

Meeting of the *London Cancer* Rehabilitation Expert Reference Group

Date: **November 1st 2017, 15:00-16:30**

Venue: **51 Wimpole Street, 1st Floor Boardroom, London, W1G 8SE**

Chair: **Sharon Cavanagh ERG Chair**

1. