LONDON CANCER ALLIANCE
West and South

Metastatic Breast Model Service Specification

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Contents

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1 Introduction

Metastatic breast cancer (MBC), also commonly referred to as secondary or advanced breast cancer (stage IV), 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 sites for metastases are the bones, liver, lungs and brain.

Metastatic breast cancer is incurable, but patients with subtypes of MBC can have their cancer managed effectively as a chronic condition for several years. The treatment goal is palliation, with the aim of maintaining and improving quality of life.

2 Epidemiology

Breast cancer is the second most common cancer in the world and, by far, the most frequent cancer among women, with an estimated 1.67 million new cancer cases diagnosed in 2012.[1] Worldwide, breast cancer accounts for 14% of the total cancer-related deaths and 60% of these deaths are found to occur in economically developing countries[2]. The majority of breast cancer-related deaths are a result of complications from recurrent or metastatic disease.[3] Access to screening programs has resulted in a higher proportion of women being diagnosed with earlier stages of disease which are imminently curable.

However, approximately 6% to 10% of breast cancers are metastatic at presentation and systemic recurrence occurs in about 30% of early breast cancer cases[4]. It is estimated that 35 000 patients in UK live with metastatic breast cancer. Metastatic breast cancer is a heterogenous disease. The 5 year overall survival is estimated to be 20% from the diagnosis of secondary breast cancer while median overall survival (OS) approaches two years, with a range from a few months to many years.[5]

The most common sites of metastasis include bone, liver and lung. Bone metastases are more common among the hormone receptor positive subtype (68%). In a retrospective analysis median survival after bone metastases diagnosis was 2.3 years in women with bone-only metastases, compared with <1 year in women with visceral and bone metastases.[6] Triple Negative Breast Cancer (TNBC) has a predilection to lung (40%) whereas HER-2 positive disease and TNBC are associated with a higher frequency of brain disease (23% and 24% respectively).

The survival of patients with newly diagnosed stage IV breast cancer has modestly improved over time with the advent of more effective systemic therapies. There are ethnic and socio-economic variations in survival with black women having an increased risk of death compared with white women.[7]

2.1 National/local context and evidence base

The management of MBC is largely based around treatment guidelines and pathway processes although the delivery of services may vary region to region. Core criteria are recognised to improve the outcomes of patients, particularly where there is greater access to multiple disciplines.[8] National guidelines advise a collaborative multidisciplinary approach in the initial diagnosis of MBC. In most breast cancer services this opportunity is best presented in the breast MDT although larger centres may have a specialist MBC MDT.[9, 10]

Subsequent to diagnosis and initial management discussion, patients with MBC should be identified as having specific needs in their treatment pathway, which allows individualisation of their treatment according to the tumour phenotype and prognosis, co-morbidities, social circumstances and information needs. This is best delivered through a core group of multidisciplinary professionals with experience and training in this area. Communication between secondary and primary care as well as between specialists' services is important. As well as a treating oncologist familiar with international practice guidelines in MBC[8, 11] access to a key worker/clinical nurse specialist with experience in MBC is needed to underpin a high quality service. The role of a CNS with MBC skills include the ability to:

- Provide continuity of care and support, offer referral to psychological services if required and liaise with other healthcare professionals, including the GP and specialist palliative care services[12]
- Assess the patient's individual preference for the level and type of information[13]
- Reassess this as circumstances change (at diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching) [13]
- Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support.[13]

3 Service Outcomes and Performance Indicators

3.1 Service outcomes

The metastatic breast service outcomes are centred on implementation and compliance against the six LCA Metastatic Breast Standards. These are:

1. Dedicated metastatic clinic(s), including lists run by specialist metastatic nurses.
2. A specialist breast metastatic nurse with responsibility for patients with metastatic breast cancer either as all or part of their role.
3. Dedicated MDT slots to discuss patients with metastatic breast cancer, either as a metastatic MDT or as a dedicated part of a main MDT meeting.
4. A database of patients with metastatic breast cancer being managed at a given site.
5. Good communication between the metastatic breast team, acute oncology services and community palliative care services. An agreed pathway to a unit that can perform semi-elective ascitic and pleural drains, bloods transfusions and other similar procedures can help avoid emergency admissions, minimise delays in intervention and improve patient experience.
6. Access to metastatic breast cancer trials.

Given patient caseloads vary from one Trust to another there is recognition that the delivery model for these six standards will need to reflect this. The LCA has therefore developed three Metastatic Breast Service models, illustrated in Appendix 1.

Those Trusts with moderate to greater patient caseloads are recommended to implement model 1, whilst those Trusts with lower patient caseloads may benefit from implementing either model 2 or model 3. Implementation of any one of these three models will meet compliance against the six LCA Metastatic Breast Standards.

Patient experience is a key service outcome and Trusts should consider all aspects of the service and pathways to maximise the experience patients receive. Patient services should include, but are not limited to; the use of Patient Reported Outcome Measures (PROMs), patients having a care plan supported with their information needs, and having their emotional and well-being regularly assessed. There should be access to expert financial and employment advice and access to support and guidance including a local, expert facilitator led support group.

3.2 Performance indicators

The performance indicators in table 1 are aligned to the six LCA Metastatic Breast Standards and the LCA Metastatic Breast Service models. Trusts are recommended to ensure robust pathways are in place to meet these performance standards and ensure the delivery of high standard metastatic breast services.

Table 1: Performance indicator

Performance Indicator	Details	Monitoring
Implementation of LCA Metastatic Breast Service model. (model 1, 2 or 3)	Implementation of LCA Metastatic Breast Service model; Model 1, 2 or 3	Compliance metric
Discussion of newly diagnosed MBC at MDT	MDT audit	Audit cycle
Breast service has a recognised MBC lead clinician nurse with MBC experience	Record of named individual	Service operational policy
MBC pathway within service	Clear pathway details of MDT discussion and subsequent clinic and treatment pathways, including the management of acute and chronic side effects (consequences) of treatment, to meet the needs of this patient group	Service operational policy
Identified medical and nursing individuals with the skills for managing MBC	Clinician with experience in MBC treatment and guidelines CNS with MBC experience (with other MBC CNS peers at a centre or specific MBC training/CME)	Service operational policy
Access to on site or clear referral pathway for multidisciplinary support for MBC patients (information, psychological support, dietetics or OT support, palliative care, AOS services	Clear detailed pathway known to all members for the treating team	Service operational policy
Clinic slots or clinics dedicated to MBC	Clear detailed pathway known to all members for the treating team	Service operational policy
Complete submission of COSD MBC minimum dataset	CR0440 – Date of recurrence (Clinically agreed) CR0450 – Cancer recurrence care plan indicator CR0300 – Source of referral for cancer recurrence CR1340 – Cancer treatment event type CR1590 – Metastatic site CR1540 – Key worker seen indicator (Cancer recurrence) CR1550 – Palliative care specialist seen indicator (Cancer recurrence) CR2030 – Date of diagnosis (Clinically agreed) CR0370 - Primary diagnosis (ICD) CR0100 – Patient date of birth CR1270 – Date of death C1290 – Patient trial status (Cancer) C1260 – Cancer Clinical Trial treatment type BR4230 – ER ALLRED SCORE BR4220 – ER Status BR4300 – PR ALLRED SCORE BR4290 – PR status BR4280 – HER2 status BR4310 – HER2 ISH status CR0840 – Morphology (SNOMED) CR3087 – Morphology (SNOMED CT)	COSD submissions Compliance metrics
Complete submission of systemic therapy given in the metastatic setting dataset	Chemotherapy dataset	SACT Submission

Performance Indicator	Details	Monitoring
Complete submission of palliative radiotherapy given in metastatic setting or other local treatment eg. Radiofrequency ablation dataset	Radiotherapy dataset	RTDS Submission
Access to trials	Clear referral pathway	Service operational policy

4 Scope

4.1 Aims and objectives

This document is aimed at all staff in the design and delivery of metastatic breast services. It outlines six LCA Metastatic Breast Standards with specifications and provides three LCA Metastatic Breast Service Model delivery options for Trusts to implement. The document provides supporting specifications for the care of metastatic breast cancer patients and for MDTs to put plans in place to support the appropriate pathways for the care and treatment of these cancer patients. This applies to both newly diagnosed and follow up patients.

