

Meeting of the *London Cancer* Psychosocial Expert Reference Group

Date: **Thursday 16 August 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 and matters arising

MBa welcomed members 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
Level 2 training		
MK and EH to coordinate dates for 2019 Q1 and 2019 Q2 training, and communicate dates to MBa and DD Update: <ul style="list-style-type: none"> Date confirmed at BHRUT/NELFT: Monday 4 February 2019 – MK to confirm location, time and main contact Royal Free to run training in May 2019 – EH to confirm date, time, location and main contact UCLH to run training on Wednesday 21 November 2018 – Mbu to confirm time and location. Main contact: Faith Warner 	MK and EH	ONGOING
DD to advertise dates on the ERG webpage, including location and contact details	DD	ONGOING
MBa to liaise with Alison Hill to disseminate info about future training to Lead Cancer Nurses in each Trust	MB	COMPLETE
CDGs		
MBu & MBa to coordinate potential Level 2 facilitators meeting – potential dates, location etc.	MBu & MBa	IN PROGRESS – see item 7
Patient experience survey: HNAs		

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

DD to send group's initial feedback to BD	DD	COMPLETE – see item 9
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 Update EH to review minutes from this meeting and send to DD to formally brand as UCLHCC psychosocial ERG and distribute to facilitators	EH	ONGOING
MBa to send DD list of L2 facilitators to disseminate this to	MBa and DD	COMPLETE
Feedback on crib sheet drafts and list of topics by end October	All	
Complete crib sheets on Hot Cross Bun (MBa) and body image (MK) – after first 9 crib sheets have been sent out	MBa and MK	
EH to send crib sheet template to MBa and MK	EH	
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 Update Emma Tingley, Strategic Partnerships Manager, Macmillan, has said there may be an opportunity to fund this via a Macmillan Service Grant	MB, PS, SC	COMPLETE
Annual report		
SC to produce draft of final report Update This will make up part of the MICa annual report, published in late August. This will be advertised on the ERG webpage	SC	ONGOING
HADS		
SC to investigate if it's possible for MICa to fund HADS licence, and let MBa know Update Again, it may be possible to fund this via Macmillan, but other options are also being explored (see item 11)	SC	COMPLETE
Other		
HM to send EH the North Middlesex local directory of cancer services	HM	COMPLETE
MK to invite Breast Cancer Haven (Nicola Cunningham) to psychosocial forum	MK	

Update from Pete Southern on translation of *telling your children* video

- EH and PS have put in bids for funding from Trust funds for this – awaiting feedback

- Working with Becky Driscoll (Patient Experience and User Involvement Programme Lead) to run focus groups with community groups to discuss considerations around cultural and language aspects to take into account when releasing the resource in other languages. This may also have an impact on funding.
- Chosen the 5 languages most spoken in London after English:
 - Turkish
 - Polish
 - Bengali
 - Somali
 - Cantonese
- Members of the group (namely **MK and EH**) offered to ask colleagues and local contacts about Polish support/community groups, as this has been the group which has been most difficult to engage. If members make any suitable contacts, please put them in touch with Pete.

Agenda items:

4. London Cancer / UCLH Cancer Collaborative update:

In Sharon's absence, Daisy provided a brief update on *London Cancer* and the UCLH Cancer Collaborative:

- Naser Turabi – Programme Director, UCLH Cancer Collaborative – is currently on shared parental leave, back early Sept
- UCLHCC e-bulletin was sent end July. Anyone who didn't receive this who would have liked to, please get in touch with DD
- MICa team recruitment updates : pleased to welcome Zoe Large, Patient Experience and User Involvement Programme Manager, and excited to advertise a post for a Macmillan Stratified Follow Up Programme Manager
- The next MICa Service Review will take place on 13 September. Following this, the psychosocial ERG will be updated on the 2018/19 objectives and plans for future funding.

5. Outcome measure review

Trusts within the Cancer Collaborative previously used HADS as an assessment tool, however the licence for this has now expired. There may be funding available from Macmillan on this, but the ERG are also looking at other alternatives.

MBa is working with Zoe Large to organise a consultation with the Patient and Carer Network to evaluate outcome questionnaires from patient perspective. They hope to run a half-day workshop in September with approx. 10-15 patients (including Daphne and Samixa). MBa will present various options to the group and ask patients to review these and in particular highlight any they wish to exclude.

If the group know of other measures which might be good candidates for consideration, please let MBa know.

The group agreed that patient consultation on this is vital. RA noted that the aims of therapy vary and as such, one might want to consider varying outcome measures depending on the proposed intervention. It was also noted that some measures are available online, and in different languages, which can be helpful – the group may wish to take this into consideration.

6. CDG facilitators' meeting, Autumn 2018

A meeting is being held on 2 November (time and location to be confirmed) for facilitators of monthly Clinical Discussion Groups (CDGs). The aim of this meeting is to bring facilitators together to share learning and best practice, support each other and ensure the revised Level 2 training is being implemented effectively, efficiently and comprehensively.

DD will send a finalised invitation to the meeting to a list of 35 CDG facilitators shortly.

7. Data gathering for TCST psychology business case

MBa has been working with TCST (Transforming Cancer Services Team, London) on a business case to help commissioners understand the importance of funding psychological support services and ensuring this is factored in to service specifications. The working group have developed a brief survey for professionals to complete with regards to their last 3 patients to demonstrate the relevance of psychological interventions in supporting patients to access their physical health care.

MBa distributed a draft of this survey and received broad support from the group on this piece of work.

MBa will email Psychological specialists across the LC region (using the CDG facilitator's distribution list) with the questionnaire to complete. ERG members to encourage colleagues to complete it.

