

Living with and Beyond Cancer Implementation ERG

Date: **Thursday 7th June 2018 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 outstanding actions from the last minutes were reviewed:

- Reminder to group to contribute to resource pack Health and Wellbeing Events (HWBE)
- Draft Recovery Package Implementation Event agenda and circulate to group – to be carried forward to next ERG meeting

2. UCLH Cancer Collaborative Update (SC)

In April 2018, the UCLH Cancer Collaborative (UCLH CC) transitioned from being a national vanguard site (along with RM Partners and Greater Manchester Cancer) to take up the cancer alliance function for NCEL. Functions remain the same: to improve survival, early diagnosis, patient experience and long-term quality of life across a whole population. New branding for the Collaborative being has been introduced. New Programme Director – Naser Turabi – started in May.

UCLH CC annual event will be held on 26 June.

3. LWBC priorities and progress (SC)

Transformation funding:

UCLH CC submitted revised transformation funding plan, with new priorities, based on London receiving 85% of funding. It was assumed that the same funding (from NHSE) would be available for quarters three and four, but this is dependent on pan-London performance on Cancer Waiting Times (CWT) target. Funds will be proportionally directed to the cancer alliances – and Trust specific funds will be distributed to Trusts via funding agreements. SC will keep the group updated on this. Pan London steering groups are being created, for the Recovery Package and Stratified Follow-Up workstreams. Terms of reference for these groups are currently being drafted. The funding agreement hopefully being signed off today (7 June) so should be released imminently.

Macmillan strategic partnership

SC is now having monthly meetings with Macmillan regional teams to avoid duplication of discussions that Trusts may be having with UCLH CC and/or Macmillan. All Trusts now

UCLH Cancer Collaborative brings together hospital trusts, GPs, health service commissioners, local authorities and patients across north and east London and west Essex.

have Recovery Package project managers/support in post – all funded by Macmillan (with the exception of BHRUT)

Macmillan Investment Prediction to Deliver RP and its outcomes 2019 – 2024

The London Alliance and TCST LWBC Leads are liaising with local partners to develop a high level 5-year forecast of resources that it is estimated will assist to improve uptake of the elements of the Recovery Package across London for individuals living with and beyond cancer. The aim of this document is to guide Macmillan in prioritising spend for Macmillan's future investments in Recovery Package to achieve maximum impact across London

Workplan

- **Stratified Follow-up:** : SC meeting with NCL Trusts and CCGs to discuss methods to accelerate implementation of NCL primary care delivered prostate stratified follow-up. Safety netting audit being signed off. Colorectal stratified follow-up pathway guidelines are currently being finalised and will be uploaded onto UCLHCC website. Link will be circulated to the group by the end of next week. The breast stratified follow-up pathway guidelines document (2014 to be updated ahead of September Pathway Board to reflect recommendations from the Breast Cancer Clinical Expert Group (CEG) published in Aug 2017. This is clinical advice to Cancer Alliances for the provision of breast cancer services.
- **Consequences of treatment:** Lymphedema audit – collating melanoma and head and neck data. SC to share data once analysis and report completed
- **LWBC Q4 Data headlines:** Across our geography, 31% receiving Holistic Needs Assessment (HNA) at diagnosis. 11% are receiving a Treatment Summary. 24% of all patients attended a HWBE.
- **Quality of Life pilot:** Data collection has not yet commenced due to issues with consent wording – needs to be agreed by NHSE. Update to be provided at September ERG.

Recovery Package funding template

The group reviewed the template and endorsed it as it was viewed as being a helpful tool for service design in terms of delivering the Recovery Package. Some changes were suggested, including:

- Requesting information to determine whether a block contract is in place and if agreement has been made that the Recovery Package be part of the block contract?
- Additional question: How are HWBEs in your Trust being paid for (e.g. third sector)? This highlights implications for commissioning
- Additional question: Capture who is delivering the activity. Could also include: “What expertise does the individual carrying out the intervention have?” This approach will help provide justification for consultant-led or nurse-led clinics.
- Include prompt to outline if variation exists across tumour sites.
- Recommended testing with STP leads to ensure everything is captured, as well as sending to Recovery Package managers and lead nurses.
- Recommended splitting HNA intervention into HNA at diagnosis and at end of treatment.
- Additional question: “Do you input HNA completion to COSD? Is e-HNA data uploaded onto Cancer Registry System or Electronic Patient Record?”
- Add column to include SNOMED codes
- Ideally treatment summaries should be sent to GPs and patients – recommended capturing this if possible.