5 Service Model

5.1 Service description and pathway

The metastatic breast service is a multidisciplinary team that manages patients with metastatic breast cancer. These patients may present with metastatic breast cancer with no known previous disease or in patients with a previous diagnosis of breast cancer. They may be referred either by GPs, oncologists, breast surgeons, CNSs or by other hospital professionals. The service model includes management by core and extended members of the MDT, specialist metastatic breast nurse, dedicated MDT discussion and clinic slots.

The service is led by a medical or clinical oncologist input with experience and training in managing metastatic breast cancer, for review of oncological treatment (systemic and radiotherapy). The patients are allocated a CNS with expertise in management of metastatic disease who partake in ongoing training and development. If a service has a dedicated metastatic CNS, it is essential that other 'non-metastatic CNSs' have basic skills and ongoing training so that they can offer business continuity during absences.

All patients should be reviewed at relapse (or whenever there are changes in diagnostic/clinical situations which require a change in management plan) either at a dedicated metastatic MDT or at a dedicated portion within the main breast MDT. A patient presenting with newly relapsed metastatic disease should be given a new patient outpatient slot in recognition of the fact that more time is needed and that this is in effect a new patient referral. Patients with follow up appointments may also benefit with an extended time slot given the complexity of discussions that often take place. These patients should also be tracked using a dedicated database and have access to clinical trials.

Good communication and robust pathways with other clinical teams such as GPs, interventional radiology, acute oncology, supportive care such as functional rehabilitation, and palliative care services are required. Patients should be referred to other specialties as appropriate for the management of their treatment and care.

These include but are not limited to:

- access to testing for BRCA mutations if criteria are reached
- consideration for re-biopsy to reassess immunohistochemistry
- access to PORT (a cath insertion for patients receiving protracted IV treatment for metastatic disease
- access to breast surgery for local disease control
- neurosurgical referrals for solitary brain metastases
- thoracic and hepatic surgeons for lung and liver metastases
- consideration for referral to appropriate stereotactic MDT
- orthopaedic referrals for skeletal/spinal stabilisations
- referral for services to support management of symptoms and side effects, including lymphoedema, arm mobility problems, breathlessness, pain, menopausal symptoms, fatigue, sleep problems, sexual difficulties and heart failure
- referral to local palliative services if required
- access to psychological support for both patients and their families.

The LCA Metastatic Breast Referral Pathway can be found in Appendix 2.

5.2 LCA metastatic breast service model standards and specifications

The LCA Metastatic Breast Service Standards are drawn from the recommendations of the Secondary Breast Cancer Taskforce[13]. The standards reflect the highlighted priority areas for people with MBC and the gaps or problems in provision within these priority areas. The proposal to adopt and embed these standards will address these issues by reducing variation in practice that currently exists, improving treatment, support and care of people living with MBC.

The LCA Metastatic Breast Service Standards are:

1. Dedicated metastatic clinic(s), including lists run by specialist metastatic nurses.
2. A specialist breast metastatic nurse with responsibility for patients with metastatic breast cancer either as all or part of their role.
3. Dedicated MDT slots to discuss patients with metastatic breast cancer, either as a metastatic MDT or as a dedicated part of a main MDT meeting.
4. A database of patients with metastatic breast cancer being managed at a given site.
5. Good communication between the metastatic breast team, acute oncology services and community palliative care services. An agreed pathway to a unit that can perform semi-elective ascitic and pleural drains, bloods transfusions and other similar procedures can help avoid emergency admissions and improve patient experience.

6. Access to metastatic breast cancer trials.

These standards define the LCA Metastatic Breast Service models outlined in Appendix 1.

5.2.1 Metastatic clinics

Standard 1:
Target standard: A dedicated metastatic clinic, including lists run by specialist nurses
or
Minimum standard: Dedicated time slots at the end/beginning of the oncology clinics (or general breast clinic)

The Secondary Breast Cancer Taskforce[13] recommends that patients with metastatic breast cancer should be seen in an outpatient clinic dedicated to this condition. These patients may be seen in tertiary hospitals or more local cancer units. The clinic for patients with metastatic breast cancer can be entirely dedicated to this condition if the hospital has a large enough caseload. Alternatively, the metastatic breast cancer clinic can be a sub-clinic of a breast oncology clinic. It is essential that the core staff for the metastatic clinic consist of a clinical nurse specialist with the knowledge and responsibility for MBC and an oncologist experienced in the management of metastatic breast cancer. Patients with metastatic breast cancer often have complex needs and thought should be given to providing longer time slots for their consultations. It is also suggested that where possible the metastatic clinic be held after the metastatic breast cancer MDT to enable input from other health professionals including palliative care, radiology and surgery.

The clinical team caring for patients with metastatic breast cancer should be research-active and enable patients to participate in clinical research trials locally or at other centres if they wish to do so.

Prompt written communication should be sent to the primary care physician and local palliative care team (where relevant) following the consultation and copied to the patient unless they have chosen to opt out of receiving clinic letters. This to allow others involved in the patient's care in the community setting to be aware of the current situation.

It is desirable for the metastatic breast cancer clinic to have good links with the local acute oncology team and access to semi-elective procedures such as drainage of fluid collections to allow patients to avoid emergency admissions.

5.2.2 Metastatic CNS

Standard 2:
A specialist breast metastatic nurse with responsibility for patients with metastatic breast cancer either as all or part of their role

The role of a breast metastatic nurse

Patients should have access to a clinical nurse specialist, at and from the point of secondary breast cancer diagnosis and onwards. This person will act as the 'key worker', coordinating the patient's care, acting as an advocate and providing/signposting the patient to support and information

Current research identifies the illness experience of women with MBC, the pattern of the disease process and their complex care needs. Women with metastatic breast cancer have high levels of unique complex and unmet supportive care needs that vary over time and differ from those with an early breast cancer (EBC) [13]. The nature of the illness trajectory demonstrates a 'decline and reprieve' process, therefore

women with MBC require fluctuating levels of support with varying intensity over an extended period of time to support their functioning at an optimal level[14].

NICE[12] recognised the need for separate guidelines for the provision of care for patients with MBC. These guidelines provided specific points for priority:

- diagnosis
- assessment
- access to specific therapy
- supportive care

The provision of supportive care should encompass the assessment and discussion of a patient's needs for physical psychological, social, spiritual and financial support.

