UCLH Cancer Collaborative and UCLH

Metastatic Breast Cancer Pathway Project Report

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Table of Contents

1.0 Executive Summary ............................................................................................................. 3
2.0 Introduction .......................................................................................................................... 4
3.0 Strategic Context .................................................................................................................. 4
   3.1 Introduction to London Cancer ............................................................................................. 4
   3.2 University College London Hospital Foundation Trust (UCLH) ............................................... 4
   3.3 The UCLH Breast Service .................................................................................................... 5
   3.4 National Cancer Taskforce .................................................................................................. 5
4.0 Method ..................................................................................................................................... 6
   4.1 Project Governance and methods overview .......................................................................... 6
   4.2 Demand and activity data collection ................................................................................... 6
   4.3 Patient Survey ..................................................................................................................... 6
   4.4 Staff interviews .................................................................................................................. 6
   4.5 Internal and London Cancer stakeholder workshops ............................................................ 6
5.0 Results ..................................................................................................................................... 7
   5.1 Demand and activity data .................................................................................................... 7
   5.2 Clinic Audit .......................................................................................................................... 8
   5.3 The Voice of the patient ....................................................................................................... 9
   5.4 Staff Interviews ................................................................................................................ 13
   5.5 Current metastatic patient pathway .................................................................................... 14
   5.6 Proposed future metastatic Breast Cancer Pathway ............................................................ 15
6.0 Discussion ............................................................................................................................. 16
7.0 Recommendations ................................................................................................................. 16
8.0 Conclusion and benefits realisation ....................................................................................... 17
9.0 Progress and next steps ........................................................................................................ 17
10.0 Appendix A - Project Board .................................................................................................. 19
11.0 Appendix C - Staff interview sheet ...................................................................................... 19
12.0 Appendix B - London Cancer metastatic Breast Cancer Best practice workshop .................. 21
13.0 Appendix D - Patient Survey Questionnaire ........................................................................ 23
1.0 Executive Summary

This project report provides detailed outcomes of the Metastatic Breast Cancer Care redesign project commissioned by London Cancer to explore options available to London Cancer Breast Cancer Services in the light of growing demand of metastatic patients and limited resources.

The project aim is: “To develop through an inclusive service redesign process safe and effective multi-disciplinary models of care for patients within the metastatic Breast Cancer setting, ensuring equitable access to timely and appropriate care across health care and at home.”

The project was tasked with examining activity on the UCLH site only, however, experience and learnings were sought from other trusts in the London Cancer area through a wider stakeholder event and the project findings will be used to inform services across the network.

Methods of data and information gathering and input included:

- Gathering the Voice of Patients via questionnaires
- Gathering the Voice of Staff through face to face interviews and a stakeholder workshop
- Current demand data gathered from hospital information systems
- Current demand of metastatic patients through a 17 week clinic audit

Data analysis undertaken from December 2015 to September 2016 has indicated that the service is operating with an ever increasing demand with a cumulative annual growth rate (CAGR) of 12.3%; further examination has demonstrated that demand from metastatic patients is even greater growing at a CAGR of 16%. A linear growth rate would suggest a real time increase of 36% on today’s current clinic demand, creating a total of over 600 clinical attendances a quarter, of which over 280 would be from metastatic patients, by Q4 2017.

The 17 week clinical audit identified that as of now 46.5% of all clinical attendances at the outpatient clinic were patients with metastatic disease, an increase of 5.4% from March 2012. On average metastatic patients returned to clinic every 16 working days.

Information gathered from both staff and patients indicated levels of frustration with the services capabilities in matters such as; time to discuss metastatic patients at the Multi-Disciplinary Team Meeting (MDM), the level of nurse resource available for metastatic patients, the level of doctor resource available at clinics, appointment waiting times and a regularity of outpatient appointments taking place without the relevant scan or report available.

The project concluded that continuing to deliver metastatic Breast Cancer services in their current form is not a sustainable option and that some restructuring of services and procurement of extra nurse resource may be required. The project recommended that a number of actions be implemented by UCLH in order to ensure the continued provision of a high quality service to patients. These include but are not limited to:

- Recruit an additional Clinical Nurse Specialist
- Review current CNS structure to ensure time dedicated to metastatic patients
- The creation of a dedicated metastatic MDM to ensure metastatic patients have sufficient time and expertise to be reviewed and discussed
- Review current radiologist capacity for the breast team
- Implement the new metastatic patient pathway
- Review oncology clinics structure, especially use of stratified follow ups and CNS led follow up clinics
- Ensure a complete data set is captured on all metastatic patients
- Ensure palliative care and nuclear medicine input into the new pathway
- Review the current chemotherapy and biopsy pathways
- That an implementation group be convened to consider all recommendations
This report was discussed by the London Cancer Breast Pathway board in December 2017 and an update on progress is included in this report.

2.0 Introduction

This project jointly developed between London Cancer and Pfizer Ltd, examined models of Metastatic Breast Cancer care delivery within the London Cancer area.

Following consultation with a number of NHS Trusts, London Cancer decided to pilot the metastatic Breast Cancer Pathway project at the University College London Hospital (UCLH) due to its significant metastatic service and challenges around increasing demand on its current resource capacity.

Through an inclusive service redesign process the project has sought to:

“Develop through an inclusive service redesign process safe and effective multi-disciplinary models of care for patients within the metastatic Breast Cancer setting, ensuring equitable access to timely and appropriate care across health care and at home.”

