

## **London Cancer Living with and Beyond Cancer Implementation ERG**

Date: **Thursday 22<sup>nd</sup> June 2017 10:00 – 12:00**

Venue: **Ground Floor Central Meeting Room, 250 Euston Road, NW1 2PG**

Chair: **Sharon Cavanagh**

### **1. Welcome and Introductions (SC)**

SC welcomed members of the group, introductions were made and apologies heard. Minutes of last ERG meeting were approved.

### **2. London Cancer and the UCLH Cancer Collaborative Update (SC)**

#### **Cancer Transformation Fund Bid Update**

SC reminded the group about the upcoming UCLH Cancer Collaborative Annual Event taking place next Tuesday 27<sup>th</sup> June. From a LWBC point of view, there will be presentations on work conducted with the NCL Cancer Commissioning Board to develop a service specification for delivering primary care follow-up for men with prostate cancer. Alison Hill will also be presenting on improving communication and care closer to home.

SC provided update on Cancer Transformation Fund monies. Release of funding pending and is contingent of specific 62 day wait trajectories and conditions being met at pan-London level.

#### **ACTION:**

- SC to update the ERG at next meeting re. the Cancer Transformation Fund

### **3. London Cancer LWBC priorities and progress (SC)**

#### **Workplan**

SC tabled the workplan. The key points discussed were:

#### **Embedding Recovery Package**

- Q4 was the first quarter in which the numbers of patients receiving HNAs at end of treatment was collected/reported. Six Trusts reported data against this metric. Overall 3% of new patents received a HNA at this point in the pathway.
- Treatment Summaries: Proportion of patients receiving a Treatment Summary fell from 5% (n.182) in Q1 to 4% (n. 173) in Q4.
- SC asked SSc if it would be possible to analyse and circulate 2015/6 and 2016/17 Recovery Package comparison data to determine improvements. SScs agreed to do so

### Implementing Stratified Follow-up

- Colorectal stratified follow up pathway resource pack being finalised – it will be presented at the September Colorectal Pathway Board.
- Work is progressing to implement primary care led stratified follow-up solution in NCL. Aim to have this up and running by August 2017. Service specification and business case have been developed. John Hines (Urology Pathway Director) and SC have now visited all NCL Trust operational and clinical leads to discuss local implications for identifying eligible patients and ensuring timely re-access to specialist services as required.

### Consequences of Treatment – Improving access to Lymphoedema Services

- SC attended Breast Cancer Pathway Board last week and fed back the results of the breast lymphoedema audit conducted between Jan-March 2016. Results show that 50% of breast cancer patients presenting with lymphoedema had moderate or severe symptoms. This has now been escalated to the pathway board so work can be done to ensure patients are reporting their symptoms to GP's and Nurses much earlier. The next lymphoedema audit will be rolled out to Gynaecology in July, followed by Urology, Sarcoma, Head & Neck, Melanoma and Colorectal cancers.

### Q4 LWBC Metrics Results

SC presented the 201/2017 annual Recovery Package and Stratified Follow-up data. Key points:

- **HNAs around diagnosis:** Our highest performing trusts by Q4 in achieving this metric were PAH and BHRUT, achieving 60% and 47% respectively. Across our geography 24% of patients were reported to have received an HNA (Cf. 23% in Q3, 27% in Q2 and 24% in Q1) at this point in the pathway.
- **Treatment Summaries:** Six Trusts now report that conducted Treatment Summaries in Q4 compared to five trusts in Q1. There was an increase in the number of TS provided from Q3 to Q4 in all six reporting trusts. However, overall, the London Cancer total is down from 5% (n.182) in Q1 to 4% (n. 173) in Q4.
- **HWBE:** The number of patients attending Health and Wellbeing Events has increased from Q1 (n. 538) to Q4 (n. 748) with Barts (n. 323) and The Whittington (n. 157) recording the highest numbers in Q4.

Next week SC and counterparts in RM Partners and SEL ACN and LWBC Lead in TCST will hold a workshop with the London Cancer Lead Nurses to discuss the impact of LWBC data and to determine how it is/can be utilised to reflect work currently going on within the system and benefit to patients.

#### **ACTION:**

- SSc to produce and circulate 2015/6 and 2016/17 Recovery Package comparison data
- Circulate June 2017 Workplan
- Distribute 2016/17 Recovery Package and stratified follow-up data presentation

### 4. E-HNA Data Discussion (SSc)

SSc presented London 2016 e-HNA data. It is significant to note that although 3980 e-HNA's were carried out, 2755 of these were conducted in Guy's & St Thomas' Hospital NHS Foundation Trust (GSTT).

