

Meeting of the *London Cancer Psychosocial Expert Reference Group*

Date: **Thursday 14th June 2018, 15:00-17:00**

Venue: 47 Wimpole Street, Basement Meeting Room, London, W1G 8SE

Chair: Mark Barrington

Minutes: Daisy Doncaster

1. Welcome and Minutes from the previous meeting & matters arising

MB welcomed members, introduced Daisy Doncaster, the new Macmillan Project Coordinator, and apologies were heard. The minutes of the last meeting were accepted as an accurate record of proceedings.

2. Review of action log:

Action	Owner	Status
Circulate information about QoL project and flyer with further information about the study	SC	COMPLETE
HEE – Role of AHPs: case study request: <ul style="list-style-type: none"> • Circulate documents and template for case study and copy in Philippa Hyman to see if any case studies that have already been written for TCST project might be relevant • Consider a social work case study • “endeavour to find a case study” 	HM PS RA	COMPLETE <i>(HM to follow up with PH separately)</i>
Liaise with PMc and group to set new date to meet to progress	EH	COMPLETE
Write annual report on ERG	MB	DRAFT COMPLETE

Agenda items:

3. Level 2 training dates

Date	Trust	Attendees / other notes
Wednesday 8 August	Barts	1 st preference – Barts employees 2 nd preference – BHRUT employees 3 rd preference – All other trusts

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

Wednesday 21 November	UCLH	1 st preference – UCLH employees 2 nd preference – RF employees 3 rd preference – All other trusts
2019 Quarter 1 (date TBC)	BHRUT	Most likely held in North London, e.g. Walthamstow
2019 Quarter 2 (date TBC)	Royal Free	

Aim to have one training day per quarter at Barts, UCLH, BHRUT and Royal Free, and on different days of the week if possible.

ACTION POINTS:

- **MK and EH** to coordinate dates for 2019 Q1 and 2019 Q2 training, and communicate dates to **MB and DD**
- **DD** to advertise dates on the ERG webpage, including location and contact details
- **MB** to liaise with Alison Hill to disseminate info about future training to Lead Cancer Nurses in each Trust

4. Review of CDG size

The group discussed the potential benefits of increasing the size of this group to 8 people. Typically, this will mean at least 4 attendees at each meeting, less variation and alleviated capacity issues.

BHRUT have piloted this, with no negative feedback so far. Approx. 5-6 people attended each meeting. As no objections were raised, local services are free to implement the same arrangement.

The team at BHRUT have considered restricting 2 people to present in each group and will share this as a case study in future if it goes ahead. BHRUT also opened CDGs to Community Palliative Care CNSs, which was considered very helpful.

The group felt it would be helpful to bring Level 2 facilitators together to share experiences of running groups. This could also be an opportunity for training for this group, or a presentation on supervision, for example.

ACTION POINTS:

- **MBu** to coordinate potential Level 2 facilitators meeting – potential dates, location etc.

5. London Cancer / UCLH Cancer Collaborative update:

Update from SC

- Naser Turabi is now in post as the new Programme Director of UCLH CC
- UCLH CC: new branding and London Cancer website moving to UCLH CC site

- Focus on Transformation Funding – this has been approved and currently being processed
- UCLH CC annual event on 26 June (EventBrite page [here](#))

6. Patient Representation themes

Draft questionnaire: Patient experience of receiving an HNA

A project initiated by Daphne and Tee, patient representatives in the Living With and Beyond Cancer ERG. This is a tool to evaluate patients' experiences of receiving an HNA and a key aim of this approach is to evaluate the impact of HNAs in influencing outcomes and/or initiating actions for patients. The first draft has been sent to the LW&BC ERG for feedback and the methodology is still being discussed.

The second draft of the questionnaire will be shared with this group for feedback too.

The group gave some initial feedback on the questionnaire, which Daisy will pass on to Becky Driscoll, who is coordinating the project.

ACTION POINTS:

- **DD** to send group's initial feedback to BD
- **DD** to send group second draft of questionnaire for feedback

6. 2017/18 Work stream updates

Crib sheets (EH)

- The workstream has completed drafts on the following topics: self-care, breaking bad news, bereavement and loss, telephone communication, and using CDGs for nurses' revalidation (additional benefits of attending the groups).
- In progress: anxiety, breaking bad news, suicidality
- Topics to cover: vicarious traumatisation, anger, body image, denial, family issues, talking to children, difficult conversations with colleagues and patients (EH to look at L2 training to see if there are any topics not covered)
- Suggestions from the group for additional topics: "Hot Cross Bun", depression, living with pain, boundaries, being non-judgemental

The group discussed the potential benefits and drawbacks to making the crib sheets available online, e.g. on the UCLH CC website, on the nhs.net network, Dropbox or Trello. No decision was made, but this will be discussed in more depth at a future meeting.

