

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

---

Date: **Thursday 1<sup>st</sup> March 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 actions from the last minutes were discussed; the only action outstanding is for SC to send members a Recovery Package funding template for completion.

#### **ACTION:**

- SC to send members a RP funding template for completion

### **2. UCLH Cancer Collaborative Update (SC)**

Naser Turabi has been recruited to the UCLH CC Programme Director post and will start in May. UCLH Cancer Collaborative will officially become an Alliance at end of March, when the two year National Cancer Vanguard programme comes to an end.

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

#### **Workplan**

SC tabled the December workplan. The February workplan is pending and will be circulated once the Q3 Recovery Package Data has been received. The key points discussed were:

#### **Embedding Recovery Package**

RNOH have agreed to begin submitting quarterly LWBC data. They are in discussions with Macmillan to recruit a LWBC Lead role.

#### **Implementing Stratified Follow-up**

Work is progressing to support implementation of primary care stratified follow-up in NCL – in collaboration with the NCL. Progress to be reported at next NCL CCB

Colorectal stratified pathway guidelines and resource pack presented at Colorectal Pathway board - final document to be ratified at the colorectal Pathway Board on March 13<sup>th</sup>

#### **Consequences of Treatment**

Lymphoedema audit being conducted to determine numbers of individuals presenting with lymphoedema symptoms, severity of symptoms at first presentation and information regarding referral pathways. This is a multi-tumour audit (head and neck, colorectal, urology, gynae., sarcoma, skin). Three-month audits have taken place in breast, gynae, sarcoma. Current audits: urology. Next audits: head and neck, melanoma and colorectal

#### **Q3 LWBC Metric Results**

Data not collated yet. Will circulate once received.

#### **Quality of Life Pilot**

Interviews conducted for the QoL Project Coordinator role but recruitment not successful so this will go out to advert again.

UCLH have begun collecting QoL data from prospective patients and currently exploring of use the eHNA platform which will enable individuals to complete the questionnaire online.

QoL national pilot progress will be presented at the National NHS England LWBC event on 20<sup>th</sup> March.

**ACTION:**

- Circulate February Workplan once Q3 Recovery Package Data received

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

Following on from discussions at the last meeting it was agreed that it is most useful for trusts to see the metric collection processes of partner trusts around them rather than across London as a whole. The data collection methodology collected from each trust will be embedded into a resource pack for new Recovery Package Managers who are recruited into post. The work for this pack will begin in April and will be led by Sharon Cavanagh and Avril Van Der Loo with contributions from Emma Sly and Liz Price. SC and AVL will update the LWBC Implementation ERG and will circulate drafts for comment.

#### **5. Patient Experience Update (SC/BD)**

There are now 64 patients and carers signed up as representatives on Pathway Boards, Expert Reference Groups and projects groups. This number has tripled in the last year thanks to the efforts of the MICa patient experience and user involvement team.

A second patient representative Induction Day was held yesterday. The day was well attended and preliminary feedback is positive.

#### **6. Colorectal Stratified Follow-up Guidance (SC)**

The final version of the colorectal stratified follow-up guidance is being finalised and will be distributed after ratification at the Colorectal Pathway Board on 12<sup>th</sup> March.

#### **7. Recovery Package Implementation Event 2018 (SC)**

SC requested feedback on holding a Recovery Package Implementation event(s) local in order to share best practice models and support acceleration of implementation. SC sought views from the group on the usefulness of holding such a local event and for ideas regarding aims and agenda items. Key themes:

- Following discussion it was agreed that local events (individuals Trusts and their local CCGs) would be more useful than one large event as this would encourage opportunities to link with and influence key contacts in CCGs.
- The group stated it would be useful if trusts in across London could attend events in neighbouring alliances in order to learn about innovations taking place. SC stated that it is not yet clear if the two other alliances in London will hold events but will update the ERG once clarity on this achieved.
- Local events take place around September so there is plenty of time to plan agendas and engage primary and secondary care clinicians.
- Need to think about these RP events in context of other training currently taking place.
- May need to be a back to basics presentation on RP as some GP's will not know about the interventions.

- It was recommended that the agenda of the event include a presentation about why the RP is being delivered and a patient voice section.
- Useful to invite CNS's to talk about the challenges faced with RP and how they overcame these.
- Link with CCG's - enabling them to use slides developed for GP training days.
- The RP events could be recorded for those who cannot attend or set up as a webinar.

Lucy Brooks and SC will work on a draft agenda, which can be tailored to each trust/locality, and circulate to the group for comment in the next few weeks.

**ACTION:**

- Draft Recovery Package Implementation Event agenda and circulate to group

## **8. Funding Recovery Package (SC)**

SC will create a template to find out the payment arrangements for delivering RP interventions for each trust. Once this has been circulated please return it so SC can collate the information and take it back to STP's to speak about any issues around funding.

This information will be included in the RP Manager resource pack. Other parts of London are interested in gathering this information and it was agreed it will be useful to obtain a broader view of how other Trusts are being paid for the activity.