NICE recommends that the assessment and discussion of a patient's needs for their physical, psychological, social and financial support should be undertaken at key points such as:

- diagnosis
- commencement, during and at the end of treatments
- at relapse and with the transition to end of life care.

It is well documented that this group of patients have a greater degree of psychosocial and health information needs. Receiving news of a diagnosis or progression of their disease can be extremely distressing, with many women reporting it being more distressing than their original early breast cancer diagnosis[15].

The effect that a diagnosis of MBC can have cannot be underestimated as it can affect numerous areas and aspects of a woman's life including finances, employment, supporting children and family, making lifestyle changes in addition to the emotional burden.[16] Many women also experience persistent physical symptoms from their metastatic cancer or from their treatment side effects such as pain, nausea, insomnia, depression or fatigue[13].

Various studies have explored the support and information needs of women with MBC which revolve around five inter related themes. These are:

1. Physical domain – includes a range of physical symptoms that may be acute, relatively short lived or ongoing, that require continuing intervention.
2. Social domain – includes a range of social and practical issues that will impact on the individual and their family and includes maintaining social networks, emotional support, employment/financial concerns.
3. Psychological domain – issues related to mental health and well-being, personal relationships.
4. Spiritual domain – changing sense of self and the challenges to their beliefs/values and existential concerns – lives dominated by trying to manage the disease and treatments.
5. Information domain – access to evidenced based information is an essential component of supportive care.[17] Accessing information about disease, treatment, support services and the healthcare system.

Women's main concerns therefore are about:

- Having a life threatening illness
- End of life care
- Worries about those close to them
- Living with a sense of uncertainty
- Worries about a loss of control amongst many other losses
- Developing strategies to cope with emotional adjustment and maintaining a state of wellness and quality of life. [15,18,19]

The MBC pathway has a varied trajectory that starts when the patient is diagnosed and follows the patient through the multidisciplinary process of planning and treatment phases. This cycle is repeated each time there is a disease progression with supported transition to end of life care.

The MBC CNS/key worker accepts referrals at any time during the disease trajectory to identify and address the individual clinical, supportive and informational needs of women with MBC. However a recent shift of treatment to the ambulatory care setting results in less time at the hospital and less face-to-face contact for assessment, support, information and referrals.[20, 13] Patients report this may have a very negative effect on the level of support they are able to access and pathways should be put in place to ensure this risk is mitigated.

An MBC CNS model of care is separate to an existing breast care nurse (BCN) service. The role and function difference can be attributed as follows:

- separate but parallel role
- the supportive care needs of the two groups of patients can differ with higher complexity for those with MBC – referral pathways
- different skill set and knowledge required by the MBC CNS.

Knowledge, skills and training

Innovative nursing roles have evolved to meet the emerging needs of a dynamic and ever changing service reflecting:

- new knowledge
- technological advances
- public need/demand.

When identifying knowledge/skills and training needs they need to meet the demands of the service and patient expectation.

The concept of 'specialist' MBC nurse can be viewed within an overarching level of higher-level practice[21] focusing on 'How' and 'What' practitioners do. Academic qualifications however are seen as the key determinant to the development of a MBC nurse's cognitive, reflective and rational ability.

In developing a knowledge and skills framework for an MBC CNS, the following should be considered:

- Developing a consistent role definition for the MBC CNS role, underpinned by a competency framework.

- Identifying structures needed for role development – may enter at a developmental level, progressing to become proficient and then continuing to become expert practitioners.
- A competency framework may reflect these levels, providing a framework for continuing development and identifying academic requirements to underpin each level – linking with Knowledge and Skills Framework (KSF)[22] and appraisals to track personal development.
- Competencies further reflect the operational and practice requirements of specialist roles and incorporate individual Trust's strategies.
- Job descriptions person specification – identify levels of specialist practice (Band 6 or 7 depending on the levels of autonomy and clinical leadership).
- Future role development within a core framework will facilitate consistency of role perception across an organisation.
- KSF serves as a generic tool which can be adapted to reflect the local context of specific roles within a specialty.

Although there is currently no specific training for metastatic breast CNSs, it is clear that training should reflect the knowledge, skills and competencies referenced in Appendix 3, and which can be completed in a series of modules. It is equally essential that other 'non-metastatic CNSs' have basic skills and ongoing training so that they can offer business continuity during absences.

5.2.3 Breast metastatic multidisciplinary team meeting

Standard 3:
Dedicated consultant led specialist metastatic MDT to discuss patient management for all new and follow up patients supported by an MDT coordinator
or
Dedicated portion of main breast MDT where the metastatic MDT members can attend to discuss patient management for all new and follow up patients supported by an MDT coordinator

Metastatic breast cancer is optimally managed through a multidisciplinary team approach. It enables best survival outcomes and quality of life. Clinical governance drives clinical excellence and high standards of care as well as dedicated discussion time for patient management and access to appropriate clinical trials. All healthcare professionals who contribute to the management of metastatic breast patients should meet weekly, either at a dedicated consultant led specialist MDT or at a dedicated portion of main breast MDT.

Although the breast surgeon and palliative care consultant are listed as extended members of the core team, their expertise as well as others listed in the extended membership will be required depending on patient need. MDTs should ensure that there is a robust pathway in place to ensure these patients are discussed in a timely manner and managed by the relevant specialist.

Core members

The core team will include:

- Oncologists (medical and clinical)
- Metastatic clinical nurse specialists
- Radiologists (diagnostic)

- Breast care nurses
- Research nurse
- MDT coordinator

Extended Members

Extended members may include:

- Breast surgeon
- Palliative care
- Radiographers
- Pharmacists
- Radiologists (interventional)
- Pathologists
- Geneticists
- Counsellors/psychologists/psychiatrists
- Social workers
- Lymphoedema therapists
- Physiotherapists
- Psychosexual therapist

Patients with metastatic breast cancer

The patients that should be discussed at the MDT are:

- All new patients including new relapses, new referrals and second opinions
- All patients requiring surgery
- All patients requiring pathology review
- All patients requiring imaging review

MDT discussions

MDT patient management discussions should include:

- Past and current treatment
- Imaging findings
- Pathology results including molecular profiling
- Treatment options: standard therapy and trial options

5.2.4 A database of patients with metastatic breast cancer being managed at a given site

Standard 4:

A database of patients with metastatic breast cancer being managed at a given site

There is a lack of available data for people living with MBC [13]. This information is important to be able to plan treatment and support services as well as service development needs and to be able to identify areas for clinical advancement.

Trusts are mandated to submit COSD, RTDS and SACT data and although some relevant information can be collected this way, there is little available to determine survival rates for patients with metastatic breast cancer. Therefore, the minimum COSD, RTDS and SACT dataset listed in table 2 has been identified in consultation with breast MDT members across the LCA in order to help develop a better understanding of metastatic breast cancer. Trusts should ensure systems are in place for completion of these fields. Most Trusts will already have an IT system that supports the COSD data collection, for example Infoflex and Somerset, and those that do not should explore the feasibility with their suppliers.