SC stated that would create a cover-sheet (including a note that the audience may include commissioners, so to tailor accordingly) and circulate for comment.

HNA patient questionnaire (BD, DE, and TF)

BD, DE and TF introduced a draft survey to capture patient experience of having an HNA. BD, DE, TF and SC worked in collaboration to draft this, and requested feedback from the group on its design. The purpose of the survey is to understand people's experiences of the process of having an HNA and a care plan, and how receiving an HNA has made a difference to them.

If Recovery Package Managers and other group members think this is a good idea, this could be implemented across the area covered by the UCLH CC.

The group suggested some additional questions: "Would you feel able to request an HNA?", "Do you know who to go to for a HNA?", "Has the HNA enabled a positive change based on the priorities you identified?" and "Did you receive a care plan?"

It was clarified that this is an evaluation survey and not a research study, and therefore ethics approval will not be required.

It was suggested that one good opportunity to distribute the survey might be during an EOT clinic, when the patient has had at least one HNA (although patients who are not discharged will not attend this clinic). BD will follow up with each Trust to understand how it could be implemented locally and agree what would trigger the survey being given to a patient.

BD will circulate an updated draft of the patient experience survey to the group – please send BD feedback by next Friday (15 June). BD will then send to members of the UCLH Cancer Collaborative Patient and Carer Network, to gain feedback from a wider group of people affected by cancer.

ACTIONS:

- SC to share data on lymphedema audit once completed
- Web link to Colorectal pathway guidelines document to be sent once uploaded onto UCLH CC website
- Quality of Life Project update to be provided at next ERG meeting
- SC will share the next iteration of the Recovery Package funding template with
- BD to circulate an updated draft of the HNA patient experience survey to the group for comments.
- Group to provide BD with feedback by next Friday (15 June)
- BD to circulate the draft survey to the Patient and Carer Network for comments.
- BD to follow up with each Trust to discuss how the survey could be implemented locally.

4. Macmillan Living with Cancer Programme in Tower Hamlets (ZR-J)

ZR-J updated on the Macmillan Living with Cancer programme in Tower Hamlets to establish partnerships with community and acute services to better meet the holistic needs of people affected by cancer in the borough. It is being evaluated externally. The aim of the programme is to evaluate partnerships and the impact on patients and carers. The

programme looks specifically at delivery of HNAs in community settings. An evaluation workshop will be held on 26 June.

ACTION:

- ZR-J to feedback on Barts external evaluation workshop (26 June)

5. TCST update (LP)

Transforming Cancer Services Team (TCST) is part of the “Healthy London Partnership”.

- Currently supporting updating of national LWBC data definitions
- Working on refreshing the Recovery Package Commissioning Guidance
- Contacts in Specialised Commissioning have expressed an interest in Stratified Follow-up in rarer cancers (e.g. curative lymphoma). Similar projects could be done on haematology, testicular, brain and endometrial pathways.
- The team have had poster abstracts accepted at international conferences, as well as the PHE Outcomes Conference
- Changes to governance structure: Pan London LWBC Board:
 - Part A: continuing working across London maintaining partnerships etc.
 - Part B: oversight of transformation fundingBoth parts of the Board will report directly to the Cancer Commissioning Board (CCB) and provide oversight between regional and national level

6. LWBC Metric Collection Standardising Processes (AVL)

AVL updated the group on a guidance document she and SC have been working on (draft shared with the group before the meeting) to provide recommendations to Trusts regarding data collection to ensure that data is robust and of high quality. The guide is aimed at Recovery Package/Stratified Follow-up project managers – with a focus on supporting new starters during their induction period.

AVL suggested that the data can demonstrate the value of EOT Clinics by building complete picture to see whether patients have received all the interventions.

Coding H&WB events: AVL discussed the benefits of patient-level data over numbers. This is more accurate as “duplicate” numbers (e.g. family/carers attending H&WB events, people attending more than once) are not counted.

Coding HNAs: AVL highlighted importance of collecting data on the number of patients who reported no concerns – this is data in itself.

