London Cancer Metastatic Breast Cancer Event Evaluation Form – Wednesday 12th June 2019 from 12:30-17:00

On Wednesday 12th June, the North Central and East London Cancer Alliance hosted a Metastatic Breast Cancer Workshop to update on current services offered and share best practice across the network, sponsored and facilitated by Pfizer. The event was attended by 17 staff members from 6 trusts, including consultant oncologists, CNSs, administrative staff, GPs and registrars.

The day started with updates from Trusts on how they had progressed since the last sector meeting on this topic in 2016. Particular areas of best practice were then shared, followed by a workshop style session on the highest priority areas for future developments, which the attendees nominated based on the Trust updates.

Feedback from the event was hugely positive, particularly in support of the opportunity to hear from other units and receive in depth presentations from the Enhanced Supportive Care team at UCLH, Haven (a charity that supports women through their breast cancer treatment) and the Health Care Worker at BHRUT. All respondents left with priority actions to take forward, many of which focused on the need for a database for metastatic patients. Respondents rated the events usefulness as 8.3 out of 10.

Summary of messages from Trust updates

- Trusts generally reported positive progress in developing the CNS workforce to support patients with metastatic breast cancer, however in the case of the Royal Free a CNS was not yet in post as the business case had taken some time to sign off.
- Access to wider support services for patients had progressed positively.
- There was a discussion about different models for running clinics, for example whether it was more effective to separate metastatic patients into a separate clinic.
- Metastatic MDT discussions had generally improved with Trusts having various models for providing this.
- The opportunity for patients to self-administer denosumab was discussed as a positive change in NCL.
- There are remaining workforce and database challenges.

SHARING/CASE STUDIES: Haven, Nicola Cunningham, Breast Cancer Haven Manager

The Haven has been running at the Whittington for 2 years with 987 attendances during that time (132 additional attendances at Fulham following attendance at the Whittington site). The Fulham service will be moving to Barons Court for 9 months and then to its new permanent home in Kings Cross.
The service is accessed by self-referral. Leaflets describing the service are available and can be ordered at the Haven website.

Patients are offered:

- 1-hour consultation to understand needs
- 6 hours of supportive therapy (can be extended by an additional 4 hours if they can travel to Fulham)
- 4 hours counselling for individuals who are BRCA carriers
- 4 hours counselling for those indirectly affected by cancer (friends, family)
- A secondary support group – 2-hour event with expert speaker on a chosen subject eg. Pain/fatigue followed by counsellor led group work. The sessions are running monthly for a 6-month trial.

**SHARING/CASE STUDIES: Patient Database and Health Care Worker, Linda Park BHRUT**

Linda shared the experience of the addition of a Macmillan Cancer Support Worker (CSW) to the team. Prior to the CSW joining, as CNS she was swamped with the volume of requests for support from patients, the complexity of their needs along with the demands of administration. The selection of the right person has been key to the success of the role – finding someone with experience of the hospital/clinical environment who is used to interacting with patients was important. There have been some questions and concerns from the wider team with regards to role clarity and there is an ongoing effort for the CSW to connect with the wider community teams. The role is non-clinical, complementary to the CNS role and all activities are agreed by and performed with oversight from the CNS.

Example of tasks that the Cancer Support Worker undertakes:

- Signposting services
- Triaging patient calls for CNS response
- Sorting appointment issues
- Chasing scans
- Making informal visits to patients during in-patient stays
- Orientating patients to the department – walking them around
- Putting together information packs
- Managing the database
- Setting up Health Needs Assessments
- Supporting more vulnerable patients (eg. Those with dementia) in navigating the system.

A local database has been established within BHRUT and is currently tracking 200+ metastatic patients. The database has been created to overcome issues when uploading data to the Somerset system when patients move from a primary to secondary breast cancer pathway. The BHRUT team have been in contact with Public Health England and a data manager from Maidstone, to share best practice and current challenges and discussions continue.

**SHARING/CASE STUDIES: Enhanced Supportive Care, Caroline Williams, Lead Clinical Nurse Specialist and Dr Tom Spiegler, UCLH**
The Enhanced Supportive Care (ESC) service is pro-actively offered to metastatic breast cancer, upper GI, Ovarian and Endometrial patients and delivered as an outpatient service based at the Macmillan cancer centre. The service has a Consultant lead, a full time CNS (prescriber) and 3 part-time GPs. All patients are automatically offered the service and provided with a leaflet about ESC.

