London Cancer Living with and Beyond Cancer Implementation ERG

Date: **Thursday 20th April 2017**
Venue: **51 Wimpole Street, 1st Floor Boardroom, W1G 8PH**
Chair: **Sharon Cavanagh, ERG Chair**

1. Welcome, Introductions, Apologies and minutes of last meeting

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 explained that the team are still awaiting the outcome of the financial decision regarding the Cancer Transformation fund bid. There is a Pan-London strategic meeting taking place Monday 24th April between RM Partners, UCLH Cancer Collaborative and South East London. SC will update the group once an outcome is confirmed from NHS England.

ACTION:
- SC to update ERG on Cancer Transformation Fund Bid outcome

3. Recovery Package Metrics Definitions

SC shared the London Living with and Beyond Cancer Data Collection Metric Definitions with the group. The metrics were discussed to help clarify them and make reporting easier. The metrics discussed were;

Metric 1: Total number of individuals receiving a Holistic Needs Assessment around diagnosis – Discussion was held re. the change to this definition. I.e. that the time limit for the HNA to be completed with an individual within 31 days of diagnosis has been removed. SC explained rationale for change: Feedback from CNSs and within LWBC ERGs (*London Cancer* and RM Partners) was that it is not always appropriate for individuals to receive their initial HNA within this timeframe. Therefore the Metric Review subgroup amended in line with these recommendations. However, it has been recognised that, in terms of best practice, all individuals should receive their first HNA within 6 weeks of decision to treat; therefore this guidance has been incorporated into the metric description.

Metric 2: Number of individuals receiving a Holistic Needs Assessment at end of treatment – This is a new pan-London metric – previously these data only collected from Trusts in SEL Cancer Alliance and RM Partners. All agreed that it is important to define exactly when end of treatment is. The guidelines state that end of treatment refers to the point on the pathway when either:

- the individual has finished receiving all cancer treatment and is being discharged back to the GP, or
- the individual will not receive any planned treatment at the acute trust for 6 months, or
- the individual is being transferred to palliative/EOLC services

Metric 3: Number of individuals receiving a treatment summary – SC sought feedback on this definition: specifically on the description of 'end of primary treatment' as this will need to be clear to trusts in order for them to embed the Treatment Summary into cancer pathways.

Metric 4: Total number of individuals attending a Health and Wellbeing Event – This metric has been changed in order to have a standardised definition across London. The major change is the incorporation of 1:1 appointments within the definition.

Metric 5: Number of individuals (with breast, colorectal or prostate cancer) stratified onto self-management follow-up pathway – SC explained that breast, colorectal and prostate patient stratified onto a self-management pathway are the areas of priority for the transformation bid for 2020 and this focus is reflected within the definition.

SC welcomed any feedback from the group as it would be helpful to get the definitions signed off promptly to standardise the collection of data. The group agreed it is a helpful tool and once the definitions are confirmed they will also be available to Commissioners and STP Footprints.

ACTION:

- Group to send any feedback on metrics definitions to SC

4. LWBC Metric Collection Standardising Processes

AVL provided a summary of the data collection methodology utilised at UCLH that she presented at last ERG meeting. AVL explained that in order to collate robust data of numbers patients receiving an HNA around diagnosis, she reviews the cancer wait patient lists (by NHS number) for each quarter and checks against these whether individuals have received an HNA. Method for collecting data on numbers of patients receiving HNA's at end of treatment is still being tested.

It was agreed by the group that use of e-HNA tool makes conducting of HNAs and data collection efficient and robust. Therefore, all Trusts present stated that they aim to roll out use of e-HNAs across their sites. However eHNA's do have their own issues such as when Wi-Fi does not work well or a lack of iPad's for CNS's in clinics.

A representative for each trust briefly disclosed their methodology for recovery package data collection, summarised below;

Barts Health (JE and MNP)

- TS: Currently only collecting TS data from breast and haematology teams. JE emails the Haematology consultant and Breast Nurse at end of each quarter to request report of numbers.
- HWBE: JE sends an email to find out how many people attended HWBE clinics/events. There is no integration of IT systems across sites, so these data recorded/reported manually.
- Self-Management Pathways: JE emails breast group team leads to obtain numbers. There is currently no way to capture data on IT system. Data held on team level database.
- HNAs: Breast team utilising e-HNA. Mixed methods by other teams. Therefore, JE sends email request to CNSs for data.

