

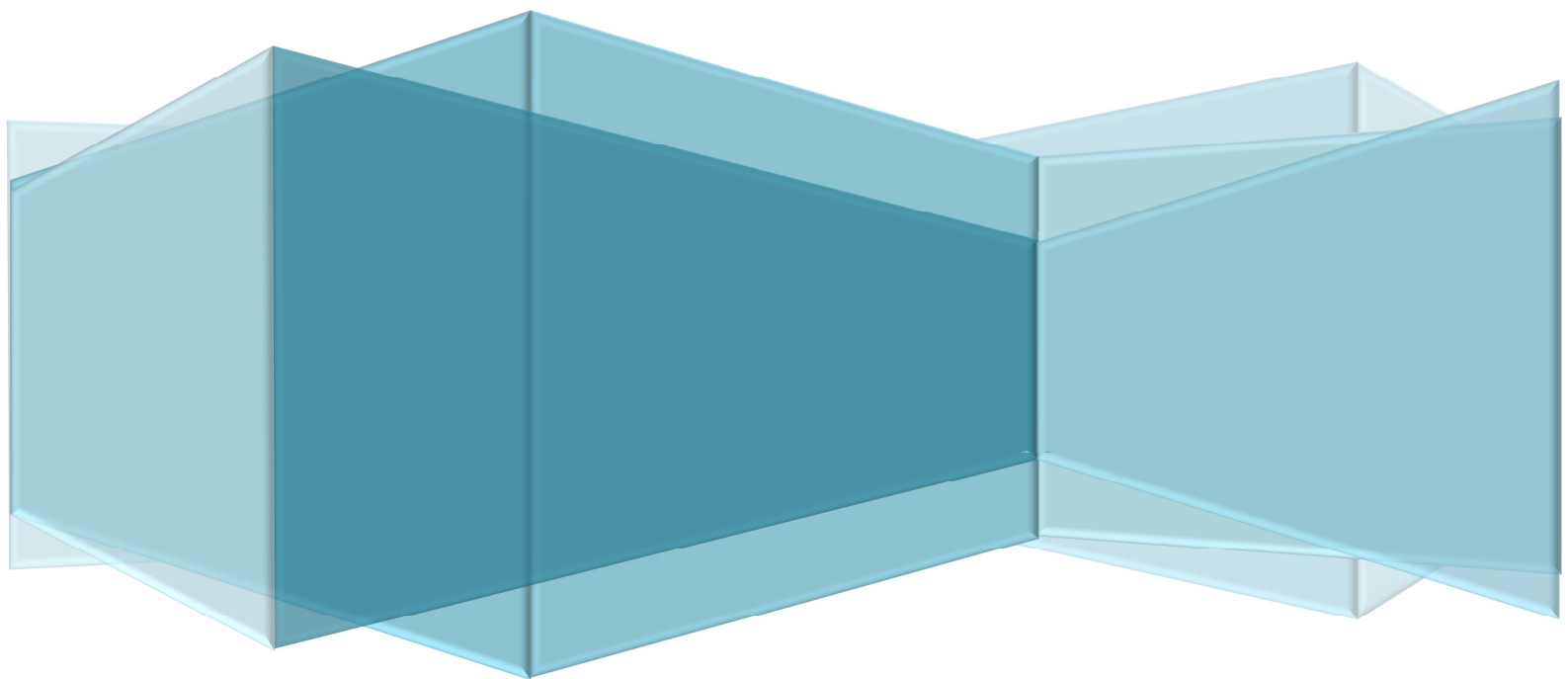


Specialist Metastatic Breast Care Nurse

Final Project Report

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Glossary Of Terms:

ABC	Advanced breast cancer (Stage IV disease)	MBC	Metastatic breast cancer
ACT	Australian Capital Territory	MBN	Metastatic breast nurse
A & E	Accident and Emergency	MDT	Multidisciplinary team
BCI	Breast Cancer Institute	MF	McGrath Foundation
		MGC	Metastatic gynaecological cancer
BCN	Breast Cancer Nurse	MO	Medical Oncology
BCNA	Breast Cancer Network Australia	NBCC	National Breast Cancer Centre
CCV	Cancer Council Victoria	NEMICS	North Eastern Melbourne Integrated Cancer Service
CDU	Chemotherapy Day Unit	NP	Nurse Practitioner
CNC	Clinical Nurse Consultant	NSW	New South Wales
DON	Director of Nursing	OF	Otis Foundation
EBC	Early breast cancer (Stage I or II disease)	PC	Palliative Care
EFT	Effective full time	POWH	Prince of Wales Hospital
FCC	Family Cancer Clinic	RN	Registered Nurse
GP	General Practitioner	SC	Supportive care
H & H	Hopes and Hurdles (kit)	SCN	Specialist Cancer Nurse
KPI	Key performance Indicators	SMICS	Southern Melbourne Integrated Cancer Service
LABC	Locally advanced breast cancer(Stage III disease)	QA	Quality Assurance
LGFB	Look Good Feel Better (program)	UK	United Kingdom
LWC	Living With Cancer (program)	WMH	Westmead Hospital

Executive Summary

Breast cancer is the most commonly diagnosed cancer in Australian women and remains the leading cause of death from cancer in women in developed countries. Early detection and improvements in adjuvant treatments are decreasing mortality rates in women diagnosed with early breast cancer (EBC), however as many as a third of these women will develop and die from metastatic breast cancer (MBC) (Aranda et. al, 2005; Cancer Institute NSW, 2009; Cardose et. al. 2010; The Specialist Breast Nurse Project Team, 2000; Warren et.al, 2012; Watts et.al. 2011). MBC is now commonly being categorized as a chronic illness, with a median survival time of 3 years. With advancements in treatment, some women are living with their disease for as long as 15 years (Aranda et. al. 2005; Bennet et. al. 2013; Cancer Institute NSW, 2009; Cardose et. al, 2010; The Specialist Breast Nurse Project Team, 2000; Warren et. al, 2012; Watts et.al, 2011).

It has been recognised by consumers both internationally and nationally that a supportive care gap exists for MBC patients. In response to this, the specialist metastatic breast care nurse (MBN) role has started to emerge in both the United Kingdom (UK) and Australia. At a local level this gap was also identified by a consumer member of the Southern Melbourne Integrated Cancer Service (SMICS) Breast Tumour Group. A regional average of 31% of health service breast cancer episodes comprises of women with stage IV breast cancer, of whom 42% will be alive in three years. For this reason it was proposed that SMICS investigate opportunities to improve access to health professionals with specialised skills to support metastatic breast cancer patients (SMICS, 2013).

SMICS provided funding for two breast care nurses (BCN), Gillian Kruss and Jenny Macindoe, to undertake a study tour to two hospitals in Sydney, Westmead and the Prince of Wales, to examine established roles and to attend the two day metastatic breast cancer practicum at the Breast Cancer Institute at Westmead Hospital. A questionnaire was sent to the MBN at Canberra Hospital, and a comparison of each role was undertaken. An extensive literature research was also conducted.

The knowledge gained informed the development of a model of care and clinical pathway to guide practice for the SMICS member health services to establish the MBN role, which is outlined in the body of this report. It was found that the role should operate independently but in parallel with EBC services to ensure that the focus is solely on the specific and complex supportive care needs of the MBC patients.

The MBN role requires an advanced skill set, experience and knowledge to provide for the needs of the patients and carers. The benefits of this role for the MBN and the health care organisation in which they provide services include:

- increased patient satisfaction and staff morale
- provision of an improved cancer service
- increased efficiency
- cost effectiveness – measured using Key Performance Indicators (KPI's)
- decreased length of stay in hospital
- decreased admissions to hospitals with complications
- decreased admissions to the Emergency Department (direct to ward admission is facilitated)
- decreased demand on breast cancer clinics and medical services.