The ESC team aims to improve QOL and patient satisfaction, improve communication between UCLH and community teams, manage the interface into palliative care (and help manage patients where palliative care services are overburdened) and reduce unnecessary admissions.

The ESC team works in a complementary fashion liaising closely with the CNS and oncology team.

The types of services offer include:

- Symptom control
- Psychological support
- Continuity of care/communication
- Support with decision making and advanced care planning
- Specialist palliative care assessments and managing referrals

**Workshop Sessions**

The following topics were selected for discussion during the workshop session:

1. Data and databases
2. Clear pathway.

**Data and Databases:**

- Challenges exist inputting data to systems such as Somerset, Infoflex and EPIC. There is a lack of confidence that data input is correctly reported in national statistics.
- All agreed that access to data around metastatic patients is not currently working or providing the information/support that teams need for successful planning of services.
- There were multiple examples cited during the days discussions of locally collected data not marrying reports from larger/national databases.
- Identifying a strategy for overcoming the current situation is fraught. A bottom up approach (creating locally driven databases) and feeding into national statistics isn’t working due to difficulties with systems such as Somerset. A bottom down approach (for example using SACT data) requires engagement at a national level to improve granularity of data which is a major task and hard to navigate.
- Potential points of access/triggers for capturing data around newly diagnosed metastatic patients discussed:
  - MDT meetings/MDT co-ordinators
  - Acute oncology inpatient admissions
  - SACT data.
- Ideas to be considered for further action:
Ask London Cancer Collaborative to connect the group with Business Intelligence services to take the conversation forward.

Access and explore pockets of best practice eg. Maidstone

Explore creating a registry for the London group to ‘shine a light’ on the disparity between the real local data and that which is being reported at a national level

Ask NHSE to talk to the group regarding what is working well and how SACT could be extended to included metrics pertinent to metastatic patients (endocrine status, palliative care etc).

Clear pathway:

What does an optimal pathway look like for the patient?

- Clear referral route for known or suspected secondary breast cancer patients
- GP Education around referral routes
- GP Access to scans (bone or CT) – referral/scan process clarity
- Clear referral point for GPs (not one stop)
- Optimise MDT arrangements and access to specialist MDTs
- Optimise clinic arrangements to suit local needs
- Agree overarching outline/guidelines (localised to site)
- Improve information flow around clinical trials - ?newsletter

Action points highlighted:

- Referral route – clarify/simplify and ensure clear referral route from primary care
- Education/training – referral route, GP, A&E etc.
- Roll out trigger points
- Set targets!

Points of general discussion raised throughout meeting:

Discussion of the burden of grouping metastic patient appointments. Can be extremely tiring due to the intensity of the appointments. Metastatic only clinics can be an emotional strain. Trust factors, i.e size of patient population, number of clinicians/CNSs could come into play – in some areas it may be possible to have a metastatic only clinic due to the variation in patient populations/behaviours.

Somerset/IT system pro-formas – what is actually going into the databases?

Discussion around. nurse-led and pharmacist-led clinics running in parallel to oncologist clinics to allow opportunity for cross over and clinician support.

Next steps

This write up from the event will be publicised and shared around the network so that those who were not able to attend might also benefit from it.
Individuals that gained insight from this event should take these shared learnings and new insights back to their trusts and implement changes that will help develop their local metastatic service. These will then be fed back to the network at a future event in order to continue the spread of best practice.
Appendix 1 – detailed Trust updates

UPDATE: Barts Health – Andaya Marilene, Breast Cancer Clinical Nurse Specialist

Currently 4 CNS for primary, 1 Macmillan funded CNS for metastatic patients (200-400 patients).

Metastatic CNS post was created in 2015, following the Breast Cancer Care Pledge Report work in September 2013 which highlighted the needs of the metastatic patient and the need for a dedicated metastatic CNS.

Barriers to optimum care for metastatic patients:

- Language/communication, requirement for advocates. Access to interpreters is becoming a problem.
- Staff retention/turnover is a constant issue. Continuity of care.
- Referral/discharge cycle with community palliative care services.
- Access to accurate data. There is 6 years of data and no database to provide access.
- Absence of adequate transport.

Status of current service:

- Communication/signposting of services – have created an information pack for metastatic patients, including 1 booklet for each potential organ site (sourced from Macmillan and Breast Cancer Care). Provide patients with the Secondary Pledge booklet.
- Access to services – refer to community services for lymphoedema.
- Site upgrades – recent update of the site has given patients access to a Maggies Centre as well as Macmillan information centre.
- Access to 24hr chemo hotline.
- Access to clinical trials is improving with recruitment from across East London.
- Access to palliative care is handled via combination of referral to St Joseph’s hospice and district nurses. Referrals need to be handled carefully in order to ensure that patients are not discharged and ongoing discussion is required around this issue. Specific detail of referrals is required (clarity around specific symptoms eg. Pain).

