

London Cancer Living with and Beyond Cancer Implementation ERG

Date: **Thursday 7th September 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.

Outstanding actions from the previous meeting are:

- Discussion around clinical review of e-HNA data (Pan-London level). SC discussed that pan-London data is published that it may be useful to clarify if there is any shared learning that could be disseminated across the capital. SC will take this discussion to the RM Partners LWBC Pathway Board Meeting this afternoon as well as the first meeting from the newly formed South East London LWBC Group.
- SC is seeking volunteers to help develop a data collection toolkit, designed to be given to new Recovery Package Project Managers as guidance around methodology of data collection on a Pan-London level. SC asked the group to contact her if they would like to be involved in this piece of work.

ACTION:

- SC to take discussion regarding e-HNA data to RM Partners & SEL LWBC Meetings
- ERG members to express an interest in developing a resource pack for new Recovery Package Project Managers

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

Cancer Transformation Fund Bid Update

SC provided an update on Cancer Transformation Fund monies. Discussions are still continuing and release of funding is still pending and is contingent on progress in London on meeting 62 day wait trajectories.

QoL Metric Pilot

UCLH Cancer Collaborative is one of five pilot sites selected by NHSE to trial a new 'quality of life metric', which uses questionnaires to measure the effectiveness of support for individuals post cancer treatment. This pilot project focuses on breast, colorectal and prostate cancer patients who received treatment at St Barts or UCLH between 1 and 2 years ago. Patients who participate will receive a link to an online patient portal where there will be a questionnaire to complete about their health and wellbeing. The individual may then take the opportunity discuss the results of the questionnaire at their next clinic appointment or with their GP. The pilot is being led by UCLH Cancer Collaborative Programme Leads, Sharon Cavanagh and Donna Chung, with clinical leadership support at each of the trusts.

ACTION:

- Circulate submitted bid for QoL Metric Pilot

3. London Cancer LWBC priorities and progress (SC)

Workplan

SC tabled the workplan. The key points discussed were:

Embedding Recovery Package

- Q1 was the second quarter in which the numbers of patients receiving HNAs at end of treatment was collected/reported. Seven Trusts reported data against this metric. Overall 7% of new patents received a HNA at this point in the pathway.
- Treatment Summaries: Proportion of patients receiving a TS rose from 4% (n. 173) in Q4 2016/17 to 6% (n. 221) in Q1 2017/18.

Implementing Stratified Follow-up

- Colorectal stratified follow up pathway resource pack will be presented by SC at the Colorectal Pathway Board on 12th September.
- Implementation of primary care led follow-up for men with stable prostate cancer will begin on 2nd October in NCL. This has been a collaborative piece of work being led by a sub group of the NCL CCB. Membership comprises: primary care cancer leads, commissioning managers, representatives from each of the CCGs, TCST and UCLH CC
- Barts are following a trust-led route to implement prostate stratified follow up. The standard operational procedure per treatment type is currently being developed.
- BHRUT are meeting this month to discuss prostate stratified follow-up implementation.

Consequences of Treatment – Improving access to Lymphoedema Services

- Gynaecology and Sarcoma Lymphoedema audits are currently running. Urology will begin their audit on 2nd October followed by Head & Neck and Melanoma. Discussions are ongoing whether the audit should be carried out for colorectal patients as the number of those developing lymphoedema in this tumour group is very low.

SC discussed the low performance across all trusts with embedding treatment summaries. This is a pan-London issue and will be addressed in an event which will take place in spring 2018. A workshop will be held within the event to share best practice re. TS implementation and how to overcome challenges to embedding these.

Liz Price informed the group that the National Cancer Programme LWBC Team will shortly release details regarding a National WebEx that will take place fortnightly for individuals with an interest in LWBC. This will provide opportunity to highlight the good work taking place in London as well as asking questions, seeking advice and learning from other teams nationally.

SC presented the pan-London spreadsheet developed by London LWBC programme which summarises work currently being done Pan-London in LWBC Teams. SC will circulate this on a quarterly basis.

RP will create a presentation comparing Q4 2016/17 & Q1 2017/18 RP & SFU data and circulate to group.

The group discussed how local data should be the focus to boost morale for staff in their teams rather than the Pan-London overview. Azmina Verjee discussed the process at Homerton where cancer patients are outsourced to Barts so they do not have high RP numbers however they focus on their local data to track progress.