It has provided recommendations, including a robust business plan, to support the delivery of the agreed pathway, supported the implementation process of a new model of care and provided a template for care delivery that can be rolled out across the London Cancer geography.

The project was broadly managed according to Prince 2 principles with oversight of the activity provided by a monthly project Board meeting. Input was sought from a wide range of stakeholders including patients (via anonymised questionnaires) and staff through one to one interviews and workshop sessions. These views have been noted in section 5.0 “Voice of the patients and “Voice of the Staff interview”. Additional opportunities for input were afforded at all stages of the project, and all views have been included in the project.

Because of the very real issue of increased demand outstripping capacity some quick wins were sought and then plans to implement a longer term strategy were suggested. A number of which have been implemented while others remain to be worked on. The overall aim is to improve the experience for patients and the UCLH Breast Cancer team alike whilst complying with the recommendations of the Independent National Cancer Taskforce.

The project was delivered between December 2015 and September 2016.

3.0 Strategic Context

3.1 Introduction to London Cancer

London Cancer is the integrated cancer provider system formed in 2012 to cover the geographical areas of North Central and East London and West Essex, with a population of 3.7 million.

London Cancer work with healthcare providers in these areas to deliver comprehensive and seamless cancer care to all patients from diagnosis, through treatment, to living with and beyond cancer. London Cancer’s goal is to develop a system where all healthcare providers come together to deliver cancer care that focuses on the needs of the patient, ensuring patients receive the same high level of care, no matter where they live across the region.

London Cancer was integrated into the newly formed UCLH Cancer Collaborative in September 2016, as one of six key work programmes.

3.2 University College London Hospital Foundation Trust (UCLH)

UCLH is a Foundation Trust hospital in North London serving the population of North Central and North East London. Its mission is to deliver top-quality patient care, excellent education and world-class research. UCLH is at the forefront of developing cancer care and is a specialist centre for many types of cancer, treating patients
from both the local area and across the country. UCLH hosts the UCLH Cancer Collaborative, which is part of the National Cancer Vanguard which aims to develop new, improved models of cancer care that can be replicated elsewhere.

3.3 The UCLH Breast Service

Each year UCLH treat more than 150 women from the local area with primary breast cancer as well as patients diagnosed elsewhere, who are then referred to the Trust for treatment. Patients will also be referred directly to the oncology service for management of their breast cancer, both primary and secondary disease, and for access to clinical trials.

3.4 National Cancer Taskforce

In July 2015, the Cancer Taskforce published its report, Achieving World-Class Cancer Outcomes, A Strategy for England 2015-2020. This included over 90 recommendations aimed at achieving a step change in cancer care in this country.

The report provides a vital roadmap to guide NHS work on cancer over the coming years. It focuses on six key priority areas:

- Prevention and public health;
- Early diagnosis;
- Patient experience;
- Living with and beyond cancer;
- Investment in a high-quality, modern service; and
- Commissioning, accountability and provision.

It was agreed that this projected was aligned to a number of these priority areas including; patient experience, living with and beyond cancer, Investment in a high-quality, modern service and Commissioning, accountability and provision.

As the population continues to grow and age, with cancer survival rates in all tumour sites improving, it is evident that without substantial capital investment, or other options for service delivery being implemented, then the current service will almost certainly not have capacity to deal with the forecast growth. Current service arrangements will inevitably become inadequate in coping with growing demand.
4.0 Method

4.1 Project Governance and methods overview

The project was resourced by Pfizer Ltd through Medical Educational Grant arrangements and led by London Cancer and UCLH personnel. The project sought the views of a range of stakeholders across the service provision arrangements as well as those of patients receiving services individually (through an anonymised patient survey, distributed, collected and collated by ULCH personnel) as well as more general overviews from patient groups. These views have all been fed into the project and have informed this project report.

Time was spent by the Project Board (for membership see Appendix A) exploring and base-lining current demand and also identifying demand growth. The board also spent time examining existing activities to explore opportunities for changes to process that could be effected within current resources before moving forward to mapping out options for potential new ways of delivering care to the patient group.

The project board identified four methods by which to collate the information to baseline the current service. These were:

4.2 Demand and activity data collection

Key metrics were identified by the project manager through discussion with the project board and two forms of data collection were identified to research the current service demand along with the specific demand of metastatic patients.

Firstly, breast clinic attendance figures were assessed from Q1 2012 to Q3 2016 to recognise growth rates of both new and follow up patients and predict future trends. This was also supported by an earlier clinic analysis conducted by Dr Robert Stein between September 2011 and March 2012, this was able to be used to understand the demand of metastatic patients during outpatient clinics and at that time their ratio compared to all patients.

Secondly a 17 week metastatic Breast Cancer clinic audit was conducted to determine an up-to-date ratio of metastatic patient attendances versus non-metastatic, and how regularly they attended clinic within that timeframe.

4.3 Patient Survey

To gain insight into the patient experience a survey was conducted in the Breast Cancer outpatient clinic targeted specifically at metastatic patients. The survey was designed between the project manager and the project board and was looking to explore questions around access to a key worker, information received, a treatment plan and involvement in decision making, as well as clinic wait times and experience.

4.4 Staff interviews

19 members of staff in different disciplines from across the team were interviewed and gave their permission for information and statements to be used.

4.5 Internal and London Cancer stakeholder workshops

Further to the staff interviews an internal workshop was attended by members from all disciplines across the team to brainstorm the current challenges and propose potential solutions. This information was also verified against the best practice and common themes information gathered from the external London Cancer wide workshop run at the beginning of the project (Appendix B).