Recommendations:

- Establish the specialist MBN role within SMICS member health services to fill the supportive care gaps that exist for MBC patients, and adapt it to local the local environment.
- Set the ideal nurse per patient ratio at 1 EFT per 150 patients.
- Institute a set of standardised KPI's to evaluate the effectiveness of the role from a consumer, health service and staff perspective.
- Develop the role to provide mentorship for other health professionals and to disseminate expert knowledge across the hospital and regional areas.
- An independent role (separate but parallel to the early breast cancer service) is suggested to focus solely on meeting the needs of MBC patients.
- Initial integration of this role into the breast multidisciplinary team (MDT) is essential until a separate MDT for MBC patients is established.
- If funding for the role is not available in the SMICS member health service then funding applications should be made to charitable organisations such as the McGrath Foundation, Sporting Chance, or private benefactors.
- Develop close links with and work collaboratively with other dedicated health professionals in the hospital and community to provide better outcomes for MBC patients.
- A senior grading (Victorian Grade 5 Clinical Nurse Consultant) is recommended due to the advanced skills and responsibilities required to function optimally in the role. Where practicable a job share position is recommended (if full time funding granted).

Introduction

It has been recognised by consumers both internationally and nationally that a supportive care gap exists for those patients with MBC. In response to this, the specialist MBN role has started to emerge in both the UK and Australia. At a local level this gap was also identified by a consumer member of the southern Melbourne Integrated cancer service (SMICS) Breast Tumour Group. With a regional average of 31% of health service breast cancer episodes being comprised of women with stage 4 breast cancer, of whom 42% will be alive in three years, it was proposed that SMICS investigate opportunities to improve access to health professionals with specialised skills to support metastatic breast cancer patients (SMICS, 2013).

SMICS provided funding for two breast care nurses, Gillian Kruss and Jenny Macindoe, to undertake a study tour to two hospitals in Sydney, Westmead and the Prince of Wales, to examine established roles and to attend the two day metastatic breast cancer practicum at the Breast Cancer Institute at Westmead Hospital.

Knowledge gained was to inform the development of a model of care and clinical pathway to guide practice for the SMICS member health services to establish the MBN role. It was found that the role required specialised skills and knowledge to address the complex and varied supportive care needs of the MBC patient. It also provided many benefits to the patients and carers, the nurse working in the role and the health care organisation.

Background

Metastatic breast cancer information and statistics

Breast cancer is the most commonly diagnosed cancer in Australian women and remains the leading cause of death from cancer in women in developed countries. Early detection and improvements in adjuvant treatments are decreasing mortality rates in women diagnosed with EBC. However, as many as a third of these women will develop and die from MBC (Aranda et. al, 2005; Cancer Institute NSW, 2009; Cardose et. al. 2010; The Specialist Breast Nurse Project Team, 2000; Warren et.al, 2012; Watts et.al. 2011).

MBC, also commonly referred to as secondary or advanced breast cancer, is stage IV disease that occurs when breast cancer cells spread from the first (primary) tumour in the breast through the lymphatic or blood system to other parts of the body. The most common parts of the body that breast cancer spreads to are the bones, liver, lungs and brain. MBC is now commonly being categorized as a chronic illness, with a median survival time of three years. With advancements in treatment, some women are living with their disease for as long as fifteen years (Aranda et. al. 2005; Bennet et. al. 2013; Cardose et. al, 2010; Warren et. al, 2012; Watts et.al, 2011).

Treatments for MBC

Despite advancements in treatment, MBC remains an incurable disease. The main treatment goal is palliation, with the aim of maintaining/improving quality of life, and possibly improving survival time. There are many factors taken into consideration when deciding which treatments to prescribe for MBC as can be seen listed in Appendix A (Cardose, et al, 2010, page 16). These may include the single use, sequential use or combination of endocrine therapy, chemotherapy, surgery, radiotherapy and targeted therapies (Cardose et. al, 2010; Watts et.al, 2011). Some treatment modalities have been developed to be administered as oral therapies (eg: capecitabine and everolimus) or subcutaneous therapies (eg: trastuzumab and denosumab), which means some patients may now have the option of having their treatments in the ambulatory or community setting. This option significantly decreases the amount of times these patients need to come into hospital for medical review. (Cardose et. al, 2010; Warren et. al, 2012).

SMICS

SMICS works together with its member hospitals (Alfred Health, Cabrini Health, Peninsula Health and Monash Health) to improve outcomes for people affected by cancer in the Southern Melbourne region and beyond (Appendix B) (SMICS, 2013). SMICS provided the opportunity to improve the supportive care outcomes for those with MBC by funding a travel grant for two Breast Care Nurses (BCN) to visit Sydney Hospitals to learn more about the role of a specialist MBN.

Methodology

An exploratory analysis of the literature and existing specialist MBN roles was undertaken. The aim was to identify the supportive care needs of those with MBC and develop a recommended model of practice for the role to be utilised and adapted by each of the SMICS member health services when initiating the role. Attendance at a 2 day Metastatic Breast Care Nurse Practicum on the 21st and 22nd October 2013, conducted by the Breast Cancer Institute (BCI) at Westmead, also provided valuable information regarding caring for people with MBC. This program covered the following topics:

- patient centred multidisciplinary approach to care and support
- role of the specialist BCN in the management of metastatic disease
- care co-ordination of patients with specific conditions
- assessment and treatment of oncological emergencies
- the impact of advancing disease on family and carers
- psychological care workshop
- self-care strategies.

Nurses in existing Specialist MBN roles at Westmead Hospital (WMH) and Prince of Wales Hospital (POWH) in Sydney were interviewed at their respective health services, to acquire more information about the development of the role. An open-ended qualitative questionnaire (Appendix C) was emailed to the Specialist MBN in Canberra and the 3 existing roles were compared.

The Supportive Care Needs of MBC Patients Literature Review:

Supportive care includes five inter-related domains of care: physical, social, psychological, spiritual and information; each of which is explained further in Appendix D (Department of Health, 2013, p.9). Women with MBC have high levels of unique, complex and unmet supportive care needs that can vary over time and differ from those with EBC (Breast Cancer Network Australia - BCNA, 2013; Watts et. al, 2011). According to Bennet et. al, 2013, p. 27), "the effect that a diagnosis of secondary breast cancer can have, cannot be underestimated as it can affect numerous areas and aspects of a patient's life enormously, including finances, employment, help supporting children and family, and lifestyle changes, in addition to the emotional burden". Patients can also experience persistent physical symptoms from their metastatic cancer or from their treatment side effects such as pain, nausea, insomnia, depression or fatigue (BCNA, 2013; The Secondary Breast Cancer Taskforce, 2008). These needs are at their highest levels at the point of diagnosis, when treatment changes, and when disease progresses (Bennet et. al, 2013; The Secondary Breast Cancer Taskforce, 2008).

It is well documented in the literature that these patients have a greater degree of psycho-social and health information needs. Receiving news of a diagnosis or progression of their disease can be extremely distressing for patients and their families, with many reporting it being even more distressing than their original early breast cancer diagnosis (Aranda et. al, 2005; The Secondary Breast Cancer Taskforce, 2008; Watts et. al, 2011). Various studies have explored the support and information needs of women with advanced breast cancer. Their main concerns revolved around having a life-threatening condition and included:

- worries about those close to them
- living with a sense of uncertainty
- worries about loss of control
- requests for strategies for maintaining a state of wellness and quality of life (Aranda et. al, 2005; Aranda et. Al, 2006; Watts et. al, 2011).

Identified Gaps In Supportive Care For MBC Patients:

The literature consistently documents that women with MBC receive inadequate or inconsistent levels of support, health information and continuity of care compared to when they were first diagnosed with EBC (Aranda et. al, 2005; Bennet, et. al, 2013; Breast Cancer Care, 2012; The Secondary Breast Cancer Taskforce, 2008; Watts et. al, 2011). BCNA (2013, page 7) recently documented in their 2013 Federal Election Submission report, "many women with secondary breast cancer tell us they feel alone and not well supported." Similar anecdotal reports have come from consumers being treated at each of the SMICS member health services. In addition, the BCN's at these hospitals report that their main focus is on the care of the EBC patient.