Table 2 : MBC Minimum dataset

COSD code	Detail
CR0440	Date of recurrence (Clinically agreed)
CR0450	Cancer Recurrence care plan indicator
CR0300	Source of referral for cancer recurrence
CR1340	Cancer Treatment event type
CR1590	Metastatic site
CR1540	Key worker seen indicator (Cancer recurrence)
CR1550	Palliative care specialist seen indicator (Cancer recurrence)
BR4230 – ER ALLRED SCORE BR4220 – ER Status BR4300 – PR ALLRED SCORE BR4290 – PR status BR4280 – HER2 status BR4310 – HER2 ISH status CR0840 – Morphology (SNOMED) CR3087 – Morphology (SNOMED CT)	Breast cancer subtype ER/PR/HER 2/Morphology status
CR2030 – Date of diagnosis (Clinically agreed) CR0370 - Primary diagnosis (ICD)	Date of first diagnosis of breast cancer (if not de-novo disease)

COSD code	Detail
CR0100	Patient date of birth
Within SACT dataset	Systemic therapy given in the metastatic setting
Within RTDS dataset	Palliative radiotherapy given in metastatic setting or other local treatment eg. Radiofrequency ablation
CR1270	Date of death
C1290 – Patient trial status (Cancer) C1260 – Cancer Clinical Trial treatment type	Clinical Trial
De-novo metastatic disease, or a known previous diagnosis of breast cancer	

In improving data availability for service planning, improvement and advancement, it would be desirable that a running database of patients with metastatic breast cancer is kept in every practice. This will enable us to understand the volume of patients with metastatic breast cancer, treatments being given and identify variations in survival amongst other agreed metrics.

Information is key to service planning as well as providing evidence and advancement for improvement. Information that may help with service planning and not available through existing national datasets are listed in table 3. The LCA have requested consideration for these items to be part of the next round of COSD upgrades in 2018.

Table 3: Proposed dataset items for future development in COSD

Proposed dataset items for future development in COSD	Description
Treatments given in the adjuvant setting (unless it is possible to track this to an "neo/adjuvant database")	Available but not easily accessible in COSD
Menopausal status	Listed field options: 'pre','peri' and 'post'
Biopsy receptor status if done	Listed field options : 'morphology': with space to write free text words 2 ER, 3 PR, 4 HER2 ,5 KI67 and other (with free text option
BRCA status if known	Listed field options: fields - '+ve','-ve' and 'unknown'
Type of recurrance	Listed field options: 'local','distal' and 'both'
Sites of metastatic disease updated over time	this is currently not sequential and would be more useful as sequential data

5.2.5 Communication

Standard 5:
Good communication between the metastatic breast team, acute oncology services and community palliative care services. An agreed pathway to a unit that can perform semi-elective ascitic and pleural drains, bloods transfusions and other similar procedures can help avoid emergency admissions and improve patient experience.

Patients with metastatic breast can have complex physical and psychological issues that require the input of different medical disciplines and health professionals. In addition, the patient's clinical condition can at times change quickly either due to cancer progression or toxicity from treatments. For these reasons, excellent communication from the MBC team to others involved with the patient is essential. This should be in the form of a written letter following each clinic visit to which the patient should be included (unless the patient has chosen to opt out). If there are urgent issues these should be communicated by direct clinician to clinician contact (email/telephone/faxed letter). The GP should also receive a summary of the MBC MDT discussion each time the patient's case is reviewed.

Good links with acute oncology, acute medicine/surgery, palliative care, radiology and neurosurgery (spinal cord compression pathway) will enable swift referral and care for patients with MBC when urgent events occur.

5.2.6 Access to metastatic breast cancer trials

Standard 6:
Access to metastatic breast cancer trials

It is desirable that women with metastatic breast cancer have access to a clinical trial portfolio in this setting. Good communication between cancer units and cancer centres is thus imperative and a robust pathway should be put in place to ensure patients have access to trials. The research nurse should also be aware of trials being offered at other LCA sites to ensure patients have full access to the most appropriate trial.

As breast cancer subtypes become more numerous (for example taking into consideration somatic and germline mutational data alongside standard immunohistochemistry) it will not be possible for all cancer centres to run a comprehensive portfolio encompassing studies for all different groups of patients. An LCA breast metastatic trials portfolio is available so that clinicians across the LCA can refer patients accordingly for suitable trials that their individual patients may be eligible for.

The trial portfolio can be found here:
http://www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/lca-clinical-trials/lca-mdt-trial-portfolio-maps/

5.3 Applicable National Service Standards

5.3.1 Breast Clinical Reference Group (CRG)

The LCA engaged with the breast CRG whilst developing the service guidance for breast cancer, which also covers essential services for patients with early, recurrent and metastatic breast cancer. Its publication will support the commissioning of breast cancer services at national and local level. The following points in the guidance align to the breast metastatic service model standards identified by the LCA:

1. The availability and importance of clinical trials should be discussed with all patients for both early and advanced disease at appropriate time points.
2. It is particularly important that all patients with recurrent or metastatic breast cancer have access to a clinical nurse specialist with specialist knowledge of secondary disease. They should be available to give information and psychological support to patients and their families.
3. Patients with recurrent/metastatic disease should be re-discussed at a dedicated metastatic MDT slot if they develop local and/or metastatic disease.
4. A record of this discussion must be filed in the notes and relevant fields in the COSD completed.

In addition it is widely agreed by those involved in the development and care of patients with metastatic breast cancer that a good service should also provide:

1. Dedicated metastatic clinic(s), including lists run by specialist metastatic nurses.
2. A database of patients with metastatic breast cancer being managed at a given site.
3. Good communication between the metastatic breast team, acute oncology services and community palliative care services. An agreed pathway to a unit that can perform semi-elective ascitic and pleural drains, bloods transfusions and other similar procedures can help avoid emergency admissions and improve patient experience.

The breast CRG is supportive of the work of the LCA and publication of the CRG national breast service guidance is expected in early 2016.

5.3.2 Secondary Breast Cancer Taskforce

Breast Cancer Care[23] has published the standards for secondary breast cancer resultant from the work carried out by the Secondary Breast Cancer Taskforce. The standards recommend that a person with secondary breast cancer should:

- have access to a clinical nurse specialist, at and from the point of secondary breast cancer diagnosis onwards. The CNS will be knowledgeable about the disease, treatment and support needs of people with secondary breast cancer. This person will act as a 'key worker': coordinating care, acting as advocate and providing/signposting to other sources of support and information
- receive a multidisciplinary team approach to their care. All healthcare professionals who contribute to the medical and nursing management of patient care should meet regularly to discuss each patient's case, so that they receive the best care. The team should include members of the oncology and palliative care teams
- experience continuity of care between the hospital and community services. Communication between the hospital-based team and GP should be as efficient as possible using different methods of communication to ensure the GP is kept informed of their patients' treatment and care. The GP should be informed and kept up to date about the patient's condition and be able to provide support and care when appropriate
- be given timely information including a care plan, on all aspects of their treatment and care both verbally and in writing and be clear on the purpose of the patient's treatment, the side effects and potential impact on well-being. Patients' information needs should be assessed on a regular basis and support should be provided alongside all information given

- have their emotional well-being assessed on a regular basis and have access to the appropriate level of psychological support. This should be when the patient needs it, but particularly at diagnosis, when the cancer progresses and at the end of each treatment
- have access to information on support services both nationally and locally. This should include the opportunity to meet/talk to others with secondary breast cancer. This could be online, on the telephone or face to face
- have access to expertise in palliative care, symptom control and ongoing management of troublesome symptoms. Patients should also be provided with information about end of life care when appropriate
- have access to support and guidance on talking to partners, family, friends and children, about the experience of living with secondary breast cancer and the impact it has on others. Partners' and families' support and information needs should be assessed separately to the patients by a healthcare professional involved in their care. They should be offered/signposted to information/support services specifically for them
- have access to expert financial and employment advice. This should include information about the patient's eligibility for relevant benefits and their rights at work under disability discrimination legislation
- have access to appropriate treatments and be made aware of the availability of clinical trials for which the patient may be eligible before treatment is started or changed.

