

London Cancer Living with and Beyond Cancer Implementation ERG

Date: **Thursday 7th December 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.

The actions from the last minutes were discussed. There is just one outstanding action; ERG members to express an interest in developing a resource pack for new Recovery Package Project Managers. SC has had two expressions of interests and requested that anyone else interested to please get in touch. This piece of work will involve creating an induction pack for new Recovery Package Project Managers coming into trusts, which will include vital information on methodology of data collection etc.

ACTION:

- ERG members to inform SC if they are interested in assisting development of the resource pack for new LWBC Project Managers

2. UCLH Cancer Collaborative Update (SC)

Cancer Transformation Fund Bid Update

SC informed the group that conversations are still ongoing regarding release of the cancer transformation funding (Recovery Package and stratified follow-up). There is no release of funding as yet. SC attended the Britain Against Cancer Conference this week where Jeremy Hunt confirmed that the release of funding will continue to be subject to regions meeting 62 day wait targets. SC will keep the group updated on future discussions.

SC recently presented at the East London Health and Care Partnership meeting (on behalf of UCLH and Liz Price, Associate Director LWBC, TCST) and discussed which pieces of work should be focused on using current resources. The Partnership prioritised continued implementation of prostate stratified follow up and a focus on delivering treatment summaries for breast cancer patients. SC will talk to Clare Stephens, Chair of NCL Cancer Commissioning Board, about next steps in NCL locality.

Nick Kirby, UCLH Cancer Collaborative Divisional Manager is leaving his post in January. Recruitment currently underway.

3. London Cancer LWBC priorities and progress (SC)

Workplan

SC tabled the workplan. Key points discussed were:

Embedding Recovery Package

Awaiting analysis of Q2 data compared to Q1 however preliminary comparison shows that;

HNAs within 31 days of diagnosis: Our highest performing trusts in Q2 in achieving this metric were PAH and North Mid, achieving 68% and 65% respectively. Across our geography 32% of patients were reported to have received an HNA (Cf. 28% in Q1) at this point in the pathway.

HNA within 6 weeks of end of treatment: This new metric was first collected in Q4 2016/17 when 3% of patients received a HNA within 6 weeks of end of treatment. In Q1 2017/18 this rose to 7% of patients and now in Q2 10% of patients.

Treatment Summaries: Six trusts are reporting Treatment Summaries within 6 weeks of end of treatment, with the overall London Cancer average increasing from 6% in Q1 to 7% in Q2.

HWBE: The number of patients attending Health and Wellbeing Events has decreased slightly from 680 in Q1 to 631 in Q2. Barts (n. 182) recorded the highest numbers of attendees in Q2.

SC spoke to Julie Woodford (Nurse Consultant, Cancer and Supportive Care) at RNOH who agreed they will begin reporting LWBC Data returns in Q3.

Implementing Stratified Follow-up

Barts, BHRUT and UCLH have all provided data for the number of individuals directed onto a self-management pathway in Q2 2017/18. Barts are reporting the highest numbers with 94 breast cancer patients on stratified follow up pathway. Overall across the UCLH Cancer Collaborative 248 patients were directed onto a stratified follow up pathway across these three sites (breast (120), colorectal (4) and prostate (124)) compared to 281 patients in Q1.

Work is progressing to support implementation of the colorectal stratified follow up pathway; guidance has been drafted and will be taken to the Colorectal Pathway Board this week. SC is waiting for final feedback within the next two weeks so that the guidelines can be published in the New Year. SC presented an overview of the draft colorectal stratified follow-up pathway. SC also talked through the contents of the resource pack.

Consequences of Treatment – Improving access to Lymphoedema Services

Lymphoedema audits are being conducted across tumour sites to determine numbers of individuals presenting with lymphoedema symptoms, severity of symptoms at first presentation and information regarding referral pathways. Three-month audits have taken place in breast, gynaecology and sarcoma. There is an audit taking place for urology at present and the next audits will be head and neck, melanoma and colorectal.

Quality of Life Pilot

SC updated the group on the Quality of Life Pilot Project; which focuses on breast, colorectal and prostate patients 1-2 years post treatment who were treated (with curative intent at Barts and UCLH). SC is going through the process of recruiting a Project Coordinator who will identify relevant patients and support them with the questionnaires they receive. SC is collaborating with Donna Chung and various Clinical Leads at UCLH and Barts to develop the protocols for each site.