Reasons for these supportive care gaps:

The literature sites the following combination of reasons for suboptimal provision of supportive care of women with MBC:

- unstructured and ill-defined care pathways that complicate the efforts of BCN's to identify and provide care for them
- a lack of BCN, resources, appropriate training and knowledge
- the recent shift of treatment to the ambulatory setting has resulted in less time at the hospital and less face-to-face contact for assessment, support, information and referrals

- many palliative care community nursing services in Victoria are now mainly accepting patients who require end of life care (BCNA, 2013; Reed et. al, 2010, The Secondary Breast Cancer Taskforce, 2008; Warren, 2012).

In response to these supportive care gaps, it is recognized in the UK and in Australia that there is a need for the development of more specialised MBN's who have the relevant skills and knowledge to competently manage MBC (Bennet et. al, 2013; The Secondary Breast Cancer Taskforce, 2008; Watts et. al, 2011).

A Literature Review of the Establishment of the Role

UK:

In 2006 a secondary breast cancer taskforce was developed in the UK and recommended the development of dedicated clinical nurse specialist roles for patients diagnosed with secondary breast cancer (The Secondary Breast Cancer Taskforce, 2008). Such a role was successfully developed and implemented at hospitals such as the Western General Hospital in Edinburgh (Bennet et. al, 2013).

Australia:

BCNA recently requested funding for the provision of twenty-five rural and twenty-five metropolitan specialist advanced cancer nurses in their Federal Election 2013 Submission Report (BCNA, 2013). At the time of writing this report, the BCNA had not yet received a response from the Federal Government regarding this particular request.

New South Wales (NSW)/ Australian Capital Territory (ACT):

There are only 3 hospitals in Australia that have successfully developed the role to date. These hospitals include the POWH and WMH in Sydney and Canberra Hospital in the ACT (BCNA, 2013). Pilot projects for the development of the role were undertaken in the past at the two Sydney Hospitals (Watts et. al, 2011).

Western Australia

An application for funding for a secondary breast cancer breast care nurse in Western Australia was rejected in 2013 (BCNA, 2013).

Victoria:

The role does not currently exist in Victoria, despite an identified need. The initiative to develop a model of care for the role for the SMICS's region was instigated by a consumer representative with MBC, who held an advisory position on the SMICS Breast Tumour Group in 2012. A travel grant was offered by SMICS for two BCN's to travel to Sydney and compare the role of existing specialised MBN positions.

Table 1: A comparison of the specialised MBN Role at 3 Australian Hospitals:

Hospital:	PRINCE OF WALES HOSPITAL (POWH) - Sydney (Eastern Suburbs)	WESTMEAD HOSPITAL - Sydney (Western suburbs)	CANBERRA HOSPITAL
Initiation of the role:	<ul style="list-style-type: none"> 18 month pilot project (2008) NSW Cancer Institute grant of \$79,352.00 0.6 Effective full time (EFT) <u>Results of project:</u> successful implementation of role role highly valued by target patients and healthcare providers role met complex needs of MBC patients full time role recommended to serve population of area POW's Hospital or NSW Cancer Institute unable to sustain ongoing funding of the role upon completion of the project. 	<ul style="list-style-type: none"> NSW Cancer Institute initiative (2002). NSW Cancer Institute unable to sustain ongoing funding. 	<ul style="list-style-type: none"> Role initiated by the Director of the Breast Oncology Unit.
Role commenced:	<ul style="list-style-type: none"> 2010 	<ul style="list-style-type: none"> 2002 	<ul style="list-style-type: none"> 2009
Effective Full Time (EFT):	<ul style="list-style-type: none"> 1 2 nurses job share 	<ul style="list-style-type: none"> 2 1 of these 2 EFT roles included care co-ordination of patients with either MBC or MGC. 	<ul style="list-style-type: none"> 1
Current source of funding source:	<ul style="list-style-type: none"> Sporting Chance - \$100,000 per year for 3 years Private POWH 	<ul style="list-style-type: none"> Westmead Hospital 	<ul style="list-style-type: none"> McGrath Foundation (MF) - 2 days per week Canberra Health - 3 days per week
Hospitals serviced:	<ul style="list-style-type: none"> Public POWH Private POWH Royal Hospital for Women 	<ul style="list-style-type: none"> Westmead 	<ul style="list-style-type: none"> Canberra Hospital nil surgical services on campus oncology inpatient/outpatient units; Chemotherapy Day Unit (CDU); radiation oncology unit
Approximate numbers (#'s) of MBC patients per year:	<ul style="list-style-type: none"> 150 	<ul style="list-style-type: none"> 300 	<ul style="list-style-type: none"> 100
Key Performance Indicators (KPI's) collected:	<ul style="list-style-type: none"> <u>Bi-annual report to Sporting chance</u> #'s of new diagnoses of MBC cases. #'s of deaths #'s of contacts per day support group data 	<ul style="list-style-type: none"> <u>MBCN data</u> #'s of contacts per day. #'s of hospital admissions prevented #'s of patient's admitted straight to the ward (bypassing Accident and Emergency - A & E). <u>Admission data (Quality Assurance - QA activity)</u> Preventable admissions Recurrent admissions with same problem 	<ul style="list-style-type: none"> <u>Quarterly reports to MF</u> #'s of new referrals to MBC #'s of contacts per day. #'s of referrals to other services Referral sources
MDT description:	<ul style="list-style-type: none"> 1 medical oncology per week 1 breast oncology per week 	<ul style="list-style-type: none"> 1 palliative care per week 1 medical oncology per week 	<ul style="list-style-type: none"> 1 EBC MDT per fortnight Nil MBC MDT

Hospital:	PRINCE OF WALES HOSPITAL (POWH) - Sydney (Eastern Suburbs)	WESTMEAD HOSPITAL - Sydney (Western suburbs)	CANBERRA HOSPITAL
	<ul style="list-style-type: none"> 1 community palliative care (PC) per week Nil MBC MDT 	<ul style="list-style-type: none"> Nil MBC MDT 	
Job description received:	<ul style="list-style-type: none"> Yes 	<ul style="list-style-type: none"> Yes 	<ul style="list-style-type: none"> Yes
Grading of nurses:	<ul style="list-style-type: none"> Clinical Nurse Consultant (CNC) 2 	<ul style="list-style-type: none"> CNC2 	<ul style="list-style-type: none"> RN grade 3.1 year 3.
Experience/Qualifications of nurses:	<ul style="list-style-type: none"> Accredited BCN Broad oncology / PC experience 	<ul style="list-style-type: none"> Accredited BCN Broad oncology / PC experience 	<ul style="list-style-type: none"> Accredited BCN Grad. cert. oncology Masters in PC Masters in Nursing Oncology and Breast Care NP 4 year's experience as BCN 15 years experience in MO, surgical, community and PC nursing.
Direct line of report:	<ul style="list-style-type: none"> Sporting Chance 	<ul style="list-style-type: none"> Nursing Executive Manager 	<ul style="list-style-type: none"> Director Of Nursing (DON) and Assistant DON
Models of care followed:	<ul style="list-style-type: none"> Role modeled on previous EBC/BCN roles but tailored to suit women with MBC. Strong supportive care (SC) role Care co-ordination Multi-disciplinary Oncology based Separate from BCN role 	<ul style="list-style-type: none"> SC Care co-ordination Multi-disciplinary Strongly oncology based Separate from BCN role 	<ul style="list-style-type: none"> SC Care co-ordination Multi-disciplinary Separate from BCN role
Referral sources	<ul style="list-style-type: none"> BCN PC Drs/nurses Medical Oncologists 	<ul style="list-style-type: none"> BCN Medical Oncologists Palliative care Drs/nurses Surgeons 	<ul style="list-style-type: none"> Medical Oncologists Radiation Oncologists Patients self-refer
Support groups	<ul style="list-style-type: none"> Once per month 	<ul style="list-style-type: none"> Once per month 	<ul style="list-style-type: none"> Nil
Recommendations for developing the role	<ul style="list-style-type: none"> Take time to develop and evolve the role. Establish strong referral pathways. Market the role to the key players. Separate the role from BCN service. Routinely elicit women's needs for information and support. Take the time to develop a close rapport and trust with each individual patient to be able to meet their supportive care needs. Offer tailored information to individual women. Be a patient advocate. Develop close rapport with oncology 	<ul style="list-style-type: none"> Define the role Set boundaries Orientate other nurses into the role (do not become a "one-person" dependent role). Include 5 domains of CNC into the role (leadership, education, research, clinical, QA) Market the role. Critique the role. Separate the role from BCN service. Integrate with community PC service. Continually develop the role. Collect baseline KPI's so can use as a comparison after role has commenced operating. 	<ul style="list-style-type: none"> Develop clear definitions of the role Develop appropriate referral pathways. Ensure gain access to all medical record systems. Do not job share the role as one person in the role is better able to build up a rapport and trust with the patients.

