doing some work on low-risk follow-up of men with prostate cancer.

### **3.2.2 Canada – Community Oncology Network, British Columbia**

The Community Oncology Network operates within the British Columbia Cancer Agency (BCCA), which delivers care and sets standards of care [23].

Components of the model include:

- clearly defined levels of service and expectations at each level (Community Oncology Network facilities must have appropriately trained and competent staff to administer chemotherapy, access to appropriate clinical diagnostic services, and the capability to respond to complications of therapy 24 hours per day)
- clear lines of responsibility (BCCA medical oncologists who transfer care to the community to receive chemotherapy are responsible for ensuring that the accepting

physician has the necessary knowledge, skill and ability to manage this care and that the facility meets BCCA standards)

- the Community Physician Oncology Network, an advanced-skill GP model which includes a two-month training course in oncology (the aim is to have at least one family physician with oncology expertise in every BC community with 15,000 people), and funding to support these positions
- continuous maintenance at the province level of Cancer Management Guidelines, Cancer Drug Manual, Chemotherapy Protocols, Evidence Based Guidelines for all disciplines, education for community health care professionals, and outcome evaluation and research.

### **3.2.3 Canada – Community Cancer Program Network, CancerCare Manitoba**

This is a model of distributed specialist centres. CancerCare Manitoba is the central province-wide cancer agency in Manitoba with responsibility for cancer care. One of its arms is the long-established Community Cancer Program Network, that operates across 16 rural Manitoba communities in partnership with specialists [23],[CancerCare Manitoba website\*]. Each of the 16 Community Cancer Programs is located at a local hospital. Telehealth facilities such as videoconferencing are used to assist collaboration between specialists and rural staff in consultation and education.

The program provides chemotherapy and follow-up care through a multidisciplinary primary care team comprising family physicians (GPs), nurses, pharmacists, and sometimes allied health professionals such as social workers and dieticians. Family physicians, nurses and pharmacists receive specialised cancer training.

### **3.2.4 Canada – UPCON Network, CancerCare Manitoba**

This is a model intended to support regular GP care. The Uniting Primary Care and Oncology (UPCON) Network of CancerCare Manitoba is a program that aims to improve communication and coordination of patient care between family physicians (GPs) and the cancer system, and to promote the role of primary care within cancer care [24]. Development of the network was assisted with three years of funding in 2003 through the Primary Health Care Transition Fund of Health Canada.

CancerCare Manitoba provides patient care in two multidisciplinary outpatient facilities affiliated with teaching hospitals in Winnipeg, Manitoba. The UPCON Network originally focused on building relationships with 12 primary care clinics in Winnipeg, a city of 700,000. The 12 clinics included 7 fee-for-service clinics, 3 community health centres and 2 academic teaching centres.

The main focus of UPCON is the 'lead physician' from each clinic, a role intended as the 'local cancer resource'. Elements of the model include:

- primary care access to the provincial electronic medical record for cancer
- small group professional development sessions for lead physicians (topics were derived from a needs assessment of lead physicians, and have included advanced

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\* [http://www.cancercare.mb.ca/home/patients\\_and\\_family/treatment\\_services/treating\\_patients\\_in\\_rural\\_manitoba/](http://www.cancercare.mb.ca/home/patients_and_family/treatment_services/treating_patients_in_rural_manitoba/)  
Accessed 4 December 2009

care planning, cancer pain management, follow-up of breast and colon cancer patients, and the human side of cancer)

- educational outreach to all clinic staff
- payment of honoraria for lead physicians to participate in orientation events, eight hours of cancer clinic exposure, periodic meetings, and monthly small group education sessions
- changes within CancerCare Manitoba to highlight the role of family physicians.

Lead physicians act as informal resources for their colleagues about cancer care questions that arise in practice, but are not expected to perform any unique patient care role, apart from accepting the occasional referral of new cancer patients into their own practices.

The network was evaluated in 2006 with positive results and it is now expanding throughout Manitoba. It is felt to be unique in its focus on relationship-building.

### **3.2.5 New South Wales – Collaboration between Cooma & Monaro Oncology Services**

This is a project to develop a shared care model that allows patients to access chemotherapy services closer to home, and was supported in 2007 by a Health Services Innovation (HSI) grant from the Cancer Institute NSW. The project includes evaluation [25].

The model comprises:

- patient assessment and establishment of a treatment program by oncology specialists in the ACT
- criteria for chemotherapy treatments which are appropriate to be administered under a shared care arrangement
- communication of the treatment program from the oncology specialist to the GP and oncology nurse.

Proposed deviations from the prescribed treatment program are assessed by the oncology specialist through communication with the local GP and oncology nurse.

### **3.2.6 New South Wales – A shared care model at the Dubbo Oncology Unit**

This model is a collaboration between the Greater Western Area Health Service (GWAHS) and Royal Prince Alfred Hospital (RPAH) in Sydney [25]. RPAH has historically provided visiting medical specialist support for the Dubbo Oncology Unit.