Through these four main activities it was considered that a strong baseline of the current service could be understood, helping to highlight areas of potential alteration to improve the service delivery for patients, staff and UCLH.
5.0 Results

5.1 Demand and activity data

Data provided by UCLH via the Infoflex registry over the period 2012 – 2016 (4 years) demonstrated that both new and follow up patient numbers and number of clinic attendances have increased year on year. New referrals into the Breast Cancer service are increasing at a cumulative annual growth rate of 13.4% and follow up patients by 12.3% respectively. Although, new patient growth rates are slightly higher than follow up, it’s important to note follow up equated to 93.2% of all clinical attendances during this time. These patients although identified as follow up will not have completed treatment, the majority will be patients with primary and metastatic disease on treatment.

No long term data was available via the Infoflex registry to understand the capacity for metastatic patients, however, the 17 week clinical audit (conducted between the 16th February and 2nd June 2016) identified that 26.15% of all new, and 46.53% of follow up attendances were from patients diagnosed with metastatic disease. A previous clinic audit conducted by Dr Robert Stein between September 2011 and March 2012 demonstrated 41.1% of outpatient attendances were with patients with metastatic disease. Utilising these two audits we are able to assume in quarter 1 2012 that 41.1% of all follow up clinical attendances were with patients with metastatic disease, rising to 46.53% by quarter 3 2016. This real time increase of 5.43% equates to a quarterly increase of 0.34% over the period of data collection. Therefore, it was agreed to utilise these assumptions to model the number of clinical attendances from metastatic patients within the total clinical demand.

Fig 1: Illustration of the current clinical demand in Breast Cancer Outpatient Clinics from Q1 2012 to Q4 2016
It is demonstrated within Fig 2 that if clinical demand continues to grow with a linear trend follow up attendances will be over 600 a quarter by Q4 2017. With a CAGR of 16.0% for all metastatic patients it is predicted that metastatic attendees at clinic will be over 300 a quarter by the same time point and they will be contributing over 47% of all the attendances at the clinics. It is projected there will be a total 2348 attendances in the 2016/17 financial year, of which 1092 will be with metastatic patients.

5.2 Clinic Audit

A 17 week metastatic Breast Cancer clinic audit was conducted between the 16th February and the 2nd June 2016. All clinic attendances were captured and anonymised to determine the ratio of metastatic patient attendances versus non-metastatic, and how regularly they attend clinic within the timeframe1.

The audit collected data from 30 outpatient clinics, which comprised a total of 757 clinical appointments, 339 of which were with patients diagnosed as having metastatic disease (46.53% of the total appointments). The average number of appointments per clinic was 25.2 with the average number of metastatic appointments being 11.3 per clinic.

Note: When conducting any real time audit it’s important to note at the start and end of the time points captured, it is possible to obtain both patients either coming to the end of their patient pathway or just starting therefore, 2 patients were excluded from the first month (1 for a hospital number error and a second who had only had one attendance due to being at the end of their patient pathway). A further 18 were excluded who only attended once as their first attendance was within the last 16 days of the audit.
In order to understand the clinical demand of metastatic patients within the outpatient clinics it was also identified that a total of 120 metastatic patients generated the total of 339 appointments within the 17 week period, showing that on average metastatic patients return to clinic every 16 working days. The range was from patients who only attended once to a number that had up to 7 outpatient appointments within the timeframe averaging an appointment every 10 working days.

The Project Board reviewed the current and prospective clinical demand and it was accepted that the baseline data collected highlighted the challenge of an ever increasing demand of outpatient clinic appointments, in conjunction with a greater than average growth demand with metastatic patients. It is widely agreed due to the stage of their disease and treatment pathway, patients with metastatic disease have higher requirements. Therefore, gaining a clear understanding of the experience of these patients would be fundamental into making improvements in the pathway, whilst making it as efficient as possible.

5.3 The Voice of the patient

29 patients diagnosed with metastatic Breast Cancer were surveyed whilst they attended the outpatient clinic. A copy of the patient survey can be found in appendix D. Questions were asked to explore patient experience in the following areas:

- Key worker
- Information and clarity received about condition
- Involvement in treatment plan
- Support
- Imaging/reports
- Information on patients’ journey to the hospital
- Waiting time for appointments
- Chemotherapy service
- Comments on the overall service
From these survey results a number of key themes were identified as areas of frustrations for patients and were also highlighted either within the staff interviews or internal stakeholder workshop these were; access to key worker, imaging/reports, waiting time for appointments.

The majority of the patients surveyed felt that the experience they have had from the breast cancer team has been very good, 86% of patients felt involved in deciding their treatment (fig 5), 72% of patients felt they had received enough verbal and written information (fig 6) and 79% patients felt they had enough time to ask the questions that they wanted (fig 7).

![Fig 5: How involved did you feel in deciding your treatment](chart1.png)

![Fig 6: Since your referral to UCLH, have you received enough information about your condition?](chart2.png)

![Fig 7: Did you feel that you had enough time to ask the questions that you wanted?](chart3.png)
**The Key Worker**

The survey validated that the service from the key worker (normally the CNS) is seen as good with regards to the information received, the ability to access them and their speed of response. However, **34% of patients** were not given the name of a key worker (fig 8), and **45%** didn’t have the details of their key worker or found the question not applicable (fig 9).