6 Access to Metastatic Services

Many patients value being treated close to home. Indeed most patients can be treated by a suitable oncologist and CNS in their local breast unit with access to chemotherapy and radiotherapy as required. Patients with metastatic cancer can be managed for a long while on oral treatment and many patients may be precluded from more intense treatment on the basis of age or co-morbidities. There should be a robust pathway in place with timely referrals for patients requiring onward care and treatment at a specialist centre.

7 Patient Information

Evidence suggests that by fulfilling informational needs healthcare professionals can improve psychological coping and quality of life for patients who are living with MBC and their families.[23,24,25] It is the responsibility of the whole multidisciplinary team to offer patients appropriate information at each stage of their pathway, as patients rely upon the services of many different departments during their cancer diagnosis and treatment.

More patients are living longer with MBC and subsequently require more comprehensive information to understand their illness, the increasing number of treatment options, and how to self-care and manage living with an incurable disease[26]

Individualised assessment of needs and expectations is recommended and can be elicited during a Holistic Needs Assessment as few characteristics of the patient predict his or her need for information and support. Patient factors such as cultural, educational, and social aspects need to be considered as this can influence how patients seek and receive information and will guide healthcare professionals as to how best to communicate and provide individualised information[12, 13.]

Written and verbal information should be provided on a continual basis. There is a comprehensive range of nationally produced booklets and factsheets developed by reputable cancer charities, the NHS and commercial companies that cover all aspects of MBC. In addition many Trusts have developed their own written patient information.

It is therefore important to ensure patients are not overwhelmed with information and it is available and appropriate at the right points in their pathway. This will also avoid duplication of information given patients may attend different hospitals during their pathway.

The LCA Breast Pathway Group recommends adoption and use of the MBC patient information checklist which has been developed specifically to support the MBC pathway.

The checklist list has been compiled using nationally available information resources aligned across the four key stages of the MBC pathway and can be found in Appendix 5. The key stages are:

- at time of diagnosis
- at commencement, during and at the end of treatment
- at the time of progression
- at the start of end of life[27]

The patient information checklist includes the minimum recommended literature and its source, and can be staggered and issued across the four stages. This standardised approach ensures every patient receives optimal quality assured information, avoiding duplication and information overload.

The patient information checklist can also constitute the patient's information prescription and be given to the patient; it should form part of the patient record and be filed in their notes (electronic or hand held).

Information on treatment options available should include potential benefits, side effects and risks of the treatment. Patient specific information should also include information about support organisations.

The CNS/key worker as the single constant contact for patients is well placed to assess the individual patient's information needs and either provide the relevant information required or signpost if needed.

A key worker leaflet should be offered at first contact with the CNS and include the following best practice information:

- who the service is for
- the name of the MBC nurse(s) involved in their care
- how the clinical nurse specialists can be contacted
- what the clinical nurse specialists can offer
- where the patient can get further information
- a section on Holistic Needs Assessment

Information can be available in a variety of formats (written, audio, DVD) and languages sourced either locally or nationally.

Sources of information include but are not limited to:

- In-house hospital written information provided by treating team
- All treatments centres (hospitals) in the network have a PALS office and some have Macmillan Cancer Support information centres to assist with providing and accessing patient information
- National charities – Breast Cancer Care, Macmillan Cancer Support, Breast Cancer Now, CRUK
- Online/websites – www.breastcancer.org; www.cancerresearchuk.org; www.macmillan.org.uk; www.breastcancernow.org
- Online discussion forums and live chat - www.breastcancernow.org
- Local sources for example hospices, Maggie's Centres, The Haven, Paul's Cancer Centre, The Mulberry Centre and Macmillan Cancer Support centres.

8 Metrics and outcome measures

The following metrics are aligned for measuring performance against the LCA Metastatic Breast Service:

- Number of breast patients with metastatic breast cancer (CWTDS/COSD)
- Quality of life indicator
  - 30 days post chemotherapy mortality data (SACT)
  - Patient experience (local/national surveys)
- Clinical trial recruitment (LCA)
- Key worker seen (COSD)
- Cancer recurrence care plan (COSD)
- Palliative care specialist seen (COSD)

At present there are little data available to determine survival rates and further work is recommended to develop this.

9 Quality Indicators

The LCA contributed to the development of the NICE Quality Standards, by submitting the LCA MBC standards for consideration. The draft NICE Quality Standards for MBC are as follows:

- Dedicated diagnostic MBC discussion at specialist metastatic MDT or a dedicated metastatic portion of the main breast MDT with core members
- MBC dedicated clinics or dedicated times in a clinic when appropriate time and support is available.
- Identified CNS with MBC skills and knowledge
- MBC pathways outlined in breast standard operating procedures, including referral pathways to supportive care and research studies

The update of the QS is on going and due to be published in spring 2016.

10 Summary

The management of MBC requires a multidisciplinary and holistic approach supported by healthcare professionals who are experienced and trained in this area. Following diagnosis and initial management discussion, it is recognised that patients with MBC have specific needs and their care plan, treatment, information and social care needs should be tailored according to the tumour phenotype, prognosis and co-morbidities. Research and clinical trials remain pivotal to understanding the disease landscape and in transforming clinical outcomes. The Global Status of MBC Decade Report, (2015)[28] identified emerging recommendations that equally align to these priorities.

Underpinned by six best practice standards, implementation of the LCA Metastatic Breast Service Model Standards and Specification provides a feasible and practical approach to address these priorities in order to improve metastatic services and importantly, patient experience.