Homerton (AV)

- As the Homerton is mostly a diagnostic centre they only get around 400 new cancer referrals a year and most patients will have treatment at Barts. AV has created a spreadsheet onto which she adds the

details of all individuals pulled from CWT each quarter. The spreadsheet contains columns for HNA, TS, HWBE etc. Over time this will provide a long term view of the numbers of patients who are receiving one or more components of the Recovery Package.

- HNA: e-HNA utilised across all tumour types. AV accesses the e-HNA 'My Care Plan' website for the details of those who received a HNA around diagnosis and end of treatment. AV compares these My Care Plan data with CWT data and notes the individuals who received the intervention onto the spreadsheet.
- TS: CNS- led rather than consultant. AV checks Somerset for TS and some consultants dictate TS as per clinic letters. Thus AV will manually search for these on the shared drive. Due to the fact that the Homerton is a small trust, AV stated that this is a manageable task.
- SM Pathways: Homerton have breast, prostate and colorectal patients but as consultants come from Barts to Homerton to do clinics they are not counted as joining the self-management pathway.

BHRUT (LB and WC)

- HNA: Mixed modal methods of conducting HNAs across BHRUT. There LB utilised multiple methods to obtain data. E.g., Electronic versions are recorded/data captured on Somerset. eHNA's are recorded and data collated from My Care Plan website. Paper versions are manually counted. Patients are booked into a HNA clinic within time frame at start of diagnosis and then another 3 months down the line which tends to align with end of treatment point in the pathway. BHRUT are currently in process of getting the required 20 iPad for eHNA's to be rolled out successfully.
- TS: Haematology and Breast teams are the only ones that have rolled out completion of TSs. These are conducted on Somerset and therefore data able to be extracted fairly easily.
- HWBE: BHRUT have introduced generic quarterly events in which patients/carers invited. Attendance rates have been rising each quarter.
- SM Pathway: In Q4 the breast team started moving eligible patients onto self-managed pathways. This process has involved building in a 45 min consultation into the pathways. Within this consultation, patients receive an end of treatment HNA and TS (LB makes sure not to double count them if they have been to HWBE). There is then a follow-up appointment 4 weeks later in a nurse led clinic. Data on numbers of patients attending these appointments is collated and reported.

GSST (GR and AB)

- HNA: e-HNA has been implemented across all tumour types. Therefore HNA My Care Plan data compared against quarterly CWT data (for HNAs conducted around diagnosis). Preliminary report that they draft is then sent to the CNSs who inform them of any corrections required. If patients decline an offer of HNA within 31 days this is also noted. For end of treatment HNAs, GR uses My Care Plan website and filters how many were conducted within the quarter time period.
- TS: Clinicians upload TSs onto local Cancer Registry system (MOSAIQ) and monthly reports are generated. Information such as tumour type not able to be pulled off electronically, therefore GR checks this information per document.
- HWBE: These take place quarterly at GSTT and Dimbleby Cancer Centre. GR contacts CNS groups who run individual groups per tumour group and requests reporting of numbers who have attended.
- SM Pathway – GSTT don't do a return on this metric at present.

PAH (CDJ)

- HNA: As per BHRUT, mixed methods of conducting HNAs occurring at PAH. There is a mix of e-HNAs, paper and desktop versions being conducted. CDJ sits with CNSs and they submit monthly numbers. Monthly data cf. CWT data.
- HWBE: PAH currently holding one per quarter, mostly generic although breast runs tumour specific events. Aiming to begin implementing mini HOPE session which would be less time consuming than the standard HOPE course in order to integrate within pathways. CDJ will report progress of this approach.

- SM Pathway: CDJ reported that they have just begun stratifying breast cancer patients at PAH. Therefore, first tranche of patients will be reported in data collection for Q1 2017/2018.

The group had a detailed discussion about standardising data collection. There was an agreement reached that this is the aspirational approach in order to maximise data robustness – recognising that there may be local variation in some Trusts. As a first step, it was agreed that for the HNA around diagnosis metric – all trusts would compare their HNAs data against CWT data.