ACTION:

- Distribute December Workplan
- Distribute SC presentation on colorectal SFU
- Distribute London Q2 2017/18 Metrics

4. LWBC Metric Collection Standardising Processes (SC/AV)

The data collection methodology collected from each trust will be embedded into the resource pack for new Recovery Package Managers.

5. Recovery Package Event 2018

SC informed the group about a series of proposed Recovery Package events which will take place in London next year. Preliminary discussions involve each Vanguard/alliance footprint holding an in April and May 2018 to share good practice models and learning re RP implementation. SC sought views from the group on the usefulness of holding such an event and for ideas regarding aims and agenda items. The group agreed it would be useful if trusts in different footprints could attend each other's events where trusts doing particularly well in delivering the RP interventions could share successes.

6. National baseline mapping – RP and stratified follow-up (SC)

SC thanked the group for their contributions for the national baseline mapping which has now been submitted to NHS England.

7. HNA – Patient experience questionnaire (TF/DE)

TF, DE, SC, BD and ZR-J met recently to discuss developing a questionnaire that will explore the impact of receiving an HNA on patient experience. The questionnaire will be a tool that trusts can utilise to scope impact of receiving an HNA and whether they are being delivered to individuals at the right time within the cancer pathway.

ZR-J suggested that she could contact Patient Leads across trusts to see how it could be implemented and ask for it to be sent to a wider group of patients for review and validation. It would be extremely helpful to collect this data trust by trust and by tumour group.

SC will add this piece of work onto the LWBC workplan and asked the group to send any thoughts regarding this to her. SC, ZRJ & BD will develop a draft and circulate it to the broader group for comment.

ACTION:

- ERG members to share ideas to shape a RP implementation learn and share event agenda.
- SC to add Patient Experience HNA questionnaire onto workplan and will update group at next ERG

8. Proposed e-HNA analysis 2017 (SSc)

Stephen Scott shared his 'Proposed e-HNA analysis 2017' presentation with the group. To summarise;

RM Partners conducted an analysis of the 2016 E-HNA results for London to review HNA data and concerns raised. The data provides information on the numbers of e-HNA's being carried out in London trusts which have introduced the e-HNA tool as well as a breakdown of number/type of concerns by tumour type, pathway stage and age.

Steve also informed the group that Imperial College Healthcare NHS Trust has been inputting HNA data onto Somerset (January – October 2017). Imperial does not have e-HNA and have been exploring Somerset functionality to determine if they are able to pull off data that is as detailed as e-HNA data. The advantages of using Somerset is the opportunity to link to other data items recorded in the Somerset system – e.g. stage at diagnosis, performance status, treatment types. Imperial has confirmed that Somerset is used fully to generate LWBC HNA quarterly audit figures. SSc is currently exploring if it is

possible to use a similar method for Infoflex data extraction. AVL looked at this for UCLH with Infoflex and discovered that Infoflex are developing a model where patients can input questionnaire entries directly.

SSc explained that next year RM Partners plan to repeat E-HNA analysis for London including data from all tools (rather than just Macmillan's), produce an overall report, and trust level reports for use locally. SSc discussed the proposed comparisons that could be made with the data i.e. analysis by ethnicity and asked anyone with additional ideas to contact him or Sharon.

Karen Robb informed the group about work currently taking place at TCST psychological support for patients at end of life. Information and training will be developed that looks at the top 10 concerns from e-HNA's and making sure these are being addressed in an evidence based way.

SC is developing a clinical group to analysis e-HNA data and wants clinical scrutiny on what is being produced. Discussions are ongoing to establish this group.

ACTION:

- Circulate 'Proposed e-HNA analysis 2017' presentation to group
- ERG members to send SC/SSc any ideas or comments for proposed comparisons by end of next week

9. AOB

AVL advised the group about information contained in a recent Macmillan blog regarding Bristol CCG - they now actively commission the Recovery Package (£100 for each HNA and TS and £25 for each patient who attends a HWBE). AVL has asked for further details and will update the group once received. SC stated that a national piece of work is being conducted by NHSE to target tariff issues.

BK recently attended the Lead Cancer Nurse Forum where mapping and tariffs where discussed. Mapping will be conducted to establish how elements of the Recovery Package are funded. SC will circulate the template for completion.