Hospital:	PRINCE OF WALES HOSPITAL (POWH) - Sydney (Eastern Suburbs)	WESTMEAD HOSPITAL - Sydney (Western suburbs)	CANBERRA HOSPITAL
	and palliative care teams. <ul style="list-style-type: none"> • Job share the role so leave can be covered. • Provide continuity of care. • Provide a full time service to increase women's access to service. 		

Benefits of the role:

Employing a specialised MBN provides many of the benefits listed in Table 2 (Bennet et. al, 2013; MBCN practicum, 2013; Oliver, 2010; The Specialist Breast Nurse Project Team, 2000;. Watts et. al, 2011) which have been summarised from the literature, information gained from the nurses who work in the existing role, and from lectures provided at the MBCN practicum (2013) at Westmead:

Table 2: Benefits of a Specialist MBN:

Benefits to the patient and their family/carers	Benefits to the nurse	Benefits to the Healthcare Organisation
<ul style="list-style-type: none"> • one point of contact • continuity of care • streamlined care • multidisciplinary care and the patient's advanced care plan are facilitated; • relationship development over time; • supportive care and information needs are met • increased satisfaction with care • less time in hospital; avoid admission through the emergency department • better communication amongst health care services • increased awareness of, and recruitment to available clinical trials. 	<ul style="list-style-type: none"> • job satisfaction • service improvement • autonomy • better use of time • improved use of services • ongoing learning experience. 	<ul style="list-style-type: none"> • increased patient satisfaction and staff morale • provision of an improved cancer service • increased efficiency • cost effectiveness – measured using KPI's • decreased length of stay in hospital • decreased admissions to hospitals with complications • decreased admissions to the Emergency Department (direct to ward admission is facilitated) • less demand on breast cancer clinics and medical services.

Using KPI'S to measure the effectiveness of the role:

When developing a new Specialist MBN role, it is important to measure the effectiveness of this role. The McGrath Foundation recommended that baseline quantitative and qualitative data are collected before initiating any new BCN role (Paynter et. al, 2013). KPI's set by the health service will enable measurement and reporting of the impact that the MBN role has upon the effectiveness of meeting the supportive care needs of MBC patients.

On a monthly basis, the specialist MBN's from each of the three hospitals (in NSW and ACT) collected and analysed data to measure against specific KPI's, providing evidence about the effectiveness of their roles, both clinically and operationally. The data collected at Westmead Hospital for the year 2012-2013 provides a benchmark for collecting and comparing future KPI's when establishing the MBN role. For example, in the year 2012 to 2013 the average length of stay was 9.75 days (range 2 to 36 days) and interventions undertaken by the Specialist MBN at Westmead resulted in:

- avoidance of forty inpatient admissions
- twenty three direct admissions to the oncology ward
- less admissions through the Emergency Department

Current baseline data has been provided (Table 3) for each SMICS member health service, to use for future comparison when the role has been initiated. These statistics reflect the length of stay for each hospital for the year 2012 to 2013.

NB: One day admissions for treatment at the Chemotherapy Day Unit (CDU) have been excluded to reflect a more accurate representation of hospital inpatient admissions.

Length of stay (LOS) for MBC patients in the SMICS member hospitals for 2012-2013.

Table 3: Average LOS for MBC patients at the SMICS Member Hospitals.

Length of stay (LOS)	Alfred Health	Monash Health	Peninsula Health	Cabrini Health
1 day	58	129	66	121
2-7 days	63	180	81	230
8-14 days	25	73	37	67
15-28 days	11	26	14	21
29-42 days	-	4	3	2
>6 weeks	-	-	2	2
Total separations	157	412	203	443
Number of patients	87	222	109	276
Average LOS for the year	5.32 days	5.49 days	6.72 days	5.2 days

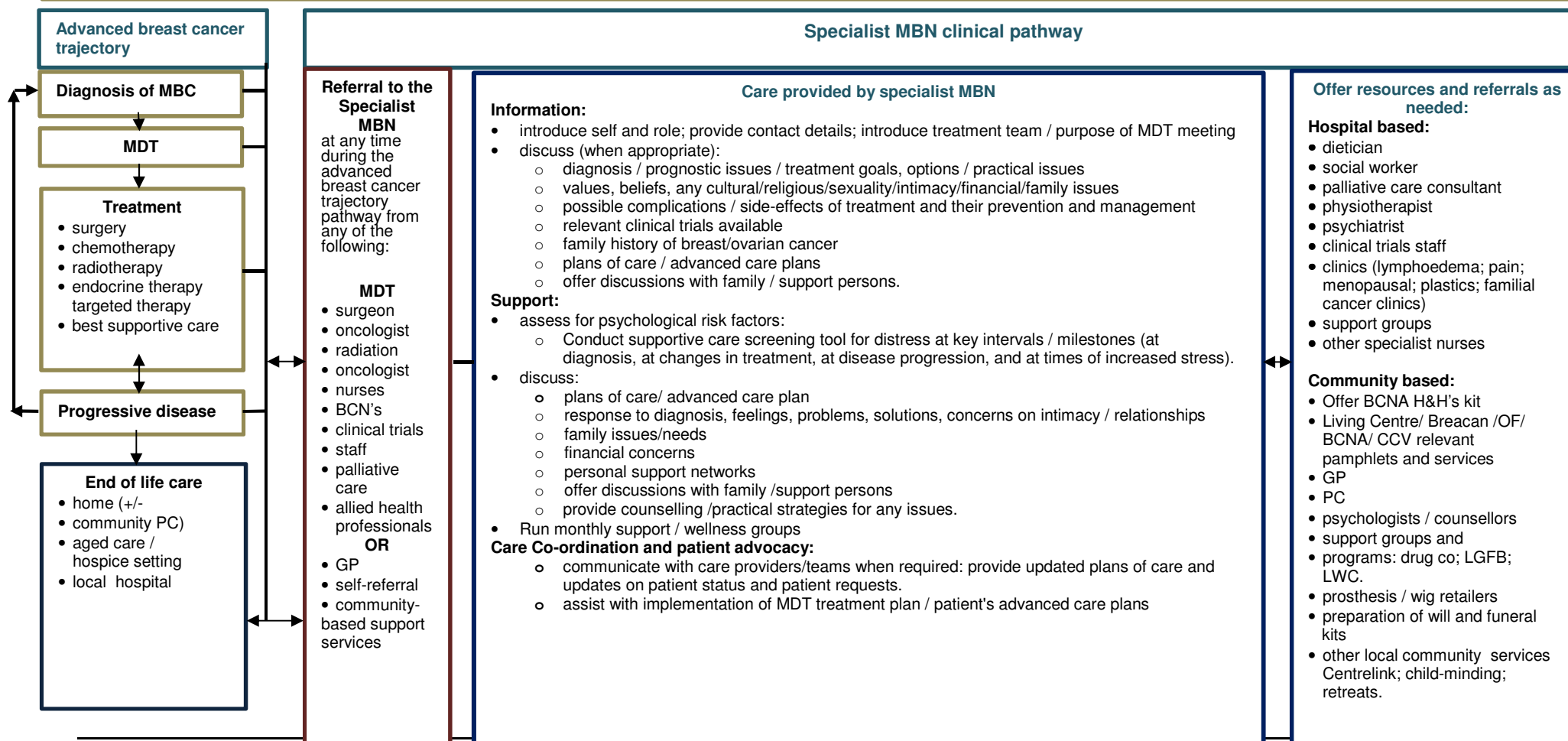
Table 4: Recommended Specialised MBN Clinical Pathway for the SMICS Group of Hospitals

(An adaption of both the NBCC Specialist Breast Nurse clinical pathway and NEMICS Advanced Breast Cancer Best Practice Pathway)

Key principles:

This role is independent but works to enhance the existing Breast Cancer Services and Breast Care Nurse models.