The group discussed results and implications regarding how the data can be used to inform practice. SC asked the group if it would be useful to have a process of clinically reviewing e-HNA. The data could then be utilised to tailor HWBE's content etc. SC will have a discussion in a subgroup for this - LP and AS volunteered to participate.

The group asked AS how GSTT has managed to conduct such high volume of e-HNAs. AS explained that achieving such great results of HNA's at GSTT has been a challenge but now it works really well and is seen as a priority. Every six weeks there is a Cancer Nursing Board which includes holding discussions identifying when CNS's come into contact with patients and how best to interact to ensure HNA's are completed at the right time for the patients. A monthly e-HNA data report is also presented/reviewed at the meeting. A huge plus to come out of this progress at GSTT is the amount of shared learning that has taken place. AS explained that consultants can now see the benefit of HNA's and TS's as the tools enables them to structure consultations and better understand the needs of the patient.

LD highlighted that the trusts succeeding in delivering Recovery Package to patients also succeed in good patient experience. Therefore it would be useful to identify what resources are used at GSTT to help the success that could be replicated at other trusts.

MNP suggested that accountability could be a factor in delivering good RP results, stating that it would be beneficial for results being escalated to monthly Cancer Boards.

The group agreed that it is advantageous to recruit informatics staff who understand the LWBC focus as well as the data - and to interrogate data when inaccuracies present has the ability to question data that may seem inaccurate. SC informed the group that this was one of the priorities included in the cancer transformation fund bid.

PH asked the group if there are any current issues with e-HNA's but there are no issues from clinical point of view with the tool. He let the group know that he is happy to come to sites and go through EHNA tools with the trusts if required. Phil also confirmed that work is underway to link people up across sites for data sharing which will have a massive positive impact.

SC thanked SSC, GSTT and Macmillan Informatics teams as the data is very rich and useful and discussions will continue on the applicability and impact.

**ACTION:**

- Distribute pan-London e-HNA metrics (2016) presentation
- Subgroup to be convened to discuss clinical review of e-HNA data (pan-London level)

## **5. Pan London LWBC Metric Definitions (SC)**

SC thanked those who provided feedback for Pan-London LWBC Metric Definitions; these will now be signed off at the London LWBC Board.

## **6. Metric Collection Standardising Process (SC)**

SC summarised that in the last meeting a representative from each trust discussed how they collect data which was incredibly useful. There was consensus that it will be helpful for each trust to review practice and standardise data collecting methods to optimise robustness of data.

It was agreed that it would be useful to develop a data collection toolkit, which can be given to new starters as part of induction. SC asked the group to get in touch with her if anyone is interested in supporting this work.

**ACTION:**

- ERG members to inform SC if they would be interested in taking part in development of data

collection tool kit.

## 7. AOB

SC made the group aware that NHS England have requested expressions of interest for pilot sites to trial the national Quality of Life metric, this will be circulated to the group today. The deadline for submissions is 14<sup>th</sup> July. There are certain conditions that must be met to become a pilot site and an expectation to be able to recruit 500 patients post treatment over 15 months with an expected 70% response rate. A Webinar is taking place 11am this Friday – SC to take part. SC stated that will be having discussions with trusts to determine how many are willing/able to participate as part of a pan-Vanguard bid.

AVL attended TYA conference this week. There was a presentation on the use of a TYA specific HNA tool – the IAM, which is being promoted and rolled out by the teenage cancer trust but also endorsed by Macmillan. Roll out is only in Bristol so far, but as it progresses it will be worth considering how to ensure this tool is used in conjunction with the eHNA. After discussion with Macmillan, AVDL felt they could work well together if the eHNA is used for the CNS care plan and the IAM is used by the patient, however will need more consideration if/when rolled out in London.

MNP informed the group that they did not recruit anyone for the recent Recovery Package Manger role at Barts so they are taking this opportunity to step back and re-review the role with the best configuration of skills before it goes out to advert again.

LB announced that Karen Phillips will be starting as the new Lead Cancer Nurse at BHRUT on 4<sup>th</sup> Sept.

### ACTION:

- Distribute National Quality of Life Metric - Call for Expressions of Interest for Pilot Sites information

**Future Meeting Date: Thursday 7<sup>th</sup> September 10am-12pm**, Ground Floor Central Meeting Room, 250 Euston Road, London, NW1 2PG.