*Imaging and reporting*

When questioned around the experience of having a scan and getting the scan reported almost ¼ (24%) experienced scans being organised **after the next scheduled clinical appointment** (fig 10). On average almost ½ (48%) have experienced clinical appointments conducted **without the relevant scan being reported** (fig 11) and according to the patients surveyed this caused an **additional appointment** or a **delay in treatment** for 24% of the patients.
Waiting times for appointments

It was recorded that, of all patients that answered, 91% waited over 30 minutes, beyond their appointment time for their appointment (fig 12). Of those delays, the most common wait times were either between 30-45 minutes or >1hour (fig 12). Of all the patients surveyed 27% of patients felt that a wait of less than 45 minutes would be reasonable and 27% felt a wait time of less than 30mins was more reasonable. (Fig 13).

Fig 12: OP Clinic wait times

<table>
<thead>
<tr>
<th>Wait Time</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>15-30 mins</td>
<td>24%</td>
</tr>
<tr>
<td>30-45 mins</td>
<td>24%</td>
</tr>
<tr>
<td>45-60 mins</td>
<td>24%</td>
</tr>
<tr>
<td>Less than 15 mins</td>
<td>21%</td>
</tr>
<tr>
<td>Over 60 mins</td>
<td>3%</td>
</tr>
<tr>
<td>(blank)</td>
<td>4%</td>
</tr>
</tbody>
</table>

Fig 13: Reasonable appointment wait time

<table>
<thead>
<tr>
<th>Wait Time</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-30 mins</td>
<td>27%</td>
</tr>
<tr>
<td>30-45 mins</td>
<td>27%</td>
</tr>
<tr>
<td>45-60 mins</td>
<td>27%</td>
</tr>
<tr>
<td>Less than 15 mins</td>
<td>8%</td>
</tr>
<tr>
<td>Over 60 mins</td>
<td>27%</td>
</tr>
</tbody>
</table>

Of the patients who answered the question 69% had a wait of over 30 minutes beyond their appointment exceeding what the majority (54%) of patients would feel is acceptable i.e. less than 30 minutes.

Patient Contact with the service

It is accepted that metastatic patients gain great benefit from being able to access and have contact with a number of support services such as palliative care, psychological/counselling and Macmillan. As would be expected almost all had had contact with an Oncologist, CNS and a pharmacist, however the vast majority had had little or no contact with these other support services (fig 14).

Fig 14: Have you had contact with any of the following members of the team?

Further verbatim comments and experience from the patient survey are available on request.
5.4 Staff Interviews

19 members of staff were interviewed between the 23rd February 2016 and the 28th April 2016. Staff were from a range of disciplines including but not exclusive to; Surgery, Oncology, Nursing, pathology, radiology, nuclear medicine, palliative care and administration. Interviewees were asked three broad questions to gather their opinions of the current metastatic Breast Cancer service and pathway (appendix C) and their answers recorded.

The three questions asked were:

- What were their opinions on the service in its current state?
- How could the service be improved?
- What challenges did they foresee in the future?

These were then collated into common themes by the project manager.

Interviews with clinical staff identified the following areas of strong performance and positive opinion:

- A high level of service support from the CNS team had been widely witnessed
- The strong reputation of UCLH had created many external referrals, and it was recognised the response rate to those referrals was good
- The standard of support services around Oncology were high, especially around symptom control/palliative care
- The Macmillan Cancer Centre resource was good, with an on call day registrar present so patients could be assessed if needed
- The wider team was viewed as supportive and approachable and strong cross departmental communication was documented
- The Palliative Care team was recognised for being very responsive to referrals and having close links with Breast Cancer service staff

Staff Interviews also revealed the following areas of concern/need for improvement and these have been grouped into the areas of Clinic Efficiency, Imaging/reporting, MDT and CNS resource.

Clinic Efficiency

- Booking staff are not always aware what doctors will be present within clinic
- Patients are routinely waiting far beyond their given clinic slot to be seen
- A disconnection between Outpatient appointments and scanning reporting, meaning a number of appointments are booked and delivered without the relevant scan or information

Imaging/Scanning:

- A lack of clarity from Oncology regarding what is exactly needed for the report
- Time taken to report on scans which impacts on other workload
- MRI scanner is over used as scans are often done when they don’t need to be
- Lack of images for comparison (external scans)
- Coordination with imaging and oncologists could be improved

MDT:

- Within the MDT meeting there is not enough time to discuss metastatic cases fully
- No separate metastatic MDT which would allow greater input from all disciplines
- Better understanding of why certain patients are discussed and what information is needed to prepare reports
- Greater understanding of which patients and the type of information required for discussion at the MDT
- Currently there is no pro-forma for the radiology team

CNS:
Currently there is a limited level of CNS resource which not only means this is stretched between too many patients, resulting in the service being reactive instead of proactive, it also means a lack of cover when the CNS is on annual leave.

Currently the resource is shared with the surgical team, not dedicated to Oncology.

These were not the only challenges recorded within the staff interviews but were the most common. Other challenges such as access to clinical trials, patient contact systems and links with other units, such as palliative care and Pharmacy were also noted.

5.5 Current metastatic patient pathway

During the staff interviews it was identified that it would be beneficial to plot the current metastatic patient pathway as it would allow the review of potential bottlenecks or areas of inefficiency to be identified. Through consultation with a number of clinical staff and review at a subsequent project board meeting the current patient pathway was identified (fig 15).