Organisation of clinics:

- CNS pro-actively monitors appointments to see who is coming in and keep things on an even keel.
- Aiming for a ‘one stop shop’ for metastatic patients on oral therapies. Trying to provide appointment with Consultant, consent and dispensing in one visit. CNS manages this process aiming to pre-assess patients and prevent their waiting times. Pharmacy use ARIA to check bloods, confirm fitness for treatment and dispense.
- No official telephone clinic but CNS does proactively call patients to check in and follow up.
- Patients do not frequently contact the CNS for support, mostly the CNS reaches out to the patients.
UPDATE: Barking, Havering and Redbridge University Hospitals, Linda Park, Secondary Breast Cancer Clinical Nurse

BHRUT currently have a Secondary CNS for 3 days per week and 1 Cancer Support Worker. CNS works with the Enhanced Supportive Care team and refers to community services. There is a large volume of call from patients with complex needs. Having a Cancer Support Worker is helping with triage of patient calls and admin, organisation and orientation of patients to the department.

Status of current service:

- Created an interactive (online) patient walkthrough, showing the patients’ journey through the department.
- MDT arrangements – whilst screening patient are discussed there is a separate discussion of metastatic patients which feels an efficient use of time. Plans are in place to create a metastatic specific MDT form.
- Communication/signposting services – patients are given an information pack with space at the back where you can add BHRUT information leaflet, details of key worker and helpline numbers. The BHRUT Bridge newsletter is used to detail the courses and complementary therapies available. Patients are given access to the ‘Orange’ line at St Francis’ Hospice.
- Access to palliative care – refer to district nurses which can be problematic as they tend to discharge patients if they don’t feel they are symptomatic. Access to services – there are more and more referrals being required for social type services.

Organisation of clinics:

- New patient clinics are currently mixed. Follow up clinics are beginning to be grouped and consideration being given to different appointment lengths in light of the need for longer appointments for metastatic patients. An audit is underway to assess the split between primary, adjuvant and metastatic patients in clinic.

UPDATE: North Middlesex University Hospital, Girija Anand, Consultant Clinical Oncologist

North Middlesex has 3 CNS but no specific metastatic CNS. All CNS’s help to identify metastatic patients.

Status of current service:

- In 2015/16 a metastatic MDT was set up. Initially the MDT ran across sites on a weekly basis, however it was challenging to get the group together and the meeting was reconfigured to run every week for 1 hour at the end of the main breast MDT. The Somerset pro-forma is used, which has some limitations.
- 2 cold cap machines have been acquired via a charitable grant.
- A new dedicated oncology pharmacist post has been created (starting this week) and the ambition is that there will be a pharmacist led clinic with the lead chemo nurse to help with screening patients for oral chemotherapy. Team are aiming for the oncology pharmacist to be a non-medical prescriber.
The cardiology pathway is under review.

**Organisation of clinics:**

- Chemo nurses also see metastatic patients. Oncologists see patients every 3 months, CNS see patients monthly.
- A denosumab specific nurse led clinic has been set up.

**UPDATE: Princess Alexandra Hospital, Dr Apostolos Konstantis, Consultant Medical Oncologist**

**Status of current service:**

- MDT arrangements – currently have a dedicated section for discussion of metastatic patients within the main MDT, 2 dedicated oncologists available.
- Established a metastatic clinic with new metastatic CNS Karen Whitelock
- Established a partnership with UCL for new patients with brain metastases.
- No database currently available ref. metastatic patients.
- No psychological support currently available.

**UPDATE: Royal Free London, Tina Kelleher, Advanced Nurse Practitioner and Lead Nurse - Breast**

A metastatic CNS is yet to be appointed. Efforts have been under way to establish this post for 21 months (took 13 months to build the business case) and the post has just been accepted with help from Macmillan.

**Status of current service:**

- A metastatic clinic was established; however, it was difficult to make it work.
- One of the lead chemo nurses has been trained as a prescriber.
- Chemo and palbociclib checks are handled by a nurse led clinic.
- Breast services are managed by the surgical division.

**UPDATE: University College London Hospital, Karen Hibbert, Breast Oncology CNS and Dr Rebecca Roylance, Consultant Medical Oncologist**

There are 2 breast oncology CNS (no dedicated metastatic CNS) employed by Women’s Health plus 2.5 days of a breast support worker. Team estimate that there are approximately 100+ metastatic patients.