## **9. HNA Questionnaire Tool (SC)**

TF, DE, and SC are in the process of drafting a questionnaire that will evaluate the impact of receiving an HNA on patient experience. The draft version will be presented at the next ERG and once it has been agreed trusts can decide how they want to implement this tool locally. It will be a resource for adapting and using locally as required

**ACTION:**

- Present draft HNA Questionnaire at next ERG

## **10. AOB**

Barry Keenan from Macmillan sent apologies today but asked SC to inform the group that Macmillan have extended their original eHNA contracts with pilot sites until June 2021. Use of the tool/platform will remain free of charge until this date – discussions will take place re. any plans to charge sites thereafter.

SC spoke about a piece of work from the Rehabilitation ERG: development of a resource pack of content (slides, videos, presentations) for HWBE's. If any members have content they think would be useful to add to this stockpile please share with SC. The content can then be tailored to each trust as and when needed.

AVL informed the group about a new Patient Information Working Group that has been set up by the MICA Patient Experience team looking at patient information pathways across the patch. The group is focussing on timed pathways in Urology and Head and Neck, mapping which information patients receive and ensuring it is at the right point of their pathway. There have been two meetings so far and it is attended by Information Leads, Lead Cancer Nurses, CNS's and Macmillan Information Managers. If ERG members interested in becoming involved, they were advised to contact Becky Driscoll.

Sarita shared a comment from Karen Robb, Rehabilitation Lead at TCST re. e-HNA data, which highlights that the top concerns in London include fear, worry and anxiety. Karen suggested that it may be beneficial for CNSs to receive additional training to manage these issues with individuals. SC informed the group that CNSs within our geography are all level 2 trained (psychological support) and that they access monthly supervision in which learning needs are identified. In addition the Psychosocial ERG work stream has created resources to be used in CNS group supervision session re. psychological issues and how to support individuals with these

AV reminded the group that TCST are carrying out Cancer Rehabilitation Service Mapping and to respond to requests to complete

**ACTION:**

- Group to share any HWBE relevant content for resource pack to SC

**Next Meeting Date:** Thursday 7th June 2018 10:00 -12:00 @ Ground Floor Central Meeting Room, 250 Euston Road, London, NW1 2PG.

**ACTION LOG**

| Action  | Owner | Date Due | Status   |
|---|-------|----------|----------|
| Circulate a Recovery Package funding template for completion              | SC    | 07.06.18 |          |
| Circulate February Workplan once Q3 Recovery Package Data received        | SC    | 15.03.18 | Complete |
| Draft Recovery Package Implementation Event agenda and circulate to group | SC/LB | 01.03.18 |          |
| Present draft HNA Questionnaire at next ERG                               | SC    | 07.06.18 |          |
| Group to share any HWBE relevant content for resource pack to SC          | All   | 07.06.18 |          |

## 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             |
| Alison Boyd (AB)             | Information Support Manager   | NMUH                                  |
| Avril van der Loo (AVL)      | Macmillan Recovery Package Programme Manager  | UCLH CC                               |
| Azmina Verjee (AV)           | Macmillan Recovery Package Project Manager  | Homerton                              |
| Daphne Earl (DE)             | Patient Representative  |                                       |
| Emma Sly (ES)                | Macmillan Recovery Package Manager  | PAH                                   |
| Jeannie Eng (JE)             | Macmillan Project Facilitator   | BH                                    |
| Lallita Carballo (LC)        | Clinical Lead Nurse   | UCLH                                  |
| Linda Athey (LA)             | Lead Cancer Nurse   | NMUH                                  |
| Lucy Brooks (LB)             | Macmillan Recovery Package Project Lead   | BHRUT                                 |
| Roxanne Payne (RP)           | Macmillan Project Coordinator   | UCLH CC                               |
| Sharon Cavanagh (SC)         | Lead for the Macmillan Integrated Cancer (MICa) Programme   | UCLH CC                               |
| Sarita Yaganti (SY)          | LWBC Implementation Lead  | TCST                                  |
| Zereen Rahman-Jennings (ZRJ) | Macmillan Living With Cancer Programme Lead   | Macmillan Local Authority Partnership |
| Tee Fabikun (TF)             | Patient Representative  |                                       |

## Apologies

| Name             | Role                                     | Trust/Organisation |
|------------------|--|--------------------|
| Alia Nizam       | Lead for Stratified Follow-Up            | UCLH               |
| Barry Keenan     | Macmillan Services Project Manager       | Macmillan          |
| Elizabeth Shaw   | Psychologist                             | NMUH               |
| Karen Phillips   | Macmillan Lead Cancer Nurse              | BHRUT              |
| Phil Hall        | Macmillan Programme Manager              | Macmillan          |
| Sarah Pearson    | Senior Nurse for Cancer                  | BH                 |
| Liz Price        | Associate Director (LWBC)                | TCST               |
| Flo Panel-Coates | Chief Nurse                              | UCLH               |
| Tina Smith       | Macmillan Lead Nurse for Cancer Services | PAH                |
| Natalie Doyle    | LWBC Pathway Chair                       | RM Partners        |
| Jacky Jones      | Lead CNS Breast                          | BH                 |