This role is specifically designed to utilise the expert clinical knowledge and skills of the specialised MBN to provide the best care for MBC patients and to fill the supportive care gaps that currently exist.



A joint initiative of Alfred Health, Cabrini Health, Peninsula Health and Monash Health
Connecting cancer care, driving best practice and improving patient outcomes

Recommended model of care for the role:

Adaptions of both the North Eastern Melbourne Integrated Cancer Services (NEMICS) Advanced Breast Cancer disease trajectory (Appendix E) and the Specialist Breast Nurse clinical pathway (Appendix F) have been used to develop a specialist MBN pathway (Table 3) (NEMICS Breast Tumour Group, 2011; The Specialist Breast Nurse Project Team, 2000). The Advanced Breast Cancer Pathway has a varied trajectory that starts when the patient is first diagnosed with MBC and then follows the patient through their multidisciplinary care planning and treatment phases, repeating this cycle each time there is disease progression until eventual end of life care is required (NEMICS Breast Tumour Group, 2011). Referrals to the Specialist MBN can be made at any time throughout the advanced breast cancer disease trajectory. The Specialist MBN clinical pathway can be used as a framework to guide the specialist MBN to identify and address the individual supportive care and information needs of those with MBC. Once supportive care needs are identified, relevant referrals to the hospital and local community support services and/or resources can be made as they are required. The specialist MBN clinical pathway can incorporate a combination of the following models of care as described below and represented in diagram 1:

- supportive care
- patient centred (and patient advocacy)
- care coordination
- multidisciplinary
- separate to existing BCN model
- community based
- wellness

Supportive care model of care:

The main function of the specialist MBN model of care is to provide supportive care to those with MBC whenever it is required throughout their advanced disease trajectory. According to Bennet et. al. (2013, p. 27), “meeting patients emotional and psychological care needs is as important as meeting their clinical needs”. As each individual’s supportive care needs are likely to change at varying points throughout their advanced disease trajectory, it is important for the specialist MBN to use the supportive care screening tool displayed in Appendix F to assess for levels of distress in any of the five inter-related supportive care domains listed in Appendix D. Screening should be undertaken at the following key intervals/milestones:

- diagnosis
- change in treatment
- disease progression
- times of increased stress.

The specialist MBN can then tailor a care plan for each individual to help them cope better throughout these stressors and provide appropriate interventions such as:

- counselling
- reassurance
- information
- practical advice
- patient advocacy
- referrals to the hospital and/or community resources.

Having well developed communication/counselling skills and being able to spend adequate time with patients at each contact is especially important for the nurse to establish trust and rapport (Breast Cancer Care, 2012). This will enable better opportunities to assess and address their changing levels of distress whilst providing best supportive care and information when it is required.

Patient centred (and patient advocacy) model of care:

When developing a new specialist MBN role, it is important to adapt and tailor the model of care to address the needs of the patients with MBC in their local settings (Bennet et. al, 2013; Paynter, et. al, 2013). It is recommended that a questionnaire be designed (and approved by the health service's Ethics Committee) to gain the consumer view on what their specific needs are and how they perceive the role could meet these needs. A purpose designed patient satisfaction questionnaire should also be completed by the consumers on a yearly basis to evaluate whether the MBN role meets their supportive care needs (Bennet et. al, 2013, Watts et. al, 2011).

Actively involving the patient and their families/carers in decision making and care planning throughout the advanced disease trajectory is essential. Allowing adequate time to explore patient values and beliefs, and informing them of health information and options of treatment, allows patients (and their families/carers) to develop plans of care that are acceptable to them (Department of Health, 2007). The nurse can act as an advocate by communicating the patient's care plan to the rest of the treatment team and facilitating the implementation of the plan.

Care Co-ordination model of care:

The other key function of the role is to provide care co-ordination. Care of patients with MBC can be fragmented and uncoordinated as it is often undertaken by many different health professionals across multiple health services within the hospital and the community sectors (Department of Health, 2006). The Specialist MBN can be one point of contact for patients and their health professionals, providing updates and implementing plans of care to facilitate a more streamlined journey for the patient.

When first developing the role, the nurse should spend time marketing the role and fostering partnerships and alliances with all the key service providers to assist with information sharing and continual improvement of clinical management and care processes (Department of Health, 2007; Watts et. al, 2011).

Multidisciplinary model of care:

Incorporating a multidisciplinary approach is another main component of the specialist MBN model of care, with the MBN playing a key role within the multidisciplinary team (MDT). It has been recommended by both the NEMICS Breast Tumour Group (2011) and by The Secondary Breast Cancer Taskforce (2008) in the UK recommend that plans of care and treatment for all MBC patients should be collaboratively discussed by a MDT. This team should include all members of the patient's clinical team, comprising of a number of specialists such as that listed in Appendix G (NEMICS Breast Tumour Group, 2011). Team discussions should take into account all aspects of the patient's physical and psychosocial needs, so that each patient is offered personalized appropriate psychosocial supportive and symptom-related interventions as a routine part of their care (Cardose et. al, 2010; Department of Health, 2013; NEMICS Breast Tumour Group, 2011; The Secondary Breast Cancer Taskforce, 2008). It is ideal that MDT meetings for MBC patients be run separately to the meetings held for EBC patients, as planning the complex supportive care for MBC patients often requires more time and discussion. The challenge

for implementing a separate meeting may be organising a regular time that is convenient for all the appropriate specialists to meet.

The specialist MBN can communicate information about the patient at the MDT meeting, act as an advocate and assist with implementing, co-ordinating and communicating plans of care to the people involved in the care of the patient (The Secondary Breast Cancer Taskforce, 2008).

The nurse can also act as a resource for other health professionals and provide regular education and training opportunities to medical, nursing and allied health staff to ensure that best supportive care for women is coordinated, and provided in a timely and appropriate manner by all members of the MDT.

Separate model of care to existing BCN service:

It is recommended that the role be developed as a separate but parallel role to the existing BCN role. If combined with an existing BCN service, there is a risk of the roles merging and the focus of care predominantly returning to supporting those newly diagnosed with breast cancer and those with EBC. Additionally:

- the supportive care needs of the two groups of patients can differ with higher complexity for those with MBC..
- a different skill set and knowledge is required by the specialist MBN
- different KPI's need to be collected by the specialist MBN to monitor whether the role is effectively providing better outcomes for the patients and the healthcare service.

Community based model of care:

There is scope to expand the specialist MBN model of care to a community-based role. The McGrath Foundation has encouraged their BCN's to use this model of care, so that the role is not restricted to a hospital campus location (Paynter et. al, 2013).

Support groups can be developed in local community settings inviting all patients with MBC in the region to attend, regardless of the sites at which they are receiving or have been treated. Non-hospital based settings may provide a more comfortable environment for support groups, potentially reducing anxiety levels or anticipatory symptoms that may occur when attending their place of treatment.

The nurse can develop close links with and work collaboratively with other dedicated health professionals in the community such as treating specialists, GP's, allied health professionals and palliative care services. There are many other community services and programs into which the specialist MBN can link patients, such as the Breast Cancer Foundations (BCNA, Cancer Council Victoria - CCV, and Breacan); the Living Centre, Living With Cancer (LWC), Look Good Feel Better (LGFB) programs; local private or public oncology rehabilitation programs; Centrelink; retreats (McDonald House, Otis Foundation); child minding services (Abracadabra).

The nurse can also play a key role in promoting breast cancer awareness in the community by becoming involved in activities such as BCNA's Field of Women days and Cancer Council Victoria's Biggest Morning Tea, Daffodil Day and Pink Ribbon Day.