8. Patient Representation Themes: HNA patient experience questionnaire

DD provided an update on the patient experience survey currently in draft which aims to measure patient experience of receiving a Holistic Needs Assessment (HNA). This was presented by Daphne and Samixa at the previous meeting.

DD passed on the group's feedback to BD, and BD's responses were shared with the group (see paper 3 for the meeting). BD provided a further update for DD to share with the group:

Daphne, Tee (patient reps on the Living With and Beyond Cancer ERG), Sharon and Becky have drafted a patient experience survey on HNAs. They plan to consult the rest of the LWBC ERG, as well as the Patient and Carer Network (approx. 70 people)

Becky has been discussing the survey and its implementation with Macmillan and with Recovery Package Managers at Cancer Collaborative Trusts, focusing on reach and practical management (e.g. administrative considerations).

Becky is also exploring the possibility of a two phase approach to gathering this insight into patient experience of HNAs, e.g. qualitative engagement (such as focus groups) to then be used to inform a wider survey (second phase).

The ERG will be updated on progress and future versions by DE, SS and DD.

9. 2017/18 Work stream updates

MBa provided an update on the progress of the ERG's 2017/18 work streams:

- Video supporting parents to tell their children about cancer – complete. Phase 2 (translation) in progress (2018/19 and see above).
- Level 2 training crib sheets – in progress, coming to the end of this piece of work

10. 2018.19 Work streams

The group also discussed the ERG's work streams for next year:

- Outcomes measures and alternatives to HADS (see above)
- Translation of video supporting parents to tell their children about cancer (see above)
- Data gathering to support TCST work regarding pan-London Service Specification (see above)
- Level 2 enhancement / support:
 - Updating and standardising documentation and systems and ensuring sustainability of running the ERG
 - Data collection on format of new Level 2 training and outcomes for nurses undertaking the training, as well as continuation of the work on crib sheets (see above)

These work streams were agreed by the group for 2018/19. MBa will send an email to the group to ask who would be willing to get involved in / lead on which work stream.

AOB

- MK to send DD articles from Journal for Healthcare Managers to distribute to ERG members
- Update from Mary Burgess (via MBa) regarding work being done at UCLH:
 - Work progressing on pre-habilitation projects
 - Surgical School: Enhanced Recovery Pathway for prostatectomy patients including surgical education session for patients and family. Sessions are intended to manage expectations, aid post-operative recovery and promote self-management. [Find out more](#) and here is a [short video](#) (3

minutes) promoting the school, and a [longer descriptive video](#) (30 minutes).

- o Additional psychology staff are currently being recruited

Date of Next Meeting: Thursday 11th October, 3-5pm, Conference Room, 47 Wimpole Street, London, W1G 8SE

ACTION LOG

Action	Deadline	Owner(s)
Level 2 training		
MK to confirm location, time and main contact of February Level 2 training at BHRUT/NELFT	ASAP	MK
EH to confirm date, time, location and main contact for L2 training at Royal Free in May 2019	ASAP	EH
MBu to confirm time and location of UCLH L2 training in November.	ASAP	MBu
DD to advertise dates and locations of L2 training on ERG webpage	TBC	DD
CDG facilitators' meeting		
DD to send final details to CDG facilitators	ASAP	DD
Crib sheets		
EH to review minutes from this meeting and send to DD to formally brand as UCLHCC psychosocial ERG and distribute to facilitators	ASAP	EH
Feedback on crib sheet drafts and list of topics	End Oct	All
Complete crib sheets on Hot Cross Bun (MBa) and body image (MK) – after first 9 crib sheets have been sent out	End Oct	MBa and MK
EH to send crib sheet template to MBa and MK	ASAP	EH
Psychosocial ERG annual report (in MICa report)		
SC to draft final version and DD to share with group when published	End August	SC and DD
Patient information video: translation		
EH and MK to ask colleagues and local contacts about Polish support/community groups and put them in touch with Pete	ASAP	EH, MK, PS
Assessment tools and HADS		
Alternatives to HADS: if any members know of other measures which might be good candidates for consideration, please let MBa know (see notes above)	ASAP	All
TCST business case		

MBa will email Psychological Specialist with the questionnaire to complete. ERG members to encourage colleagues to complete it.	End Sept	MBa
2018/19 Work Streams		
MBa to send an email to the group to ask who would be willing to get involved in / lead on which work stream	30/09/2018	MBa
Other		
MK to send DD articles from Journal for Healthcare Managers to distribute to ERG members	ASAP	MK
MK to invite Breast Cancer Haven (Nicola Cunningham) to psychosocial forum	ASAP	MK
DD to investigate options for a password protected folder/website for ERG members to access	27/11/2018	DD

Attendees

Name	Role	Trust/organisation
Mark Barrington (chair)	Macmillan Psychosocial Lead	Barts Health
Daisy Doncaster	Macmillan Project Coordinator	UCLH CC
Elaine Heywood	Macmillan Counsellor and Information Officer	Royal Free
Marc Kingsley	Consultant Clinical Psychologist	BHRUT / NELFT
Su Yin Yap	Consultant Cancer Psychologist	North Middlesex
Samixa Shah	Patient Representative	
Pete Southern	Palliative Care Social Worker	Barts Health
Sue Gibbons	Clinical Psychologist	Whittington
Ruth Allen	Clinical Psychologist	Whittington
Clare Stevenson	Clinical Psychologist	Homerton

Apologies

Name	Role	Trust/organisation
Mary Burgess	Consultant Clinical Psychologist	UCLH
Sharon Cavanagh	MICa Programme Lead	UCLH CC
Daphne Earl	Patient Representative	
Esther Hansen	Clinical Psychologist	Royal Free