Drafting this document has prompted the idea for a guide for new Recovery Package Programme Managers, which would include:

- A list of key contacts in each Trust
- Examples of best practice (e.g. auditable eHNA systems)
- Advice on engaging funders /maintaining funding

ACTION:

- AVL to send updated version of draft Data Standardisation Guide to the group for feedback

7. eHNA results (SS)

SS updated the group on results of 2017 eHNA data. Highlights include:

- Compared to 2016 (the first year of data collection), numbers of eHNAs completed has more than doubled (partially attributable to involvement of Imperial)
- Care plans conversion rates:
 - 60% of individuals had a care plan completed
 - For 20% a care plan was not required
 - 17%: left blank – not recorded whether a care plan was given

Feedback from the group:

- Over time: want to capture whether setting influences range and types of topics covered and who is conducting the HNA and the impact this has. (Further reading: Professor Snowden's current research project)
- Capturing data on whether care plans are being sent to GPs. There is a tick box on systems for this, but it is not routinely used. If we share the little data we have on this, it may raise awareness of this.
- Proportions of eHNA by tumour type broken down by numbers of concerns reported by patients

Next steps:

- To review actions conducted following care plans
- Comparisons of concerns across tumour sites/pathway points
- Creating Trust specific reports

Requests from group members:

- (AV) Concerns analysis by male versus female (across all tumour groups). This is particularly helpful in designing H&WB events (e.g. erectile dysfunction etc.).
- (BQ) If possible also link to ethnicity and sexual preference data in local Trusts. This is helpful for services and also commissioners.

ACTION:

- Group to feedback any further comments on the document to SS by 29 June

8. AOB

BQ: event aimed at staff, professionals, and people involved in projects to mark 25 year relationship between Barts and Macmillan to be held on Tuesday 12 June, 16:00-18:00 in the Great Hall at Barts Hospital. All ERG members are welcome to attend – and to circulate information locally.

ACTION:

- Group to make any relevant contacts aware of this event

Next Meeting Date: Thursday 6th September 2018 10:00 -12:00 @ Ground Floor Central

Meeting Room, 250 Euston Road, London, NW1 2PG.

ACTION LOG

Action	Owner	Date Due	Status
Group to contribute to resource pack Health and Wellbeing Events (HWBE)	SC	06.09.18	
Draft Recovery Package Implementation Event agenda and circulate to group	SC/LB	06.09.18	
SC to share data on lymphedema audit once completed	SC	01.08.18	Complete
Web link to Colorectal pathway guidelines document to be sent once uploaded onto UCLH CC website	SC	01.08.18	Complete
BD to circulate an updated draft of the HNA patient experience survey to the group for comments.	BD	11.07.18	
Group to provide BD with feedback by next Friday (15 June)	All	15.07.18	
BD to circulate the draft HNA survey to the Patient and Carer Network for comments.	BD	06.09.18	
BD to follow up with each Trust to discuss how the survey could be implemented locally.	BD	06.09.18	
ZR-J to feedback on Barts external evaluation workshop being held on 26 June	SC	06.09.18	
AVL to send updated version of draft Data Standardisation Guide to the group for feedback	AVL	01.08.18	
Questions on eHNA data collection report to SS	All	29.06.18	
Circulate info about Barts/Macmillan event on 12 June to relevant contacts	All	12.06.18	

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
Daisy Doncaster (DD)	Macmillan Project Coordinator	UCLH CC
Becky Driscoll (BD)	Macmillan Patient Experience and User	UCLH CC

Name	Role	Trust/Organisation
	Involvement Lead	
Daphne Earl (DE)	Patient Representative	
Tee Fabikun (TF)	Patient Representative	
Alia Nizam	Lead for Stratified Follow-Up	UCLH
Liz Price	Associate Director (LWBC)	TCST
Barry Quinn	Lead Cancer Nurse	BH
Zereen Rahman-Jennings (ZRJ)	Macmillan Living With Cancer Programme Lead	Macmillan Local Authority Partnership
Stephen Scott (SS) – guest	Head of Informatics	RM Partners
Emma Sly (ES)	Macmillan Recovery Package Manager	PAH
Avril van der Loo (AVL)	Macmillan Recovery Package Programme Manager	UCLH CC
Azmina Verjee (AV)	Macmillan Recovery Package Project Manager	Homerton
Nicholas Wong (NW)	Macmillan Recovery Package Programme Lead	BH

Apologies

Name	Role	Trust/Organisation
Lucy Brooks (LB)	Macmillan Recovery Package Project Lead	BHRUT
Kerry Guile (KG)	Lead Cancer Nurse	Royal Free