Wellness model of care:

Conducting local support groups in the community provides a forum for the specialist MBN to teach patients strategies for promoting a state of wellness. Guest speakers may be invited by the specialist MBN to teach the group skills such as meditation/relaxation techniques, strategies for coping with stress, music therapy and recommendations for healthier lifestyle changes such as healthy diet, exercise and alcohol reduction recommendations.

Nurse Practitioner (NP) model of care:

There is scope to expand the role from a Clinical Nurse Consultant (CNC) to a NP for MBC patients in the future. In doing so, advanced assessment and symptom management as well as prescription of routine tests and certain medications may be additional skills that can be added to the nurse's scope of practice (EdCan, 2009). Having a nurse with skills such as this could further reduce the pressure on the breast oncology clinics.

Diagram 1: Specialised MBN Model



Recommended credentials for a specialist MBN role

To implement the above model of care, the nurse requires diverse and advanced knowledge, skills and experience in oncology, palliative care and breast cancer care; and should strive to make a difference to the quality of care received by women with MBC (Paynter et. al, 2013; Secondary Breast Cancer Taskforce, 2008). The Secondary Breast Cancer Taskforce (2008, p. 22) concur with this recommendation by stating, "the nurse would need to be at a high grade or with sufficient experience to ensure they are able to cope with the complex management of MBC patients." On the basis of the recommended skills and responsibilities required, the position should be allocated a senior grading (Victorian Grade 5 Clinical Nurse Consultant level) and report operationally and professionally to the Director of Nursing, and clinically to the Heads of Breast Oncology and Surgery (diagram 2). The nurse will fulfil the 2009 EdCan National Cancer Nursing Education Project's competency standards for Specialist Cancer Nurses (SCN) summarized in Appendix I, in addition to having (or be working towards) the following specific competencies to function optimally in the role (Specialist Breast Nurses, 2000; Secondary Breast Cancer Taskforce, 2008).

Qualifications:

- an Australian Health Practitioner Regulation Authority (AHPRA) Registered Nurse
- breast care nurse accreditation (BreastCare Nursing Foundations for Practice from LaTrobe University)
- post graduate certificate in Breastcare and/or Oncology/Palliative Care Nursing (Diploma or Masters qualification desirable)
- validated training in communication and counselling skills
- attendance at the two day Metastatic Breast Care Nurse practicum run by the BCI at Westmead or a similar accredited program.

Knowledge and experience:

- five years post-registration experience in oncology, palliative care or breast cancer nursing
- comprehensive oncology/palliative knowledge
- demonstrated specialist knowledge in the clinical area of patients with advanced breast cancer across the disease trajectory
- demonstrated knowledge of the treatments and clinical trials available for patients with MBC
- demonstrated understanding of the implications of living with a long-term illness
- demonstrated knowledge of the assessment and treatment of oncology emergencies
- ongoing commitment to attend any annual breast care nurses and oncology conferences in order to maintain skills, knowledge and contacts
- knowledge of local community and national support services for MBC patients
- experience in the education of staff and patients
- demonstrated commitment to the provision of quality health services
- experience with provision of services in an ambulatory setting
- commitment to nursing research.

Skills:

- well-developed clinical, interpersonal and counselling skills
- advanced assessment skills in the 5 interrelated domains of supportive care (Appendix D)
- ability to complete and implement the supportive care tool in Appendix G at the relevant times
- demonstrated ability to coordinate complex care for patients and their families
- demonstrated ability to implement changes to practice including relevant research findings
- proven ability to work effectively as part of a multidisciplinary team
- ability to assist with decision-making
- ability to follow, implement, adapt and tailor the above model of care to practice
- effective time management skills / excellent organisational skills
- ability to liaise with, and educate hospital and community treatment team members
- ability to discuss end of life issues and palliative care
- ability to offer relevant information, resources and referrals to the patient
- ability to be the patient's advocate
- ability to identify the need for personal support
- demonstrated computer skills for collecting and entering data, analysing data and preparing reports and presentations.

Recommended structure:

Nurse patient ratio:

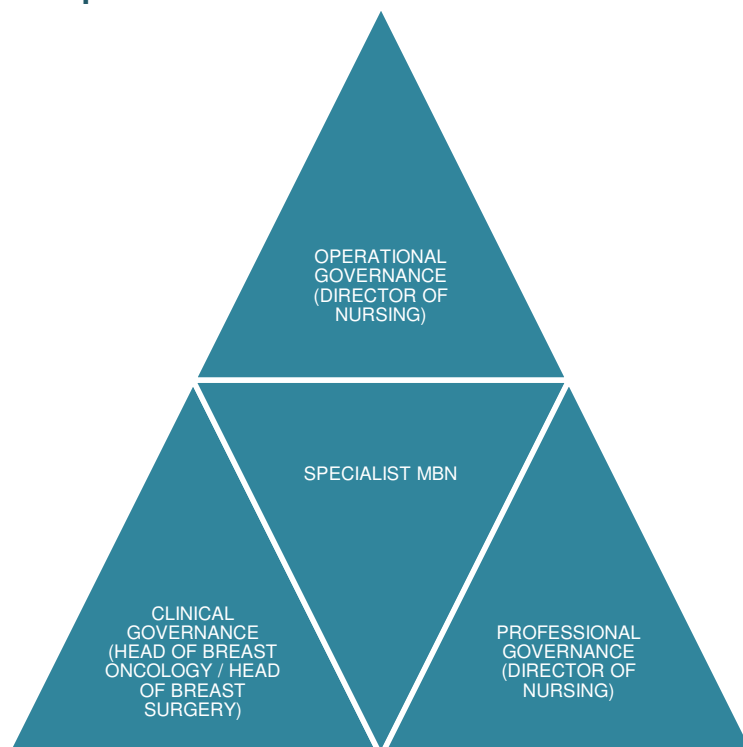
As guided by the established MBN's from the three hospitals examined, the nurse per patient ratio should be calculated at 1 EFT per 150 patients.

Job sharing capacity:

If applications for EFT funding of the role are successful, it is ideal that the one EFT role is job shared between two part time qualified nurses due to the following reasons (Secondary Breast Cancer Taskforce, 2008):

- the potentially stressful nature of the role on a full time person
- to cover leave
- to ensure the role does not become dependent on one person to successfully operate.

Diagram 2: Specialist MBN Governance Flowchart



Recommendations for establishing the role based on the above model of care:

- Establish the metastatic breast care role within SMICS member health services to fill the supportive care gaps that exist for MBC patients, and adapt it to local the local environment.
- Set the ideal nurse per patient ratio at 1 EFT per 150 patients.
- Institute a set of standardised KPI's to evaluate the effectiveness of the role from a consumer, health service and staff perspective.
- Develop the role to provide mentorship for other health professionals and to disseminate expert knowledge across the hospital and regional areas.
- An independent role (separate but parallel to the early breast cancer service) is suggested to focus solely on meeting the needs of MBC patients.
- Initial integration of this role into the breast MDT is essential until a separate MDT for MBC patients is established.
- If funding for the role is not available in the SMICS member health service then funding applications should be made to charitable organisations such as the McGrath Foundation, Sporting Chance, or private benefactors.
- Develop close links with and work collaboratively with other dedicated health professionals in the hospital and community to provide better outcomes for MBC patients.
- A senior grading (Victorian Grade 5 Clinical Nurse Consultant) is recommended due to the advanced skills and responsibilities required to function optimally in the role. Where practicable a job share position is recommended (if full time funding granted).