ACTION POINTS:

- **EH** to look at L2 training topics to see if anything has been missed
- **EH** to disseminate up-to-date list of topics by **13 July**

- **MB** to send **DD** list of L2 facilitators to disseminate this to
- **All**: feedback on crib sheet drafts and list of topics by **end October**

Parents' video and resources

MB provided an update from Pete Southern regarding the translation of the [animation on telling children about cancer \(Fruit Fly Collective, 2016\)](#).

- Plans for translation to Bengali/Turkish/Somali/Polish/Cantonese or Vietnamese
- Unclear if this will be funded by Macmillan, but this is still in discussion

ACTION POINT:

- **MB** to ask PS to send quotes for translation to **SC**, who will liaise with MICa contacts in Macmillan to see if support is available for this

Annual report

MB has provided SC with content for report. The report covers a summary of 2017/18 work undertaken by the group, and plans for 2018/19.

ACTION POINT:

- **SC** to produce draft of final report

HADS

Licence required for use of HADS. The group discussed whether this needed to be a separate work stream for 2018/19, as well as the pros and cons of using other tools.

The group decided to explore funding options for using the HADS, then revisit potential future projects for alternative measures later.

ACTION POINTS:

- **SC** to investigate if it's possible for MICa to fund HADS licence, and let **MB** know
- **MB** to ask Caroline Dancyger for more specific details about previous use of the tool

AOB

EH asked if any members of the group had a local service directory template they could share. DD sent EH the link to the [London Cancer directory of services](#), and HM will send the North Middlesex directory too.

MK reported an intention to work with Breast Cancer Haven in BHURT. MK to invite Nicola Cunningham (via DD) to forum.

ACTION POINTS:

- **HM** to send EH the North Middlesex local directory of cancer services
- **MK/DD** to invite Breast Cancer Haven (Nicola Cunningham) to psychosocial forum

Date of Next Meeting: Thursday 16th August, 3-5pm, Conference Room, 47 Wimpole Street, London, W1G 8SE

ACTION LOG

Action	Owner	Status
Level 2 training		
MK and EH to coordinate dates for 2019 Q1 and 2019 Q2 training, and communicate dates to MB and DD	MK and EH	
DD to advertise dates on the ERG webpage, including location and contact details	DD	
MB to liaise with Alison Hill to disseminate info about future training to Lead Cancer Nurses in each Trust	MB	
CDGs		
MBu to coordinate potential Level 2 facilitators meeting – potential dates, location etc.	MBu	
Patient experience survey: HNAs		
DD to send group's initial feedback to BD	DD	COMPLETE
DD to send group second draft of questionnaire for feedback	DD	
Crib sheets		
EH to look at L2 training topics to see if anything has been missed and disseminate up-to-date list of topics by 13 July	EH	
MB to send DD list of L2 facilitators to disseminate this to	MB and DD	
Feedback on crib sheet drafts and list of topics by end October	All	
Parents' video		
MB to ask PS to send quotes for translation to SC , who will liaise with MICa contacts in Macmillan to see if support is available for this	MB, PS, SC	
Annual report		
SC to produce draft of final report	SC	
HADS		
SC to investigate if it's possible for MICa to fund HADS licence, and let MB know	SC	
Other		
HM to send EH the North Middlesex local directory of	HM	

cancer services		
MK/DD to invite Breast Cancer Haven (Nicola Cunningham) to psychosocial forum	MK/DD	

Attendees

Name	Role	Trust/organisation
Mark Barrington (chair)	Macmillan Psychosocial Lead	Barts
Mary Burgess	Consultant Clinical Psychologist	UCLH
Lallita Carballo	Information Service	UCLH
Sharon Cavanagh	MICa Programme Lead	UCLH CC
Daisy Doncaster	Macmillan Project Coordinator	UCLH CC
Daphne Earl	Patient Representative	
Elaine Heywood	Macmillan Counsellor and Information Officer	Royal Free
Marc Kingsley	Consultant Clinical Psychologist	BHRUT / NELFT
Heather Munro	Cancer Psychologist	North Middlesex
Samixa Shah	Patient Representative	

Apologies

Name	Role	Trust/organisation
Ruth Allen	Macmillan Clinical Psychologist	Whittington
Pauline McCulloch	Lead Colorectal Nurse	Homerton
Peter Southern	Palliative Care Social Worker	Barts
Clare Stevenson	Clinical Psychologist in Cancer Care	Homerton