Fig 15. Existing UCLH metastatic Breast Cancer patient pathway

The review of the existing pathway identified a number of quick wins in improving patients’ initial entry into the metastatic pathway, such as, the development of a “Direct to Oncology” referral for patients with suspected disease progression instead of the standard 2 week wait referral pathway. This needs both education for local GPs on the pathway and internal trust arrangements for suspected metastatic patients to be offered oncology appointments rather than one stop clinic appointments. This would reduce the length of time a patient would have to wait to have a confirmed diagnosis of metastatic disease, as currently the patient attends a surgical clinic before being progressed to the Oncology clinic or MDM. This development is coupled with a more robust process of communication with the AOS team for any suspect cases that present through A&E.

The part of the pathway which required most reorganisation and improvement was the pathway for patients newly diagnosed with secondary disease. The vast majority of these patients do not benefit from the advantages of being discussed within a specialist metastatic MDM, having routine access to a metastatic CNS, and limited access to clinical trials and palliative care.
The new metastatic patient pathway (Fig 17) has been proposed as the optimal pathway to implement. It is recommended that all suspected new cases of metastatic disease should be seen by an oncologist or where appropriate go ‘straight to diagnostic tests’ and these results be reviewed in a metastatic MDM. It is proposed the creation of a specialist metastatic MDM, and metastatic clinic, would have a significant improvement in the patient and service experience and outcomes. Especially when aligned with an increase in CNS resource and closer links with other services such as palliative and community care. It is suggested a number of these services could be run away from the clinic and by other teams rather than the Oncology consultants alone.

**5.6 Proposed future metastatic Breast Cancer Pathway**
Business Needs

While maintaining the status quo can be an attractive option, capacity within the Breast Cancer Outpatient clinic is already stretched, with the current clinical resources available. The data collected identified for UCLH to be able to continue to deliver their current standard of care or to make improvements in the experience their metastatic patients receive, there is a need to increase the resource availability across a number of clinical areas as well as redesigning the current service to improve it.

6.0 Discussion

This project concluded that the current metastatic Breast Cancer service delivered within the trust is one which staff and patients feel provides a high standard of care. However, demand versus capacity trends have demonstrated that the current service is significantly stretched across a number of areas and with predicted growth rates within the metastatic Breast Cancer service, it is foreseeable that the current provision may not be fit for purpose in the future. The clinical audit has demonstrated the growth in numbers of metastatic patients within clinic is greater than that of non-metastatic patients, and in the current structure will become the mainstream attendee at clinic in the future. With the recognition metastatic patient management is more complex due to the fact they return to clinic more regularly, require a greater number of touch points, and benefit from having access to a wider range of specialities, there is a real demand to create a dedicated metastatic MDM to ensure these patients are discussed appropriately and go on to receive the appropriate service.

The patient and staff surveys also flagged the current challenge around imaging and reporting. It has been demonstrated that this is having a knock on effect with regards to clinic volume and patient experience, with 24% of patients either having a delay in treatment or requiring their appointment to be reorganised due to not having the relevant scan results available. Within the patient questionnaires 5 patients (17%) experienced having to have an additional appointment, due to not having a scan result. It is suggested this currently could equate to an additional 167 outpatient appointments a year (981/100*17). By reducing this figure to just 5% it would reduce the yearly number of clinical attendances by 120, whilst also helping to reduce patient wait times and improving the experience for both patients and staff alike. A number of further recommendations have been made by the project board to improve the current service and a full list can be found in section 7.0. On writing this report a number of these recommendations have started to be actioned and have progressed. If these recommendations can be actioned it will ensure the service is capable of dealing with the current and future capacity demand, and continue to deliver a high level of patient care and satisfaction.

7.0 Recommendations

After a full review of the baseline data, patient survey and staff interviews, a clinical workshop was conducted along with a subsequent project board meeting where the following recommendations were agreed:

- Recruit an additional Clinical Nurse Specialist
- Review CNS structure to ensure time dedicated to metastatic patients
- Creation of a dedicated metastatic MDM to ensure metastatic patients have sufficient time and expertise to be reviewed and discussed
- Review radiologist capacity for the breast team
- Review and document metastatic patient pathway
- Review oncology clinics structure, use of CNS led follow up clinics and stratified follow ups
- Ensure a complete dataset is captured on all metastatic patients
- Ensure palliative care and nuclear medicine input into pathway and attendance at metastatic MDM
- Review chemotherapy and biopsy pathways
8.0 Conclusion and benefits realisation

Through the baseline of the current clinical service, in conjunction with patient and staff surveys it has been possible to identify a number of areas which will require focus and reorganisation within the current service to ensure it is able to meet the needs of patients, staff and the Trust in the future. The full implementation of the recommendations, which we expect to be relevant to other Trusts in the London Cancer network, is expected to deliver the following benefits:

<table>
<thead>
<tr>
<th>Benefits to Patients</th>
<th>Benefits to Staff</th>
<th>Benefits to Trusts</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Appropriate care, delivered by appropriately trained professionals, in the appropriate setting</td>
<td>• Optimal clinic management</td>
<td>• Optimal patient safety</td>
</tr>
<tr>
<td>• Optimised patient and care experience</td>
<td>• Enhanced working experience</td>
<td>• More effective and efficient use of all clinical resources</td>
</tr>
<tr>
<td>• Equitable informed treatment choices for patients across the London Cancer geography</td>
<td>• Best possible knowledge of patient expectation</td>
<td>• Improved management of clinic numbers</td>
</tr>
<tr>
<td>• Optimum satisfaction with services</td>
<td>• Unambiguous working processes</td>
<td>• Optimum levels of staff satisfaction and engagement</td>
</tr>
<tr>
<td>• A strong voice in the development of services</td>
<td>• Ownership of new pathways</td>
<td>• Optimum compliance with relevant standards and guidelines</td>
</tr>
<tr>
<td>• Enhanced patient safety</td>
<td>• Benefits of effective multi professional working within a sustainable service delivery model</td>
<td>• Optimal stakeholder engagement in pathway and service development</td>
</tr>
<tr>
<td>• Maximise clinical outcomes</td>
<td></td>
<td>• Reduced risk associated with vulnerable / single handed practice</td>
</tr>
</tbody>
</table>

It is concluded that if all the recommendations within the project are delivered the service and the Trust will be in a position to ensure it continues to give the highest standard of care to its metastatic Breast Cancer patients. This will be through a patient pathway which is streamlined and efficient and will ensure patients have access to appropriate specialist services. The creation of a specialist MDM consisting of a highly dedicated, expert multidisciplinary team will ensure patients receive the highest quality of care, access to clinical trials and routine entry to support services both within the hospital and the community.

9.0 Progress and next steps

<table>
<thead>
<tr>
<th>Recommendations (UCLH specific)</th>
<th>Progress up to July 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Recruit an additional Clinical Nurse Specialist</td>
<td>• Successful business case and new CNS in post at UCLH</td>
</tr>
<tr>
<td>• Review CNS structure to ensure time dedicated to metastatic patients</td>
<td>• This has been completed – in addition to the new CNS there has been reorganisation of the current staff to ensure there is sufficient cover for leave. With the increased capacity CNS’s have developed a Secondary Breast Cancer Support Group which is meeting monthly and is open to all patients within the London Cancer geography – not just UCLH patients</td>
</tr>
<tr>
<td>• Creation of a dedicated metastatic MDM to ensure metastatic patients have sufficient time and expertise to be reviewed and discussed</td>
<td>• Infrastructure is in place (e.g MDT co-ordinator, available room and time in oncology job plans) but implementation date awaited due to radiology capacity limitations</td>
</tr>
<tr>
<td>Action</td>
<td>Status</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Review radiologist capacity for the breast team</td>
<td>No increase yet in radiology provision</td>
</tr>
<tr>
<td>Review and document metastatic patient pathway</td>
<td>Ongoing (and partly dependent on MDT)</td>
</tr>
<tr>
<td>Review oncology clinics structure, use of CNS led follow up clinics and stratified follow ups.</td>
<td>Implementation date for metastatic clinic agreed</td>
</tr>
<tr>
<td></td>
<td>Implementation of stratified follow up in progress</td>
</tr>
<tr>
<td></td>
<td>New development of joint appointments with other trusts as part of the metastatic review and aim to improve care across the whole geography:</td>
</tr>
<tr>
<td></td>
<td>1. Whittington medical oncologist will start joint clinics in September, which will improve clinical trials access for those patients and will give oncology cross-cover for leave, as currently lone practitioner at the Whittington</td>
</tr>
<tr>
<td></td>
<td>2. New Consultant Oncologist post approved with Princess Alexandra Hospital Harlow, also to facilitate metastatic patients access to clinical trials.</td>
</tr>
<tr>
<td>Ensure a complete dataset is captured on all metastatic patients.</td>
<td>Not yet fully implemented</td>
</tr>
<tr>
<td>Ensure palliative care and nuclear medicine input into pathway and attendance at metastatic MDM.</td>
<td>Palliative care attend clinics to provide Enhanced Supportive Care for all new metastatic patients and those at critical decision points in their pathway. In another service development palliative care also join the consultant ward round weekly to improve the care of metastatic in-patients.</td>
</tr>
<tr>
<td></td>
<td>Nuclear medicine consultant now attends the main MDM for discussion of relevant metastatic cases</td>
</tr>
<tr>
<td>Review chemotherapy and biopsy pathways</td>
<td>Deferred until some of the other improvements in place</td>
</tr>
</tbody>
</table>
10.0 Appendix A - Project Board

**Executive Sponsors**
Professor Kathy Pritchard-Jones – Chief Medical Officer, *London Cancer*
Jonathan Wright

**Project Board**
Dr. Rebecca Roylance – Project Executive, Medical Oncologist and *London Cancer* Breast Pathway Board Director
Prof Rob Stein – Medical Oncologist
Dr. Glen Blackman – Clinical Oncologist
Dr. Kate Hawkin
Karen Hibbert - Macmillan Breast Care Specialist Nurse
Dr Anna Goringe - Palliative Medicine Consultant
Chrissie O’Leary – General Manager
Jonathan Wright
Dan Jones – Project Manager

**Quality Assurance**

**Operational Management Team**
Dr Rebecca Roylance
Chrissie O’Leary
11.0 Appendix C - Staff interview sheet

Metastatic Breast Cancer Pathway Redesign Project

Semi Structured Interviews

Meeting notes: Date

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Meeting time</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

| Name : |

What are your opinions on the service in its current state?

How could the service be improved? Give examples....

What challenges do you foresee?

NOTES

[Blank space for notes]
12.0 Appendix B - London Cancer metastatic Breast Cancer Best practice workshop

Overview of the common themes:

1. Number of patients unknown (database issues)
2. Generally metastatic patients are slotted in around other services and clinics
3. Not all specialties required are present in every MDT
4. Specialist management of specific issues such as brain Mets
5. CNS services vary, but need to be conscious one size doesn’t fit all
6. Varied ease of access to clinical trials
7. Access to support services for patients e.g. Psychology
8. Access to Palliative care and link with community care support

The Future: What could the pathway look like?