The shared care model involves training for a Dubbo-based GP/Visiting Medical Officer (GP/VMO) to support the care provided by the visiting specialist. This includes:

- training for the GP/VMO at RPAH
- clearly defined guidelines and protocols.

The shared care guidelines will be formally evaluated and are designed to allow translation to other sites potentially applying similar models.

### 3.2.7 Queensland – 'Inala model' of complex diabetes care

The 'Inala model' is a \$1.8 million pilot of a community-based tertiary service for people with diabetes who have complex needs. It is a partnership with the Endocrinology Department outpatient clinic at Princess Alexandra Hospital (PA) and aims to provide primary care capacity building by integrating care protocols and 'virtual' tertiary support. It is staffed by an advanced skill trained GP, a diabetes educator and a visiting endocrinologist.

They found they could deliver care for a quarter the price, high levels of patient satisfaction and better outcomes (lower HbA1C levels). Waiting lists at PA dropped from a year to three weeks (oral communication, Professor Claire Jackson; findings yet to be published).

### 3.3 Core elements for successful shared care

There was a wide general consensus among consultation participants in relation to most of the core elements for successful shared care, although expert opinion about who should develop the care plan was divided (some parties felt strongly that the care plan could only be developed by the specialist, while others felt it could be written by GPs, or practice nurses with oversight by GPs). From a consumer perspective the defining issue is whether the care plan covers the entire patient journey, with specialist treatment being an important element in overall care, or whether the care plan covers only specialist treatment. Further work must be conducted to identify elements to be included in the care plan and it is likely that this work will resolve the point in the patient journey at which a care plan should be developed, which in turn should identify the most appropriate provider to prepare it.

From the consultation it is proposed that the following 'core elements' of shared care should be included in any model proposed for the Australian setting (see also Appendix D, Facilitators of shared care):

- i. **Shared patient records** or patient-held records.
- ii. **Systematic communication pathways** and information sharing between providers, and infrastructure to facilitate communication (e.g. tele/video conferencing, virtual consultations) including a local care coordinator who has a relationship with the patient and understands the local service delivery model.
- iii. **Clear role definition according to a care plan** that promotes teamwork. The care plan should be based on cancer type, an individual patient risk assessment, and appropriateness of care setting, and should include care protocols, referral pathways and clear prompts (or thresholds) for referral.
- iv. **Procedure for rapid referral** to specialist care when needed, and a procedure for rapid advice (e.g. phone hotline) for primary care providers to speak directly with a specialist, in shared care arrangements which include delivery of chemotherapy.
- v. **Realistic payment models** for GP and nurse involvement, which remunerate for longer consultation times, non face-to-face activities such as multidisciplinary meetings and phone, text and email support, and provision of information to patients to facilitate informed consent.
- vi. **Consumer involvement** in service development.

- vii. High-quality **information materials** for patients and primary health care providers with education on how to use materials to the greatest effect.
- viii. Active **patient and/or carer involvement** in the process of care.
- ix. Ongoing **interprofessional education** to improve the culture of professional respect and increase understanding of the role and activities conducted by various care providers and the opportunities for teamwork that lead to improved health outcomes.
- x. **Infrastructure** to support the development of governance, quality control and champion-based change management processes including ongoing data collection, analysis and feedback.

### 3.4 Barriers to effective shared care

The literature review suggests the following barriers to effective shared care:

- i. **Inadequate and/or delayed communication** between care providers; GPs being 'left out of the loop' especially in regional and remote areas
- ii. **Lack of clarity about the GP's role** in ongoing care
- iii. Perceived or actual **lack of sufficient knowledge** among GPs
- iv. **Patient preferences and/or expectations** that cancer care and follow-up be provided by specialists, and doctors' views of patients' expectations
- v. Patients' **perceptions of GPs as being too busy** to provide care for chronic disease
- vi. **Lack of time and willingness** among primary care and specialist providers to follow new administrative and communication routines
- vii. **Lack of additional funding** for primary care providers to provide protected time for enhanced communication and routine reviews
- viii. Limited access to and support from **allied health providers** in the primary care sector
- ix. **System barriers** such as poor organisation, lost medical records and/or administrative delays in referrals
- x. Increased **out-of-pocket costs** for patients, in systems where hospital care is free for all patients and GP care is not
- xi. Increased **cost per visit**, in studies that investigated the use of outreach services.

Additional barriers identified in consultation were:

- **Role protection** by providers of cancer services, inter-practice jealousy and patch protection with the risk of suboptimal patient outcomes. Oncologists like to have follow-up patients in the mix of patients they see because...  
*"it's a nice balance to the misery as well as enjoying the continuity of the relationship with the patient."*
- Concerns about **quality control**: GPs have to keep up with a lot and only see people with cancer infrequently.
- **'Capture' of patients** by specialist service providers: this is related to role protection and quality concerns, and occurs where a person with cancer is initially referred to a specialist (such as a medical oncologist or surgical oncologist) and that service provider has an incentive, either financial or concern about quality of care, to not

refer the person to other services even though they may be closer to the patient's home.