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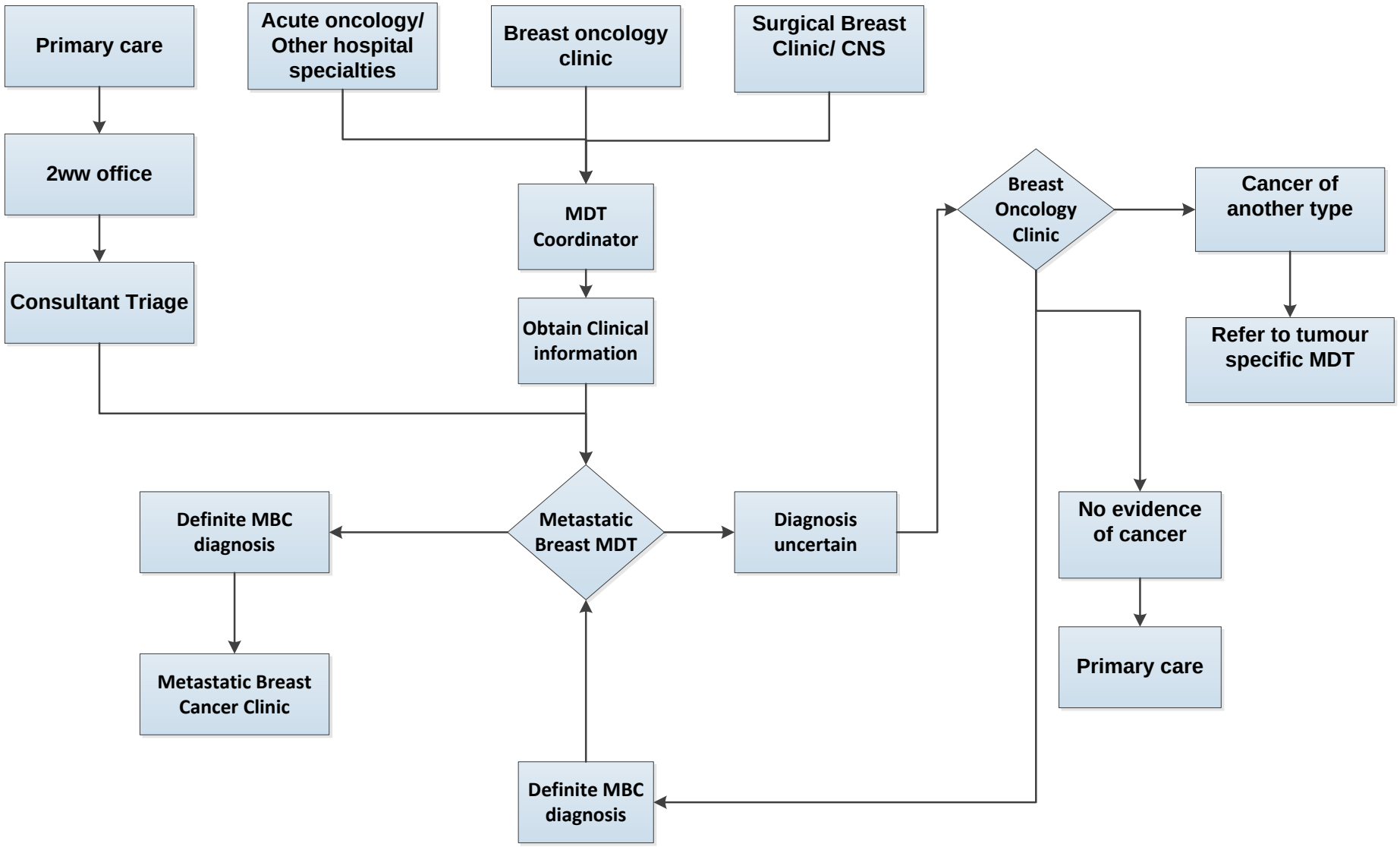
Appendix 1: LCA Metastatic Breast Service Model

* Italic text clarifies how the standard can adapted to meet the variation in patient caseloads across the LCA

STANDARD	A dedicated metastatic clinic, including lists run by specialist nurses	A specialist metastatic breast nurse with responsibility for patients with metastatic breast cancer either as all or part of their role	Dedicated MDT slots to discuss patients with metastatic breast cancer, either as a metastatic MDT or as dedicated part of a main MDT meeting.	A database of patients with metastatic breast cancer being managed at a given site	Good communication between the metastatic breast team, acute oncology services and community palliative care services.	Access to clinical trials
Model 1	Dedicated metastatic clinic(s), including lists run by specialist nurses	A specialist metastatic breast nurse with responsibility for patients with metastatic breast cancer either as all or part of their role	*Dedicated consultant led specialist metastatic MDT to discuss patient management for all new and follow up patients supported by an MDT coordinator*	Dedicated database that tracks patients in active treatment and those in survivorship phase	Good communication between the metastatic breast team, acute oncology services and community palliative care services.	Access to LCA wide metastatic clinical trial
Model 2	Dedicated metastatic clinic(s), including lists run by specialist nurses	A specialist metastatic breast nurse with responsibility for patients with metastatic breast cancer either as all or part of their role	**Dedicated portion of main breast MDT where the metastatic MDT members can attend to discuss patient management for all new and follow up patients supported by an MDT coordinator*	Dedicated database that tracks patients in active treatment and those in survivorship phase	Good communication between the metastatic breast team, acute oncology services and community palliative care services.	Access to LCA wide metastatic clinical trial
Model 3	*Dedicated time slots at the end/beginning of the oncology clinics (or general breast clinic)	A specialist metastatic breast nurse with responsibility for patients with metastatic breast cancer either as all or part of their role	*Dedicated consultant led specialist metastatic MDT to discuss patient management for all new and follow up patients supported by an MDT coordinator* *OR* **Dedicated portion of main breast MDT where the metastatic MDT members can attend to discuss patient management for all new and follow up patients supported by an MDT coordinator*	Dedicated database that tracks patients in active treatment and those in survivorship phase	Good communication between the metastatic breast team, acute oncology services and community palliative care services.	Access to LCA wide metastatic clinical trial

Appendix 2: LCA Metastatic Breast Referral Pathway



Appendix 3: Metastatic CNS Knowledge, Skills and Competencies

Knowledge

- Specialist knowledge of metastatic breast cancer, treatment and the illness trajectory.
- Specialist oncology knowledge
- Understanding of the implications of living with a chronic illness.
- Understanding of the psychosocial, spiritual/existential impact of metastatic breast cancer on the patient and their family
- Palliative care knowledge
- Knowledge of local and national support services for metastatic breast cancer patients.
- Knowledge of current clinical research and trials
- Knowledge of end-of-life care guidance
- Knowledge of national and local information and support to patients' families

Skills

- Ability to support patients in decision making
- Ability to case-manage complex care, acting as a coordinator for patient care and liaising with all health/social care and other professionals involved in patient care
- Advanced communication skills
- Managing conversations with family members including children
- Advanced assessment skills
- Ability to discuss long-term illness issues, palliative care and end-of-life issues.
- Ability to provide information to the patient using a number of different models and tools
- Ability to identify patients who may require individual counselling
- Ability to be the patient's advocate
- Ability to support patients with a self-management approach to their care
- Resilience training/CNS workload
- Group facilitation

Competencies

- Linked with KSF framework – Band 6-7
- Ongoing specific clinical supervision/reflective practice

Appendix 4: Example Job Description and Specification

Aim of the role

To provide specialist nursing knowledge and expertise with the aim of educating and supporting patients, their families and healthcare professionals in the care, management and treatments associated with secondary breast cancer.