MDTs

- Improve radiology integration and collaboration
- Capacity needs to be identified and managed
- Palliative care should be present within MDT’s
- Psychological support within the MDT
- Neuro team in attendance to assist with brain mets
- Need to improve efficiency as bigger MDT teams will slow down case throughput

Questions:

- Will specialist metastatic MDTs take external referrals from other centres
- More MDT’s could impact on treatment decisions causing greater delays
- Communication is key

CNS access for metastatic patients

- Physical presence is important
- Ability for a metastatic CNS’s have the ability to say no to non-metastatic patients
- Would be great for the nurse to follow the patient not move the patient around physically
- Patient capacity needs to be identified and capped to provide a successful service
- Need to be linked in with community

Clinical Trials

- Communication is key
- Research numbers shared across network
- London Cancer website updated and available for all showing open trials and point of contact

Patient Support Services

- Find a way to share all the information across London Cancer with patients highlighting all the support services available
- A one place where all information and links are available
- Macmillan support Officer should be contacted around best practice and how to share across London Cancer
- Currently no information is available to HCP as to what patients are available to what by postcode/ GP practice
Palliative Care & Community

- Currently postcode dependent and varied
- Currently difficult to navigate services between trusts
- Symptom driven rather than progress driven
- Where should resources and services sit, not all services are best delivered or appropriate to be delivered in hospices
- A clear definition of what Palliative care does

Identify someone to look at creating a metastatic patient database

- Identify the minimum data set
- Detail vs usability
- What is the objective? What will it be used for?

A specific Metastatic Breast Cancer pathway

- Specialist metastatic MDT’s across a number of sites
- Patients offered access to clinical trials along the whole pathway
- Link to psychology and other support services
- Support to GP’s and other HCP’s
- Specialist management of brain mets
- Complex patients clinic, for patients requiring extra support
## 13.0 Appendix D - Patient Survey Questionnaire

Survey of patient experience of UCLH breast cancer outpatient services

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Date survey completed</th>
<th>Were you given a named person (Key Worker) to contact for information and advice at UCLH (other than your Consultant)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>1.</td>
<td>DD/ MM/ YYYY</td>
<td>□ Yes □ No □ Can't remember □ If you answered yes, please give the name:</td>
</tr>
<tr>
<td>2.</td>
<td>2.</td>
<td></td>
<td>□ Yes □ No □ Can't remember □ If you answered yes, please give the name:</td>
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<td>3.</td>
<td>3.</td>
<td></td>
<td>□ Yes □ No □ Can't remember □ Not applicable □ If you answered yes, please give details:</td>
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<tr>
<td>4.</td>
<td>4.</td>
<td></td>
<td>□ Easy □ Adequate □ Difficult □ Not applicable □ If difficult do you have any suggestions to improve contact?</td>
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<tr>
<td>5.</td>
<td>5.</td>
<td></td>
<td>□ Same day □ Next day □ Next week □ Never □ N/A</td>
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<tr>
<td>6.</td>
<td>6.</td>
<td></td>
<td>□ Yes □ Partly □ No □ Can't remember □ Written □ Verbal information</td>
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<td>7.</td>
<td>7.</td>
<td></td>
<td>□ Yes □ No □ Can't remember □ Not applicable □ How could we do things better?</td>
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<tr>
<td>8.</td>
<td>8.</td>
<td></td>
<td>□ Very clear □ Fairly clear □ Not very clear □ Can't remember □ Not applicable</td>
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<tr>
<td>9.</td>
<td>9.</td>
<td></td>
<td>□ Yes □ Partly □ No □ Can't remember □ Written □ Verbal information</td>
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<td>10.</td>
<td>10.</td>
<td></td>
<td>□ Yes □ No □ Can't remember</td>
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<td></td>
<td>Question</td>
<td>Options</td>
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<td>-----------------------------------------------------------------------------------------------</td>
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<tr>
<td>11.</td>
<td>How involved did you feel in deciding your treatment plan?</td>
<td>□ Completely involved □ Partly involved □ Not at all involved □ Did not want to be Involved □ Can’t remember</td>
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<td></td>
<td></td>
<td>If you answered Partly involved, or Not at all involved, please say why:</td>
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<tr>
<td>12.</td>
<td>If you felt partly or not involved in deciding your treatment plan, would you have liked more involvement?</td>
<td>□ Yes □ No □ No preference □ Can’t remember □ Not applicable</td>
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<td>If you answered yes, please give details:</td>
<td></td>
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<tr>
<td>13.</td>
<td>Did you feel that you had enough time to ask the questions that you wanted?</td>
<td>□ Yes □ No □ No preference □ Can’t remember □ Not applicable</td>
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<td>If you answered yes, please give details:</td>
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<tr>
<td>14.</td>
<td>Do you know who to contact for out-of-hours support at weekends or overnight?</td>
<td>□ Yes □ No □ Can’t remember</td>
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<td></td>
<td></td>
<td>How could we do things better?</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Have you had contact with any of the following members of the team?</td>
<td>Tick all that apply:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 □ Oncologist 2 □ Surgeon 3 □ Specialist breast nurse (CNS) 4 □ Occupational Therapist 5 □ Dietician 6 □ Pharmacist 7 □ Hospital palliative care nurse 8 □ Community palliative care nurse 9 □ Hospice 10 □ MacMillan Support and Information Service 11 □ Social worker 12 □ Physiotherapist 13 □ Lymphoedema Nurse Specialist 14 □ Counselling/psychological service 15 □ Other - please specify ________________________________ □ No contact with any □ Can’t remember</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Thinking of your recent outpatient appointment at UCLH, did the team take account of the following?</td>
<td>Physical needs: □ Yes □ No □ Can’t remember</td>
<td></td>
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<td>Emotional needs: □ Yes □ No □ Can’t remember</td>
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<td>Practical needs: □ Yes □ No □ Can’t remember</td>
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<td></td>
<td></td>
<td>Psychological needs:</td>
<td></td>
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<td>Question</td>
<td>Options</td>
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<td>□ Yes                             □ No                             □ Can’t remember</td>
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<td>Spiritual needs:</td>
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<td>□ Yes                             □ No                             □ Can’t remember</td>
<td></td>
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</tr>
<tr>
<td>How could we do things better?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17. Were there any symptoms or issues you would have liked more help with?  
□ Yes                             □ No                             □ Can’t remember                       |                          |
| If yes, please give details:                                               |                          |