SCo informed the group that he met with Andrew Brittle to discuss pan-London data collection. At present, data to be provided to SCo and he will analyse/distribute. The group agreed that eHNA is the route that should be followed as it is clinically valid and makes data collection/reporting much easier. At present there is not complete confidence in the eHNA platform due to connection problems and challenges engaging clinicians. SC invited the group to outline the main concerns so that they can be passed onto the Macmillan Project Managers (Andrew Brittle and Amanda Watson). Another suggestion was to create a 'How to collect LWBC Data' document to support new RP Project Managers when they come into post. SC to take forward.

MNP highlighted that one big difficulty is sustainability of collecting Recovery Package Data in the current way. SC explained that this has been taken into account and addressed in the Cancer Transformation Funding bid. Funds have been allocated to support each trust to configure IT systems to automate data extraction.

SC recognised the challenges each trust has been facing in RP data collection and suggested that it would be useful to explore developing a pan-London approach. SC to take this to pan-London LWBC TF meeting.

ACTION:

- All Trusts to compare/report local HNA data against CWT data (for HNAs conducted around diagnosis
- SC invited the group to outline the main concerns with eHNA's to be passed onto the Macmillan Project Managers.
- SC to explore development of a data collection toolkit for trusts
- SC to distribute details of Pan-London Meeting

5. AOB

None.

Future Meeting Date: Thursday 22nd June 10am-12pm, Ground Floor Central Meeting Room, 250 Euston Road, London, NW1 2PG

ACTION LOG

Action	Owner	Date Agreed	Status
Update ERG on Cancer Transformation Fund Bid outcome	SC	20-04-17	Done
Send any feedback on metric definitions to SC	All	20-04-17	Done
All Trusts to compare/report local HNA data against CWT data (for HNAs conducted around diagnosis	All	20-04-17	Done
Outline the main concerns with eHNA tool – send to Sharon Cavanagh	All/SC	20-04-17	Done
SC to explore development of a data collection toolkit for trusts	SC	20-04-17	Ongoing
Explore pan-London approach to standardising data collection	SC	20-04-17	Ongoing

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
Avril van der Loo (AVL)	Macmillan Recovery Package Programme Manager	UCLH
Azmina Verjee (AV)	Recovery Package Project Manager	HUH
Carmel Devine-Judge	Project Lead, Macmillan Recovery Package	PAH
Graham Roberts (GR)	Cancer Information Manager	GSTT
Jeanie Eng (JE)	Macmillan Project Facilitator	Barts
Lallita Carballo (LC)	Clinical Head for the Macmillan Support and Information Service	UCLH
Lucy Brooks (LB)	Recovery Package Project Lead	BHRUT
Mary Newell-Price (MNP)	Macmillan Programme Manager	Barts
Natalie Doyle (ND)	Nurse Consultant LWBC	RM Partners
Roxanne Payne (RP)	Macmillan Project Coordinator	*London Cancer*/UCLH Cancer Collaborative
Stephen Scott (SCo)	Head of Informatics	RM Partners
Wendy Chinnery (WC)	Cancer Data Manager	BHRUT

Name	Role	Trust/Organisation
Vanessa Brown (VB)	LWBC Senior Project Manager	RM Partners

Apologies

Name	Role	Trust/Organisation
Liz Price	Senior Strategy Lead (Living with and beyond cancer)	TCST
Denise O'Malley	Senior Matron	Royal Free
Elaine Heywood	Macmillan Counsellor	Royal Free
Suzette Ferreira	Clinical Lead Therapist	BHRUT
Alia Nizam	Lead for Stratified Follow-up	UCLH
Flo-Panel Coates	Chief Nurse	UCLH
Elizabeth Shaw	Psychologist	NMUH
Sarah Anne Brewer	Project Manager - Breast Open Access Follow Up	Barts
Claire Barry	Macmillan Programme Lead LWBC	Imperial
Daphne Earl	Patient Representative	
Jenny Watmore-Eve	Programme Manager for Cancer Patient Experience	BHRUT
Karen Phillips	Macmillan Lead Cancer Nurse	WH
Michelle Kenyon	Post BMT CNS	Kings
Tee Fabikun	Patient Representative	
Alison Hill	Lead Cancer Nurse	UCLH