Key areas of practice

- Provision of specialist, high quality, expert nursing care and support for patients with a diagnosis of secondary breast cancer and for their carers
- To act as a resource for patients and the clinical team by the provision of comprehensive specialist advice, information, teaching and training both within the Trust and externally regarding secondary breast cancer
- Undertake, where appropriate, nursing research with published outcomes, and updating own knowledge to promote excellence in advanced clinical practice
- To set appropriate quality standards within advanced breast cancer care at the Trust
- Contribute in audit processes; formulate annual report/clinical audit of own CNS service outcomes
- Active involvement in the development of the service locally and nationally

Main tasks and responsibilities

Clinical responsibility for patient care

- Undertake a full specialist nursing assessment to identify the specific needs of the above patient groups and their families/carers. To develop and implement individualised, specialist nursing care.
- To provide support and advice accordingly with the aim of promoting optimal quality of life.
- Actively work with other breast care specialists and colleagues within the Trust, other hospitals and the community to provide seamless coordination of patient care across the patient pathway to maximise patient satisfaction and outcomes.
- Provide specialist advice at multidisciplinary team meetings and to its members and health professionals from the wider healthcare community on issues specific to the management and care of patients with secondary breast cancer. This will include the disease pathway and its associated treatments, i.e. hormone therapy, chemotherapy, biological therapies, clinical trials and radiotherapy.
- Demonstrate expert knowledge and understanding of breast cancer to allow collaboration with medical colleagues to ensure that patients and their families are fully informed and understand proposed patient investigations and treatments.
- Act as patient's advocate and counsel when informed discussion may lead to choices being made concerning treatment options and quality of life issues. Ensure that all relevant information is accurately documented in patient health records, electronic and paper.

- Communicate sensitive and complex condition related information to patients and their families/carers to enable an understanding of treatment and its aims, continually reviewing and assessing their understanding as their needs change.
- Maintain a support network and contact link for patients' families/carers and other relevant healthcare professionals during and following treatments.
- Support patients and their families/carers through difficult and sensitive end of life issues. Use higher levels of communication to overcome anxieties, fears and denials that they may experience in accepting prognosis.
- In conjunction with specialist palliative care team ensure optimal symptom control.
- Complete full patient assessment to fulfil requirements of social services and palliative care assessment criteria to allow decision regarding funding of care packages for patients. Act as advisor on complex discharges for secondary breast patients.
- Ensure bereavement follow-up is made available to families/carers, supporting them with any concerns or difficulties that may arise. Ensure formal counselling offered if wished

Management

- Maintain an effective referral and documentation system.
- Organise and manage nurse-led breast care clinics to provide optimum conditions for continuity of care
- Contribute to the development of policies, procedures and guidelines for the management of patients with secondary breast cancer.
- Maintain effective communications with colleagues including: other members of the multidisciplinary team, members of the primary care team, district/community nurses, community specialist palliative care teams, social workers and voluntary organisations as appropriate.
- Continually evaluate the changing needs of the role, making recommendations on the ongoing development of the service both at a local and national level.

Education of patients and staff

- In order to provide expert education, maintain an up to date awareness of all types and sources of information available. Provide appropriate and timely information for patients and their carers regarding the disease process, treatments and services available for them.
- Liaise closely with local patient support groups or facilitate the development of such groups as appropriate.
- Facilitate user involvement when producing relevant work relating to secondary breast cancer.
- Identify the training needs of staff working with this particular patient group. Work collaboratively with relevant educational staff/providers, to deliver teaching programmes to meet these needs.
- Be available nationally as expert in issues relating to secondary breast cancer and teach on national and internal courses.

Research and clinical audit

- Participate in the development and implementation of evidence based nursing practice for patients with secondary breast cancer, including the use/development of protocols to ensure appropriate, specialist care is provided for improved quality of care.
- Through understanding of research theory and its process, and in liaison with the research nurses working in the breast unit, act as a facilitator regarding appropriate recruitment of patients with secondary breast cancer to research trials.
- Undertake nursing research and to publish the outcomes as appropriate.
- Participate in local and/or national research and development initiatives as appropriate.
- Participate at Trust level working parties relevant to secondary breast cancer.

Personal Development

- Update own knowledge to promote excellence in clinical practice. Attend and present at national and international educational events as appropriate
- Maintain membership of national professional groups to facilitate updating and development within specialist field
- Take responsibility for own professional development through the appraisal system and work towards completing agreed personal development plan
- Actively engage in appropriate supervision

Candidates must demonstrate	Essential/Desirable	Assessed by
Qualifications		
First level registration	Essential	Application Form
First level degree in relevant subject	Essential	Application Form
Master's degree or working towards one	Desirable	Application Form
Oncology qualification or qualification/experience relevant to specialty	Essential	Application Form
Experience		
Relevant post		
Registration experience, at Band 6 or above, in cancer, palliative care or the specialty	Essential	Application Form/Interview
Experience of teaching	Desirable	Application Form/Interview
In-depth specialist experience	Essential	Application Form/Interview
Leadership and management experience	Desirable	Application Form/Interview
Experience of multi-professional working	Essential	Application Form/Interview
Evidence of advanced communications skills	Essential	Application Form/Interview
Ability to lead and influence change	Essential	Application Form/Interview

Candidates must demonstrate	Essential/Desirable	Assessed by
Skills		
Relevant clinical expertise and skills in breast cancer nursing	Essential	Application Form/Interview
Ability to communicate with others at all levels in the organisation	Essential	Application Form/Interview
Ability to set up and maintain efficient administrative systems	Essential	Application Form/Interview
Computer literate Microsoft Outlook, Word, Excel and PowerPoint	Essential	Application Form/Interview
Ability to work with others to teach specific clinical skills	Essential	Application Form/Interview
Knowledge of current evidence to underpin practice	Essential	Application Form/Interview
Ability to set and monitor standards	Essential	Application Form/Interview
Ability to work under pressure.	Essential	Application Form/Interview
Ability to show tact and manage boundaries.	Essential	Application Form/Interview
Capabilities		
Diplomatic	Essential	Application Form/Interview
Calm and objective	Essential	Application Form/Interview
Assertive, confident, yet approachable	Essential	Application Form/Interview
Personally and professionally mature	Essential	
Recognition of own limitations	Essential	Application Form/Interview
Demonstrates enthusiasm	Essential	Application Form/Interview
Able to travel between sites	Essential	Application Form/Interview
Other		
Clear understanding of the role of clinical nurse specialist and the associated professional responsibility and accountability	Essential	Interview
Evidence of continued professional development	Essential	Application Form/Interview
Able to be flexible to meet the needs of the role	Essential	Interview

Appendix 5: LCA MBC Patient Information Checklist

This information is to be used as part of the patient record and should be filed in their notes (electronic or hand held).

INFORMATION CONTENT	METASTATIC BREAST CANCER INFORMATION	DATE GIVEN	BY WHO AND SIGN
INITIAL CONTACT	**Standard Requirement**		
Key worker details	Local key worker information leaflet		
AT DIAGNOSIS	**One relevant booklet explaining the cancer diagnosis should be offered**		
Understanding secondary breast cancer	Macmillan Cancer Support http://be.macmillan.org.uk/be/p-238-understanding-secondary-breast-cancer.aspx [Web]		
Secondary breast cancer	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Secondary breast cancer resource pack	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Understanding secondary cancer in the bone	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Understanding secondary cancer in the lung	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Understanding secondary cancer in the liver	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Understanding secondary cancer in the brain	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
TREATMENT	**As needed**		
Treatment for secondary breast cancer	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Making treatment decisions	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		