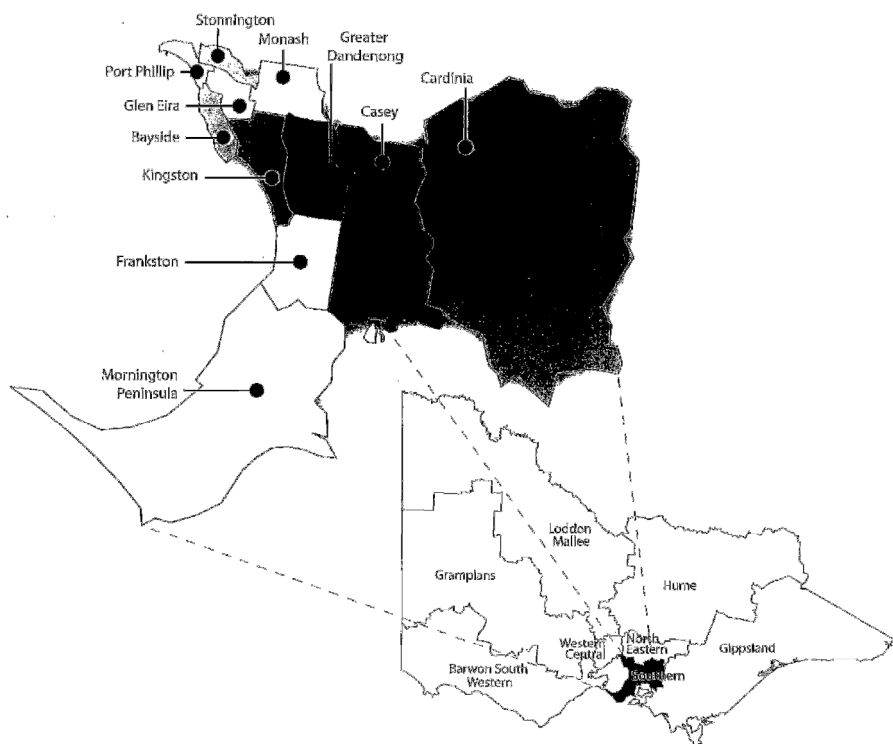
Appendix A

Factors to consider when deciding treatment options for MBC:

- previous therapies and response to them
- disease-free interval
- endocrine responsiveness
- HER2 status
- tumour burden (defined as number and site of metastases)
- menopausal status
- biological age
- co-morbidities (including organ dysfunction)
- performance status
- need for rapid disease/symptom control
- socio-economic and psychological factors
- patient's preference (regarding treatment options and methods of treatment administration – oral or intravenous)
- available therapies in the patient's country

Appendix B

Map of the region served by SMICS:



Appendix C

Qualitative questionnaire sent to specialist MBN at the Canberra Hospital:

- Did you conduct a pilot project to develop the role and prove that it is required and cost effective?
- Is your role a full time position?
- Is your role job shared?
- How many patients would you have contact with for the year?
- What is the classification of your role? CNC2?
- Who do you report to?
- What are the recommended qualifications/experience for the role?
- Where do you receive funding for the role? Is funding outsourced or hospital funded?
- Do you have a model of care?
- Do you collect stats (KPI's) and if so, what?
- Do you have a dedicated MDT meeting to discuss/plan treatments and care of MBC patients? How often is it run?
- Who do you receive referrals from?
- Do you run support groups? How often are they scheduled?
- Can you provide a brief description of your role/routine.
- Do you have any recommendations/advice on setting up the role?
- Do you operate separately from the EBC BCN role?
- Do you have a position description? Is it possible to obtain a copy?

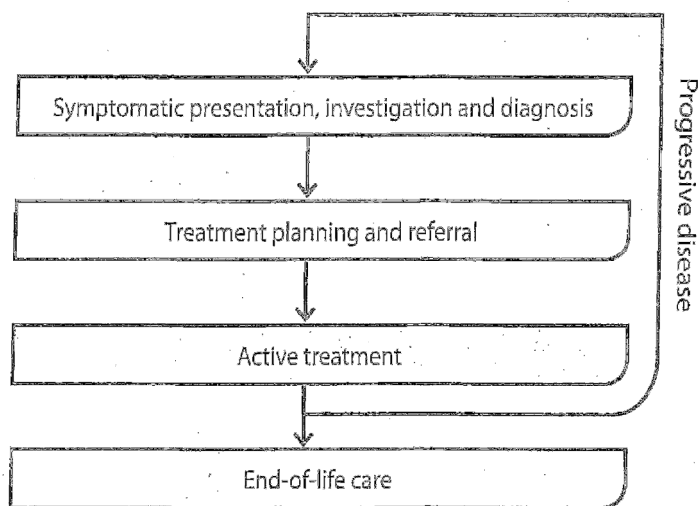
Appendix D

Five inter-related domains of supportive care:

- 1) Physical domain:
 - Includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation.
- 2) Social domain:
 - Includes a range of social and practical issues that will impact on the individual and family such as the need for emotional support, maintaining social networks, and financial concerns.
- 3) Psychological domain:
 - Includes a range of issues related to the person's mental health, wellbeing and personal relationships.
- 4) Spiritual domain:
 - Focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns.
- 5) Information domain:
 - Transects the above domains with people needing to access information about their disease and treatment, support services and the health system overall. (Department of Health, 2013, p.9).

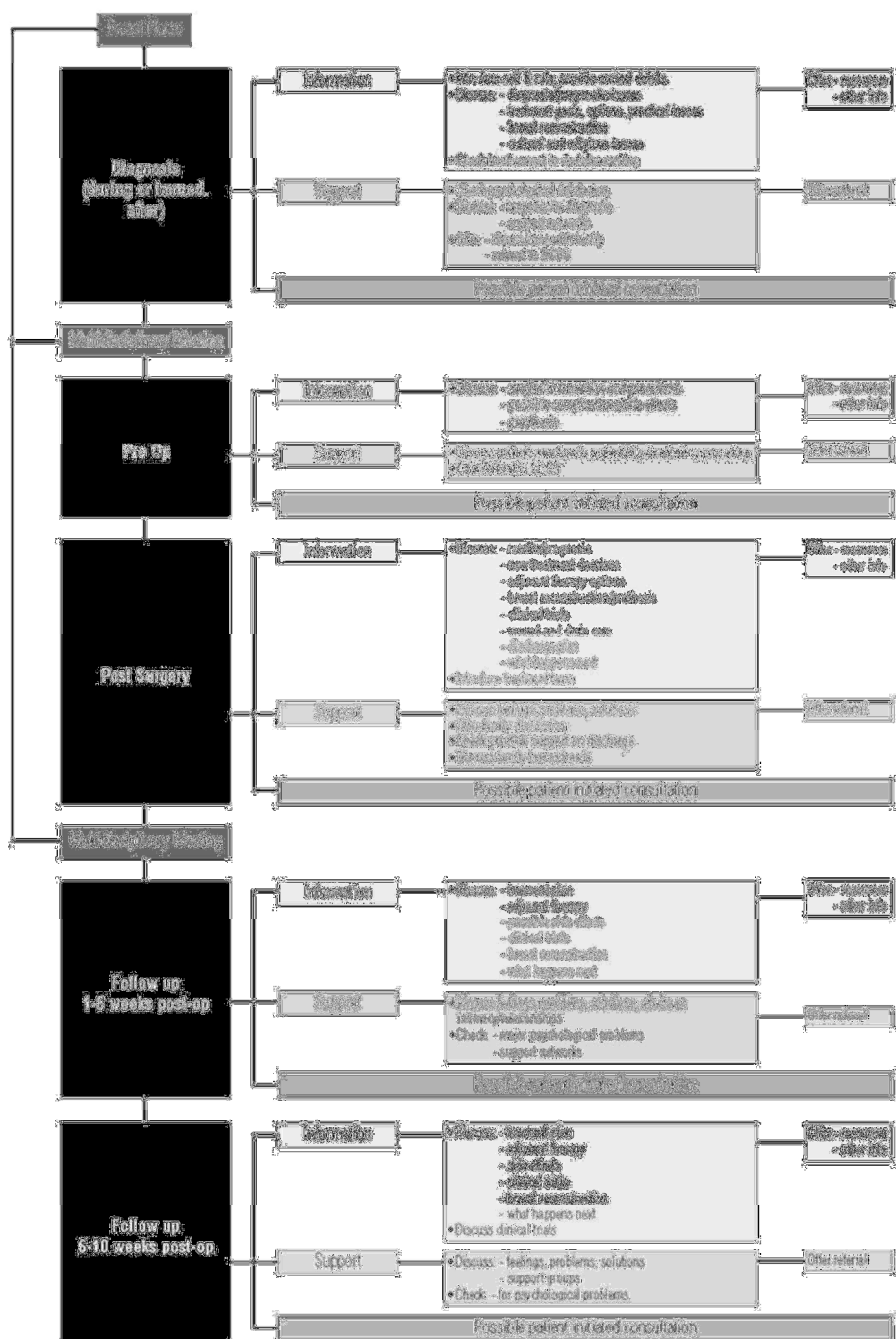
Appendix E

NEMICS Advanced disease pathway (NEMICS Breast Tumour Group, 2011, p. 5)

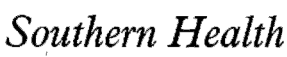













Appendix F:

Specialist breast nurse clinical pathway (The Specialist Breast Nurse Project Team, 2000, P.10).