**Status of current service:**

- Improved pathways are in place ie. Pleural drainage and self-administration of denosumab.
- Data and database is still a struggle.
- MDT arrangements – struggling due to radiology resource.
- Access to palliative care services have improved significantly due to the work of the Enhanced Supportive Care team.
- Access to clinical trials is increasing due to links with PAH, North Middlesex, Whittington, Barts and is driven by relationships between staff and word of mouth advertising trials.
Having identified the need for a metastatic patient support group, the team worked jointly with the Haven and Macmillan to start an early evening group offering support from a psychologist, CNS and Macmillan support worker. The pilot ran for 1 year but didn’t take off (only about 6 patients or so used regularly). The group was re-designed in light of feedback from patients that they wanted to be with other metastatic patients (and worried about discussing their issues in front of non-metastatic patients) and a group within the Macmillan Information and Support area was started. Unfortunately, this group was also poorly attended. Now planning to offer Health and Wellbeing events for metastatic patients (similar to Christie) offering educational talks around self-care and issues such as fatigue.

Appendix 2: Attendees

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<tr>
<th>Name</th>
<th>Role</th>
<th>Trust/Organisation</th>
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<tbody>
<tr>
<td>Girija Anand</td>
<td>Consultant Clinical Oncologist</td>
<td>NMUH</td>
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<tr>
<td>Marilene Andaya</td>
<td>Breast Cancer Clinical Nurse Specialist</td>
<td>BH</td>
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<tr>
<td>Charlotte Atkinson</td>
<td>Specialist registrar</td>
<td>BHRUT</td>
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<tr>
<td>Nicola Cunningham</td>
<td>Breast Cancer Haven Manager</td>
<td>Haven</td>
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<tr>
<td>Karen Hibbert</td>
<td>Breast Oncology Clinical Nurse Specialist</td>
<td>UCLH</td>
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<tr>
<td>Tina Keller</td>
<td>Advanced Nurse Practitioner &amp; Lead Nurse - Breast</td>
<td>RFL</td>
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<tr>
<td>Judy King</td>
<td>Consultant Medical Oncologist</td>
<td>RFL</td>
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<tr>
<td>Apostolos Konstantis</td>
<td>Consultant Medical Oncologist</td>
<td>PAH</td>
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<tr>
<td>Albena Naydenova</td>
<td>Breast Data Coordinator &amp; Administrative support</td>
<td>BHRUT</td>
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<tr>
<td>Elsa Papadimitraki</td>
<td>Consultant Medical</td>
<td>UCLH</td>
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<td>Linda Park</td>
<td>Secondary Breast Cancer Clinical Nurse Specialist</td>
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<td>Rebecca Roylance</td>
<td>Consultant Medical Oncologist</td>
<td>UCLH</td>
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<tr>
<td>Tom Spiegler</td>
<td>GP, The Statham Grove Surgery</td>
<td>ULCH/The Statham Grove Surgery</td>
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<tr>
<td>Liz Tee</td>
<td>Breast Oncology Clinical Nurse Specialist</td>
<td>UCLH</td>
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<tr>
<td>Karen Whitelock</td>
<td>Clinical Nurse Specialist</td>
<td>PAH</td>
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<tr>
<td>Caroline Williams</td>
<td>Lead Clinical Nurse Specialist - Enhanced Supportive Care Team</td>
<td>UCLH</td>
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<tr>
<td>Lai Cheng Yew</td>
<td>Consultant Clinical Oncologist</td>
<td>NMUH</td>
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**Organisers and facilitators**

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<tr>
<th>Name</th>
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<tr>
<td>Lisa Edge Davies*</td>
<td>Patient Experience Manager</td>
<td>Pfizer Ltd</td>
</tr>
<tr>
<td>Larissa Quinn</td>
<td>Programme Coordinator</td>
<td>NCEL Cancer Alliance</td>
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<tr>
<td>Helen Saunders</td>
<td>Programme Manager</td>
<td>NCEL Cancer Alliance</td>
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*Lisa Edge Davies (Patient Experience Manager) is contracted from Pfizer to UCLH Cancer Collaborative to provide management consultancy services as part of a Medical and Educational Goods and Services arrangement.  
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Pfizer Sponsor
Lisa Edge Davies

Name
UK_PIH_UCLH London Cancer Collaborative metastatic breast cancer workshop_Meeting summary (MEGS)

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