ACTION:

- Circulate September 2017 Workplan

- Circulate Macmillan London LWBC Programme Dashboard Q1 2017-18
- Circulate Q4/Q1 LWBC RP & SFU Metrics Comparison Presentation

4. TCST Update (LP)

Liz Price updated the group on these key points from TCST:

- Recovery Package and Stratified Follow-Up commissioning guidelines are being refreshed; a survey has been circulated to commissioning managers, primary care cancer leads, and Macmillan nurses within CCG landscapes to gather feedback and suggestions about this guidance. The feedback already received is very constructive, with questions regarding funding and operational queries, data collection and how CCGs understand the process of implementation of RP & SFU. The survey closes in the next couple weeks and rewriting work will begin in Oct/Nov.
- Karen Robb is leading on the development of Cancer Rehabilitation commissioning guidance. Included within this piece of work is development of a minimum data set, what this could look like and arranging pilots in selected services. This is a key priority as currently rehabilitation data reported centrally is particularly poor. Richer data collection will provide evidence of the impact AHPs have on quality of life, reducing visits to A&E and length of hospital stay.
- Karen Robb has been updating the lymphoedema guidance for best practice. The Lymphoedema Support Network (a national service user forum) has been working closely with the National Lymphoedema Partnership to produce national guidance to improve access to services and workforce. This is based on TCST's London guidance and is due to be co-branded with the LSN.
- TCST are hosting a Psychological Support for Cancer Consultation event on Wednesday 11th October. They would like to get a good representation from service users and a range of professionals across mental health and cancer. LP will circulate the details to the group.
- Barbara Gallagher has created a 'National Cancer Patient Experience Survey London STP Overview' document which pulls together STP level NCPES data focussing on LWBC. BG will also be producing CCG level data.

ACTION:

- Circulate details for TCST Mental Health event on 11th October
- Circulate National Cancer Patient Experience Survey London STP Overview document from TCST

5. e-HNA Discussion – Expired Assessments and Decline Process (AVL)

Avril Van der Loo opened discussion regarding expired and declined HNA's. Key questions and discussions points:

- **Should trusts should count HNAs that have been declined by patients?**

It was agreed that trusts should not include declines in numbers submitted to quarterly metrics but this should be recorded locally so that conversations can take place with those patients who decline in order to explore reasons. Barry Keenan stated that he raised this point with Andrew Brittle, Technical Project Manager at the Macmillan Informatics Team, confirmed a decline button will be added to e-HNA's by early 2018.

- **If an e/HNA expires (i.e. if a patient exceeds the limit that the e/HNA link is valid for) can it be taken that the patient does not wish to complete it and therefore it should be counted as a decline?**

Currently an individual's web link to complete an e-HNA expires in two weeks of it being produced. There are two issues with this – the information leaflet handed to patients provides information that the link will be live for 10 days (as opposed to 14) and a number of CNSs are finding that this 2 week timeline is too short for a number of patients so are manually changing the length of the link being active on the system.

BK stated that he also raised these issues with the Macmillan e-HNA team. Feedback is as follows:

- 1) The default length of time to complete the e-HNA will remain at two weeks. The rationale for this is that e/HNA's should generally be carried out soon after a clinic appointment whilst patients remain on the active case load as they may be missed otherwise and needs can change over time. The option to manually change the expiry to six weeks is to facilitate cases where that is needed.
- 2) The paper passcode slips referencing '10 days' are old and the team is planning to get these updated so that no deadline is stated.

LB explained that at BRHUT they are undertaking an audit in which patients who are provided with the e-HNA link will be contacted by an administrator to remind them to complete and ensure that they understand the method to complete.

TF and DE suggested sending a reminder out to patients about the e/HNA as they may be overwhelmed in the first weeks of diagnosis and have simply forgotten to complete it. This is the time when they may be in denial of their diagnosis.

- **When a patient states that they do not want to have their e/HNA data to be stored electronically – it is not clear if they are also declining a HNA**

BK agreed he will speak to Andrew Brittle at Macmillan about adding a note on the e/HNA that a patient refusing that their data be stored electronically is separate from a patient declining to complete the e/HNA completely.

ND stated that would take these talking points to the RM Partners LWBC Pathway Board this afternoon.

6. LWBC Metric Collection Standardising Process (SC)

SC informed the group that the pan-London LWBC metric definitions have now been signed off at the London LWBC Pathway Board.

ACTION:

- Circulate final pan-London LWBC metric definitions document

7. Baseline mapping and data collection toolkit

SC gave a presentation of the results from the trust scoping work regarding methods of LWBC data collection. Key points:

We received data collection/reporting methods from 7 trusts in total (Barts, BHRUT, Homerton, PAH, Royal Free, UCLH, Whittington)

- Electronic Patient Record System utilised: 3/7 trusts (43%) use Cerner Millennium, 1 trust use Medway, 1 trust (14%) uses Cosmic, 1 trust uses Carecast and 1 trust uses ICE as their EPR System.
- Cancer Registry System utilised: 4/7 (57%) trusts use Somerset for Cancer MDT, 3/7 trusts (43%) use Infoflex.