ZR-J and BD gave the group an update on the new User Involvement and Patient Experience Steering Group. Thus far, ten patients have been appointed onto the group including a Chair and Vice Chair. The first steering group meeting will be on 13th December. Group members have been treated across seven within our geography. The aim is for another ten people to join the steering group. An advert for these positions will be put out within the next month.

The PE team held an Improving Quality and Experience Day in October with lead cancer nurses, information managers, and members of TCST who came together to talk about NCPES. There will be many more Patient Experience meetings in 2018, with at least two more Improving Quality and Experience Day's and two more Peer to Peer Events for existing patient representatives on ERG's and PB's. An Induction Day for new patient and carer reps also took place on 16th November.

ZR-J announced that she will be leaving UCLH CC in January 2018 and Becky will be attending the LWBC ERG in the interim to keep the group updated on any patient involvement news. SC thanks ZR-J for all of her work in supporting the LWBC programme and ERG during her time in post.

ACTION:

- SC to send members a RP funding template for completion

Future Meeting Date: Thursday 1st March 2018 10am-12pm, Ground Floor Central Meeting Room, 250 Euston Road, London, NW1 2PG.

ACTION LOG

Action	Owner	Date Agreed	Status
ERG members to inform SC if they are interested in assisting development of the resource pack for new LWBC Project Managers	All	07.09.17	Ongoing
Distribute December Workplan	SC	07.12.17	Completed
Distribute SC presentation on colorectal SFU	SC	07.12.17	Completed
Distribute Overall Q2 2017/18 Metrics	SC	07.12.17	Completed
Add Patient Experience HNA questionnaire onto workplan and will update group at next ERG	SC	07.12.17	
Circulate 'Proposed e-HNA analysis 2017' presentation	SC	07.12.17	Completed
ERG members to send SC/SSc any ideas or comments for proposed comparisons by end of next week	All	07.12.17	Ongoing
SC to send members a RP funding template for completion	SC	07.12.17	

Attendees

Name	Role	Trust/Organisation
Sharon Cavanagh (SC)	Lead for Macmillan Integrated Cancer Programme, Living with and Beyond Cancer and Allied Health Professionals	UCLH Cancer Collaborative
Alison Boyd (AB)	Information Support Manager	NMUH
Avril van der Loo (AVL)	Macmillan Recovery Package Programme Manager	UCLH CC
Barry Keenan (BK)	Project Manager	Macmillan
Becky Driscoll (BD)		UCLH CC
Daphne Earl (DE)	Patient Representative	
Emma Sly (ES)	Macmillan Recovery Package Manager	PAH
Jeanie Eng (JE)	Macmillan Project Facilitator	BH
Karen Robb (KR)	Macmillan Rehabilitation Clinical Lead	TCST

Name	Role	Trust/Organisation
Lallita Carballo (LC)	Clinical Lead Nurse	UCLH
Linda Athey (LA)	Lead Cancer Nurse	NMUH
Nicole Ciulea (NC)	Breast CNS	NMUH
Roxanne Payne (RP)	Macmillan Project Coordinator	UCLH CC
Saran Evans (SE)	Associate Director of Nursing	BH
Stephen Scott (SSc)	Head of Informatics	RM Partners
Tee Fabikun (TF)	Patient Representative	
Zereen Rahman-Jennings (ZR-J)	Macmillan Patient Experience and User Involvement Lead	UCLH CC

Apologies

Name	Role	Trust/Organisation
Liz Shaw	Psychologist	NMUH
Karen Phillips	Macmillan Lead Cancer Nurse	BHRUT
Michelle Kenyon	Post BMT CNS	Kings College Hospital
Lucy Brooks	Macmillan Recovery Package Project Lead	BHRUT
Alia Nizam	Cancer Stratified Follow - Up Project Lead	UCLH
Vanessa Brown	LWBC Senior Project Manager	RM Partners
Kerry Guile	Lead Cancer Nurse	RFL
Natalie Doyle	LWBC Pathway Chair	RM Partners
Anne Brewer	Project Manager - Breast Open Access Follow Up	BH
Liz Price	Associate Director (LWBC)	TCST
Claire Barry	Macmillan Programme Lead LWBC	Imperial
Jacky Jones	Lead CNS Breast	BH
Mary Newell-Price	Senior Project Manager	BH
Alison Hill	Lead Cancer Nurse	UCLH