18. Thinking of your most recent imaging – was your scan(s) appointment(s) arranged  
□ Within One week before next appointment                         |
□ Within 2 weeks before next appointment                           |
□ Same day                                                          |
□ After next appointment                                             |

19. Was the scan reported when you returned to clinic for the results  
□ Yes                             □ No                             |
| If no did this result in an additional appointment Y/N  |
| Or delay in treatment Y/N                                          |

20. How long did your journey to clinic take today?  
□ Less than 1 hour       □ 1-2 hours             □ Over 2 hours                        |

21. How important to you is it that your journey time is short?  
□ Very important        □ Important            □ I don’t mind                        |

22. How long did you wait for your appointment today?  
□ It was on time    □ Less than 15 mins   □ 15-30 mins                        |
□ 30-45 mins                                       □ 45-60 mins                        |

23. How long do you feel it is reasonable to wait for an appointment?  
□ Less than 15 mins   □ 15-30 mins   □ 30-45 mins                        |
□ 45-60 mins                                       □ I don’t mind                        |

24. If you have experienced any delays, were you informed how long you would be waiting?  
□ Yes                             □ No                             □ Not applicable                       |
| How could we do things better?                                           |

25. How would you like to be called for your appointment?  
□ Intercom                  □ TV screen             □ Buzzer/pager                        |
□ Name called by nurse                                       □ I don’t mind                        |

26. How long did your consultation today take?  
□ Less than 15 mins   □ 15-30 mins   □ 30-45 mins                        |
□ 45-60 mins                                       □ Over 60 mins                        |
27. Since being diagnosed, have you felt at any point that you did not want to continue the treatment?
   - Yes - previously
   - No
   - Can’t remember
   - Yes - currently
   - Not applicable
   If Yes - currently:
   Please arrange an appointment with your Consultant Oncologist, or contact another member of your clinical team.

28. If you received chemotherapy, did you have enough privacy during your treatment?
   - Yes
   - No
   - Not applicable
   How could we do things better?

29. If you received chemotherapy today, did you feel that during the treatment you had an opportunity to discuss your emotional well-being if you wanted to?
   - Yes
   - No
   - Not applicable
   How could we do things better?

30. If you have experienced delays while receiving chemotherapy treatment which of these apply?
   - Waiting for a nurse
   - Waiting for a doctor
   - Waiting for medication to be delivered
   How could we do things better?

31. How would you rate your overall experience on the chemotherapy day unit? (1=very poor, 10=perfect, please ring your answer)
   1 2 3 4 5 6 7 8 9 10
   How could we do things better?

32. Have you had any support other than from your Consultant?
   - Yes
   - No
   - Can’t remember
   - Not applicable
   If Yes, please give details:

33. Have you experienced any delays in treatment?
   - Yes
   - No
   - Can’t remember
   If Yes, were these delays in (tick all appropriate boxes):
   - Blood tests
   - Clinic appointment time
   - Chemotherapy appointment time
   - Radiotherapy appointment time
   - Reporting of radiology scans
   - Other
   If Other please give details:

34. If you have any further comments regarding the service you have received please include them here

We would like to collect some general information about you
35. What is your age
- □ Under 30
- □ 30-40
- □ 40-50
- □ 50-60
- □ 60-70
- □ 70-80
- □ 80+

36. Who is at home with you
- □ Live alone
- □ Live with partner/spouse
- □ Live with family member
- □ Any children under 18 – if so list ages

37. What is your ethnic group?
- WHITE □ British □ Irish
  - □ Any other White background, please specify:
- MIXED □ White and Black Caribbean □ White and Black African □ White and Asian
  - □ Any other Mixed background, please specify:
- ASIAN OR ASIAN BRITISH □ Indian □ Pakistani □ Bangladeshi
  - □ Any other Asian background, please specify:
- BLACK OR BLACK BRITISH □ Caribbean □ African
  - □ Any other Black background, please specify:
- CHINESE OR OTHER ETHNIC GROUP □ Chinese
  - □ Any other ethnic group, please specify:

Thank you for taking the time to complete this questionnaire.
Please return the survey to tray on the Reception desk on departure.

I DO NOT WISH TO TAKE PART IN THIS SURVEY □