Supportive care screening tool: page 2:

ONCOLOGY SUPPORTIVE CARE			Unit Record Number: _____ Surname: _____ Given Name: _____ D.O.B.: _____ Age: _____ Sex: _____ <i>Affix Patient Identification Label</i>							
	<input type="checkbox"/> Dandenong Hospital <input type="checkbox"/> Monash Medical Centre - Clayton <input type="checkbox"/> Kingston Centre <input type="checkbox"/> Monash Medical Centre - Moorabbin <input type="checkbox"/> Jessie McPherson <input type="checkbox"/> Community Health Services <input type="checkbox"/> Casey Hospital <input type="checkbox"/> Cranbourne Integrated Care Centre									
	5. To help the dietitian assess your nutritional needs, would you please CIRCLE your answer to the following questions.		Please tell us what your three most important concerns are: 1 _____ 2 _____ 3 _____							
	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left;">QUESTION</th> <th style="text-align: left;">SCORE</th> </tr> </thead> <tbody> <tr> <td style="padding: 5px;"> Have you lost weight in the last 3 months without trying? No⁰ Unsure² Yes (please circle the amount) 1-5kg¹ 6-10kg² 11-15kg³ + 16kg⁴ </td> <td style="width: 20%;"></td> </tr> <tr> <td style="padding: 5px;"> Have you been eating poorly because of a decreased appetite? No⁰ Yes¹ </td> <td></td> </tr> <tr> <td style="padding: 5px;"> TOTAL SCORE (office use only): </td> <td></td> </tr> </tbody> </table>	QUESTION	SCORE	Have you lost weight in the last 3 months without trying? No ⁰ Unsure ² Yes (please circle the amount) 1-5kg ¹ 6-10kg ² 11-15kg ³ + 16kg ⁴		Have you been eating poorly because of a decreased appetite? No ⁰ Yes ¹		TOTAL SCORE (office use only):		6. Please CIRCLE the number (0-10) that best describes how much you need help for these concerns. <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;">Desperately</div>  <div style="margin-left: 10px;">10</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">9</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">8</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">7</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">6</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">5</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">4</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">3</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">2</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"></div>  <div style="margin-left: 10px;">1</div> </div> <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;">Can manage by myself</div>  <div style="margin-left: 10px;">0</div> </div>
QUESTION	SCORE									
Have you lost weight in the last 3 months without trying? No ⁰ Unsure ² Yes (please circle the amount) 1-5kg ¹ 6-10kg ² 11-15kg ³ + 16kg ⁴										
Have you been eating poorly because of a decreased appetite? No ⁰ Yes ¹										
TOTAL SCORE (office use only):										
	FOR OFFICE USE ONLY Staff member: _____ Diagnosis: _____ Date of diagnosis: _____ Completed by: PATIENT / NURSE / BOTH Next appointment: _____ Interpreter Required: Y / N Information Provided: <input type="checkbox"/> Verbal information <input type="checkbox"/> Written Information <input type="checkbox"/> Nutrition Pack Other: _____ Referral Required: Patient: CONSENTED / DECLINED Refer to: _____ _____ _____ Comments: _____ _____ _____ _____									
MRD31										

Appendix H

Ideal composition of an MBC MDT:

(NEMICS Breast Tumour Group, 2011, p.11)

- Medical Oncologist
- Breast Cancer Surgeon
- Radiation Oncologist
- Palliative care specialists
- Pathologists
- Radiologists
- Specialist MBN
- Other specialist nurses – breast care, oncology, and palliative care (community and hospital based)
- Social worker
- Psychologist
- Clinical trials co-ordinators
- Other relevant specialist nurses
- GPs
- Dietician

Appendix I

Summarised version of the EdCan National Cancer Nursing Education Project Competency Standards for Specialist Cancer Nurses (SCN) (2009, pp. 29-43):

Domain 1: Professional practice

This domain comprises competencies that reflect the SCN's ability to develop professionally, participate effectively in clinical governance and influence cancer-control efforts at the systems level

- 1.1 Engages in and contributes to informed critique and exerts influence at the professional and systems level of health and cancer care.
- 1.2 Uses appropriate mechanisms for monitoring own performance and competence as a SCN.
- 1.3 Practises in accordance with legislative, professional and ethical standards for nursing and cancer care.

Domain 2: Critical thinking and analysis

This domain comprises competencies that reflect the SCN's ability to practise within an evidence-based framework, participate in ongoing professional development, ensure optimal standards of cancer care and lead the ongoing development of cancer nursing.

- 2.1 Contributes to quality improvement activities aimed at improving outcomes for people affected by cancer.
- 2.2 Practises within an evidence-based framework and contributes to the development of evidence for practice.
- 2.3 Embraces continuing professional development to ensure practices that incorporate best available evidence and emerging developments in specialist cancer nursing and cancer care.
- 2.4 Provides advice and mentorship to nursing colleagues and others involved in cancer care to promote optimal standards.

Domain 3: Provision and coordination of care.

Provision and coordination of care relates to the coordination, organisation and provision of nursing care. It includes the assessment, planning and implementation and evaluation of care for people affected by cancer, and consists of the following four practice dimensions:

- 3.1 Disease and treatment related care
 - 3.1.1 Participates in activities that contribute to reducing the risk of developing cancer and that promote early detection of cancer.
 - 3.1.2 Identifies potential and actual adverse effects of having cancer and receiving cancer therapies.
 - 3.1.3 Participates in the safe and effective management of cancer and the delivery of cancer treatments.
- 3.2 Supportive care
 - 3.2.1 Identifies, validates and prioritises potential and actual health needs across all domains of health of the person affected by cancer throughout the cancer continuum.
 - 3.2.2 Effectively provides and ensures access to a range of supportive care services and interventions to meet the multiple health needs of the person affected by cancer.
- 3.3 Coordinated care
 - 3.3.1 Coordinates implementation of care across different phases of the cancer journey and across health-care settings to facilitate continuity of care and effective use of health-care resources relevant to the needs of the person affected by cancer.
- 3.4 Information provision and education.
 - 3.4.1 Provides comprehensive and specialised information in a coordinated manner to assist people affected by cancer to achieve optimal health outcomes, reduce distress and make informed decisions.
 - 3.4.2 Provides education to the person affected by cancer to enable them to be active participants in their care and engage in self-management of health-related needs where appropriate to achieve optimal health outcomes across the cancer continuum.

Domain 4: Collaborative and therapeutic practice

This domain comprises competencies reflecting the SCN's ability to develop effective collaborative relationships with people affected by cancer that will assist to maximise health outcomes, and to establish a collaborative approach to working effectively as part of a MDT across the care continuum. These competencies include recognition of the critical interdependence between the roles of the SCN, other health professionals and organisations and the establishment of partnerships with people affected by cancer to maximise outcomes.

- 4.1 Develops therapeutic relationships with people affected by cancer to anticipate and meet their multiple care needs across the cancer continuum.
- 4.2 Initiates and ensures ongoing improvements in collaborative relationships with the person affected by cancer and other members of the health-care team to optimise health outcomes.

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