### ACTION LOG

| Action   | Owner | Date Agreed | Status    |
|--|-------|-------------|-----------|
| SC to update the ERG at next meeting re Cancer Transformation Fund               | SC    | 22.06.17    | Ongoing   |
| SSc to produce and circulate 2015/6 and 2016/17 Recovery Package comparison data | SSC   | 22.06.17    | Completed |
| Circulate June 2017 Workplan   | SC    | 22.06.17    | Completed |
| Distribute 2016/17 Recovery Package and stratified follow-up data presentation   | SC    | 22.06.17    | Completed |
| Distribute pan-London e-HNA metrics (2016) presentation                          | SC    | 22.06.17    | Completed |

|   |     |          |           |
|---|-----|----------|-----------|
| Subgroup to be convened to discuss clinical review of e-HNA data (pan-London level)                             | SC  | 22.06.17 | Ongoing   |
| ERG members to inform SC if they would be interested in taking part in development of data collection tool kit. | All | 22.06.17 | Ongoing   |
| Distribute National Quality of Life Metric - Call for Expressions of Interest for Pilot Sites information       | SC  | 22.06.17 | Completed |

### Attendees

| Name                        | Role  | Trust/Organisation                      |
|-----------------------------|---|---|
| Sharon Cavanagh (SC)        | Lead for Macmillan Integrated Cancer Programme, Living with and Beyond Cancer and Allied Health Professionals | London Cancer/UCLH Cancer Collaborative |
| Ashley Bowcock (AB)         | Survivorship Pathway Tracker  | GSST                                    |
| Amanda Shrewbridge (AS)     | SEL Macmillan Project Lead for LWBC   | GSTT                                    |
| Avril van der Loo (AVL)     | Macmillan Recovery Package Programme Manager  | UCLH CC                                 |
| Daphne Earl (DE)            | Patient Representative  |   |
| Elleanor Chrisham (EC)      | Student Nurse   | RM Partners                             |
| Emma Sly (ES)               | Macmillan Recovery Package Manager  | PAH                                     |
| Graham Roberts (GR)         | Cancer Information Manager  | GSTT                                    |
| Jeanie Eng (JE)             | Macmillan Project Facilitator   | Barts                                   |
| Liz Price (LP)              | Senior Strategy Lead LWBC   | TCST                                    |
| Louisa Daly (LD)            | Macmillan Partnership Quality Lead  | Macmillan                               |
| Lucy Brooks (LB)            | Recovery Package Project Lead   | BHRUT                                   |
| Mary Newell-Price (MNP)     | Macmillan Programme Manager   | Barts                                   |
| Natalie Doyle (ND)          | Nurse Consultant LWBC   | RM Partners                             |
| Phillip Hall (PH)           | Macmillan Programme Manager   | Macmillan                               |
| Roxanne Payne (RP)          | Macmillan Project Coordinator   | UCLH CC                                 |
| Saran Evans (SE)            | Associate Director of Nursing   |   |
| Stephen Scott (SSc)         | Head of Informatics   | RM Partners                             |
| Vanessa Brown (VB)          | LWBC Senior Project Manager   | RM Partners                             |
| Zereen Rahman-Jennings (ZR) | Macmillan Patient Experience and User Involvement Lead  | UCLH CC                                 |

## Apologies

| <b>Name</b>       | <b>Role</b>   | <b>Trust/Organisation</b> |
|-------------------|---|---------------------------|
| Daniel Thomson    | Macmillan Primary Care Project Manager                | UCLH                      |
| Elizabeth Shaw    | Psychologist  | North Mid                 |
| Karen Phillips    | Macmillan Lead Cancer Nurse                           | Whittington               |
| Lallita Carballo  | Head of the Macmillan Support and Information Service | UCLH                      |
| Claire Barry      | LWBC Programme Lead                                   | Imperial                  |
| Kerry Guile       | Consultant Lead Cancer Nurse                          | Royal Free                |
| Jenny Watmore-Eve | Macmillan Programme Manager                           | BHRUT                     |
| Elaine Heywood    | Macmillan Cancer Counsellor                           | Royal Free                |
| Azmina Verjee     | Macmillan Recovery Package Project Manager            | Homerton                  |
| Flo Panel-Coates  | Chief Nurse   | UCLH                      |
| Sarah Pearson     | Senior Nurse for Cancer                               | Barts                     |