- Data collection methods for HNAs conducted at diagnosis and end of treatment: Three trusts (43%) use Macmillan e-HNA, 2 trusts (29%) use paper based returns, 1 trust (14%) uses Somerset and 1 trust uses a combination of paper and e-HNA.
- Collection of Treatment Summary data: Three trusts (43%) use a local excel spreadsheet, 2 trusts (29%) use paper based returns, 1 trust (14%) uses Somerset and 1 trust emails relevant team members to collect data.
- Collection of data regarding numbers of patients attending HWBE's: Three trusts (43%) are using paper based returns, 2 trusts (29%) are using a local excel spreadsheet, 1 trust (14%) emails relevant team members to collect date and 1 trust (Royal Free) is not currently collecting this data.
- Collection of date regarding numbers of patients stratified onto self-management breast pathway: Three trusts (43%) are using a local excel spreadsheet, 1 trust (14%) are using paper based returns and 1 trust is emailing team members to collect data. Two trusts (29% - Homerton and Royal Free) are not currently collecting this data.
- Colorectal stratified follow-up data collection: Two trusts (29%) are using a local excel spreadsheet, 1 trust (14%) is using paper based returns and 1 trust is emailing relevant team members, 3 trusts (43%) Barts, BHRUT & Royal Free are currently not collecting these data.
- Collection of patients stratified onto self-management prostate pathway: Two trusts (29%) are using a local excel spreadsheet, 1 trust (14%) is using System One and 1 trust is emailing relevant team members, whilst 3 trusts (43%) are not currently collecting this data.

ACTION:

- Circulate LWBC Baseline Mapping Presentation

8. AOB

None

Future Meeting Date: Thursday 7th December 10am-12pm, Ground Floor Central Meeting Room, 250 Euston Road, London, NW1 2PG.

ACTION LOG

Action	Owner	Date Agreed	Status
Take discussion regarding e-HNA data to RM Partners & SEL LWBC Meetings	SC	07.09.17	Completed
ERG members to express an interest in developing a resource pack for new Recovery Package Project Managers	SC	07.09.17	Ongoing
Circulate submitted bid for QoL Metric Pilot	SC	07.09.17	Completed
Circulate September Workplan	SC	07.09.17	Completed
Circulate Macmillan London LWBC Programme Dashboard Q1 2017-18	SC	07.09.17	Completed
Circulate Q4/Q1 LWBC RP & SFU Metrics	SC	07.09.17	Completed

Comparison Presentation			
Circulate details for TCST Mental Health event on 11th October	LP	07.09.17	Completed
Circulate National Cancer Patient Experience Survey London STP Overview document from TCST	LP	07.09.17	Completed
Circulate final pan-London LWBC metric definitions document	LP	07.09.17	Completed
Circulate LWBC Baseline Mapping Presentation	SC	07.09.17	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
Avril van der Loo (AVL)	Macmillan Recovery Package Programme Manager	UCLH CC
Azmina Verjee (AV)	Macmillan Project Facilitator	Homerton
Barry Keenan (BK)	Project Manager	Macmillan
Daphne Earl (DE)	Patient Representative	
Emma Sly (ES)	Macmillan Recovery Package Manager	PAH
Jeanie Eng (JE)	Macmillan Project Facilitator	BH
Karen Phillips (KP)	Lead Cancer Nurse	BHRUT
Lallita Carballo	Clinical Lead Nurse	UCLH
Liz Price (LP)	Associate Director (LWBC)	TCST
Louisa Daly (LD)	Partnership Quality Lead	Macmillan
Lucy Brooks (LB)	Recovery Package Project Lead	BHRUT
Natalie Doyle (ND)	Nurse Consultant LWBC	RM Partners
Roxanne Payne (RP)	Macmillan Project Coordinator	UCLH CC
Tasha Thavayogarajah (TT)	PA to Natalie Doyle	RM Partners
Tee Fabikun (TF)	Patient Representative	
Zereen Rahman-Jennings (ZR)	Macmillan Patient Experience and User Involvement Lead	UCLH CC

Apologies

Name	Role	Trust/Organisation
Elizabeth Shaw	Psychologist	NMUH
Denise O'Malley	Senior Matron	RFL
Elizabeth Pegers	Urology Project Manager	RM Partners
Vanessa Brown	LWBC Senior Project Manager	RM Partners
Sarah Brewer	Nurse Practitioner Project Manager	BH
Alison Hill	Lead Cancer Nurse	UCLH
Phil Hall	Macmillan Services Project Manager	Macmillan
Jacky Jones	Advanced Nurse Practitioner	BH
Jenny Watmore-Eve	Macmillan Programme Manager	BHRUT
Mary Newell Price	Macmillan Programme Manager	BH

The UCLH Cancer Collaborative is a part of the national Cancer Vanguard, working with Greater Manchester Cancer Vanguard Innovation and RM Partners