- **Payment models** in the hospital or private sector that provide disincentives for shared care, e.g. reliance on income from day chemotherapy.
- Lack of shared **governance**: an equal share of power and control must reside with the primary health care team, the community and the patient/carer/family.
- Reluctance among oncologists to take-up advances in **technology** to support patient care, for example to fill out patient-held records (where these have been trialled), because it took time and duplicated hospital records.
- **Clinical trial recruitment** and maintenance.
- Access to sophisticated **imaging**.
- A limiting of the **role of community nurses** due to infrastructure and politics in a situation where these nurses could greatly enhance the shared care model.
- Current **information systems** – inadequate or delayed communication occurs because we rely on humans to communicate information such as test results, and we rely on humans at one end to know what a human at the other end needs. This could be overcome by a centralised shared electronic record, but also by breaking down administrative silos, e.g. by allowing GPs to access hospital records.
- Lack of **IT infrastructure** in remote areas – 'real time' may not always be a possibility
- Lack of **formal arrangements** for shared care such as a Memorandum of Understanding. Providers will be reluctant to buy into shared care if arrangements are too casual, or if they've had no say in developing the arrangements.
- **Funding streams** – state versus federal.
- **Cost for patient**, both time and financial, need to be considered – including travel, accommodation, paying for meals away from home and so on.
- **Country patients** don't always engage with health care with the same enthusiasm as patients in the city – one of the factors lowering survival is lack of engagement, not just lack of access.
- **Patients slip through the net** – care (e.g. palliative care) often ends up failing with the GP, who can't give the patient enough time when they see people in 10-minute increments from 7am to 7pm.
- **Access to staff** – there is a shortage of GPs (patients may wait 5 days for an appointment), high turnover and heavy workloads. It can be difficult to get the right person in the right position. In addition, rural areas have a very mobile workforce, so GPs may move on after being trained up. Succession planning is needed.
- **Communication** – There is a lack of recognition among primary care providers of the need to communicate back to the oncologist. Rural care providers also have a non-confrontational culture and may not tell oncologists when things don't work, or if they don't understand something. The chain of communication always falls over particularly in remote/Indigenous communities when getting back to families after treatment.
- **Cultural** – respect is needed for keeping to appointment times, even if done via videoconference. Language in communications is a real barrier - often English is the third or fourth language.

- **Lack of reward** – staff need to feel appreciated for their efforts or they become discouraged.
- **Medical culture** – doctors "don't like sharing" and often are not used to team-based care. In a team, the people below may resent the people above and the people above resent the people below; they need to think of it not as a pecking order, but as a patient-centred approach with the team operating around the patient.
- **Care coordination** – the lead clinician can be hard to identify; it is important to have a leader.
- **Medico legal risk** – shared care creates uncertainty, which needs to be clarified – it will affect whether providers want to be involved. It is not clear whether clear role delineation is sufficient to clarify medico legal responsibility.
- **Education and expertise** – members of the team may be unaware of, or may not appreciate, other members' expertise; there may be lack of recognition of the expertise required as well as lack of reward/motivation to learn the skills required. It is difficult for GPs to maintain skills and knowledge across multiple disciplines. Appropriate training for nurses is more restrictive than enhancing.
- **Patients as agents of change** – patients will pick up when carers are unsure; the biggest safety measure for shared care is "training the patient". There is also a need to increase patients' and primary care providers' understanding of the importance of follow-up.
- **General lack of confidence** by patients in local service providers (skills, knowledge, communication abilities), partially due to what they see on TV; there's a general understanding that care in a big hospital is better.

### 3.5 Findings from the consultation

The consultation found that there are many services across Australia offering a degree of shared care which sometimes is quite well developed. There has, for example, been high quality development of shared care models for specific health areas such as maternity care. There are also significant policy initiatives currently being implemented that can be expected to have a significant impact on the way in which shared care is delivered in the future, including the move towards GP Superclinics and the Federal Government's Regional Cancer Centres program.

A clear message from the consultation is that there should be multiple models of shared care to suit local circumstances, skills and jurisdictional policies, with setting being the greatest determinant. In rural and regional areas, non-cancer specialists often have a role in cancer care and follow-up alongside oncologists and primary care providers.

Despite this variety of service delivery models, the consultation strongly supported the findings of the literature review in that there are some key characteristics that must be present for shared care to be successfully implemented:

1. Shared care is a crucial tool and integral to effective interdisciplinary and multidisciplinary care, but should not be the driver of specific service delivery models.
2. That it is possible to provide the elements to support the successful implementation of shared care in a manner that allows individual services to

integrate shared care into current service delivery models, or to flexibly develop new services to meet the needs of the community.

3. Clear role delineation should be formally identified and agreed to in care plans.
4. Role delineation should be based on the credentials and competencies of the provider rather than pre-determined to specific clinicians.

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