INFORMATION CONTENT	METASTATIC BREAST CANCER INFORMATION	DATE GIVEN	BY WHO AND SIGN
Treatment and side effects	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
TREATMENT: ENDOCRINE THERAPY	**At least one relevant resource explaining the proposed cancer treatment should be offered**		
Tamoxifen	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Breast/Treatingbreastcancer/Hormonaltherapies/Tamoxifen.aspx [Web]		
Letrozole (Femara)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Hormonaltherapies/Individualhormonaltherapies/Letrozole.aspx [Web]		
Anastrazole (Arimidex)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Hormonaltherapies/Individualhormonaltherapies/Anastrozole.aspx [Web]		
Exemestane (Aromasin)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Hormonaltherapies/Individualhormonaltherapies/Exemestane.aspx [Web]		
Fulvestrant (Faslodex)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Hormonaltherapies/Individualhormonaltherapies/Fulvestrant.aspx [Web]		
Megestrol acetate (Megace)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Hormonaltherapies/Individualhormonaltherapies/MegestrolAcetate.aspx [Web]		
Goserelin (Zoladex)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Hormonaltherapies/Individualhormonaltherapies/GoserelinBreast.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
TREATMENT: CHEMOTHERAPY	**At least one relevant resource explaining the proposed cancer treatment should be offered**		
Out of hours contact details	Local information leaflet		
Understanding Chemotherapy	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		

INFORMATION CONTENT	METASTATIC BREAST CANCER INFORMATION	DATE GIVEN	BY WHO AND SIGN
Chemotherapy for breast cancer	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF] Macmillan Cancer Support www.macmillan.org.uk [Web]		
EC Chemotherapy	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publication/fec-chemotherapy-bcc96 [PDF] Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Combinationregimen/EC.aspx [Web]		
Epirubicin	Local information leaflet		
Capecitabine (Xeloda)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Individualdrugs/Capecitabine.aspx [Web]		
Docetaxel (Taxotere)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Individualdrugs/Docetaxel.aspx [Web]		
Paclitaxel (Taxol)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Individualdrugs/Paclitaxel.aspx [Web]		
Vinorelbine (Navelbine)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Individualdrugs/Vinorelbine.aspx [Web]		
Eribulin (Halaven)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Individualdrugs/Eribulin.aspx [Web]		
Gemcitabine (Gemzar)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Individualdrugs/Gemcitabine.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Carboplatin	Breast Cancer Care www.breastcancer.org.uk [Web]		
Coping with hair loss	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Breast cancer and hair loss	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Central venous access devices	Local information leaflet		

INFORMATION CONTENT	METASTATIC BREAST CANCER INFORMATION	DATE GIVEN	BY WHO AND SIGN
TREATMENT: RADIOTHERAPY	**At least one relevant resource explaining the proposed cancer treatment should be offered**		
Understanding Radiotherapy	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Stereotactic Radiotherapy	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
TREATMENT: BIOLOGICAL THERAPIES	**At least one relevant resource explaining the proposed cancer treatment should be offered**		
Targeted therapies for secondary breast cancer	Macmillan Cancer Support http://www.macmillan.org.uk/information-and-support/breast-cancer-secondary/treating/targeted-biological-therapies/targeted-biological-therapies-explained/targeted-biological-therapies-secondary-breast.html [Web]		
Trastuzamab (Herceptin)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Biologicaltherapies/Monoclonalantibodies/Trastuzumab.aspx [Web]		
Trastuzumab Emtansine (Kadcyla)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Biologicaltherapies/Monoclonalantibodies/Trastuzumabemtansine.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Pertuzumab (Perjeta)	Cancer Research UK http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/cancer-drugs/pertuzumab-perjeta [Web]		
Everolimus (Afinitor)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Biologicaltherapies/Cancergrowthinhibitors/Everolimus.aspx [Web]		
Denosumab (Xgeva)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Biologicaltherapies/Monoclonalantibodies/Denosumab.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		

INFORMATION CONTENT	METASTATIC BREAST CANCER INFORMATION	DATE GIVEN	BY WHO AND SIGN
TREATMENT: BISPHOSPHONATES	**At least one relevant resource explaining the proposed cancer treatment should be offered**		
Bisphosphonates for secondary bone cancer	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Bonesecondary/Treatingsecondarybonecancer/Bisphosphonates.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Sodium clodronate (Bonefos)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Bonesecondary/Treatingsecondarybonecancer/Bisphosphonates.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Zoledronic acid (Zometa)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Bonesecondary/Treatingsecondarybonecancer/Bisphosphonates.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Ibandronic acid (Bondronat)	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Bonesecondary/Treatingsecondarybonecancer/Bisphosphonates.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Disodium pamidronate (Aredia	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Bonesecondary/Treatingsecondarybonecancer/Bisphosphonates.aspx [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
TREATMENT: OTHER	**As needed**		
Radiofrequency ablation	Macmillan Cancer Support http://www.macmillan.org.uk/information-and-support/treating/supportive-and-other-treatments/other-treatments/radiofrequency-ablation.html [Web]		
CLINICAL TRIALS	**At least one relevant resource explaining the proposed cancer treatment should be offered**		
Understanding cancer research trials	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		

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Patient focused research information	Cancer Research UK www.cancerhelp.org.uk [Web]		
Clinical trial	Local clinical trial patient information		
SIDE EFFECTS AND SYMPTOMS	**As needed**		
Side effects of cancer treatment	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Controlling the symptoms of cancer	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Coping with fatigue	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Managing breathlessness	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Controlling cancer pain	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Understanding lymphoedema	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Menopausal symptoms and breast cancer	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
PALLIATIVE CARE/END OF LIFE	**As needed**		
Coping with advanced cancer	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Caring for someone with advanced cancer	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Palliative care	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Your life and your choices: plan ahead	Macmillan Cancer Support http://be.macmillan.org.uk/be/s-448-downloadable-pdf-files.aspx [PDF]		
Secondary breast cancer: difficult choices and decisions at the end of life	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		

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SUPPORT/COPING	**As needed**		
Living with secondary breast cancer	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/secondary-metastatic-breast-cancer/living-secondary-breast-cancer [Web]		
Local support groups	Macmillan Cancer Support www.macmillan.org.uk [Web]		
Anxiety and depression with secondary breast cancer	Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Younger Women with Secondary Together	https://www.breastcancercare.org.uk/search?search_api_views_fulltext=Younger+Women+with+Secondary+Together [Web – links to information on events for younger women with secondary breast cancer]		
OTHER	**As needed**		
Help with the cost of living with cancer	Macmillan Cancer Support www.macmillan.org.uk [Web]		
Guide to benefits and financial help	Macmillan Cancer Support www.macmillan.org.uk/financialguidance [Web]		
Getting travel insurance	Macmillan Cancer Support http://www.macmillan.org.uk/information-and-support/organising/travel-and-holidays/travel-insurance [Web]		
Diet and cancer	Macmillan Cancer Support http://www.macmillan.org.uk/information-and-support/coping/maintaining-a-healthy-lifestyle/healthy-eating/healthy-diet-benefit.html [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Body image and cancer	Macmillan Cancer Support http://www.macmillan.org.uk/information-and-support/breast-cancer-secondary/coping/changes-to-appearance-and-body-image [Web]		
Cancer and complementary therapies	Macmillan Cancer Support http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		

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Talking to children when an adult has cancer	Macmillan Cancer Support http://www.macmillan.org.uk/information-and-support/coping/talking-about-cancer/talking-to-children [Web] Breast Cancer Care https://www.breastcancercare.org.uk/information-support/publications [PDF]		
Community services available	Local information leaflet		

Information factsheets on specific treatments also available on NHS Choices www.nhs.uk and CRUK www.cancerresearchuk.org websites.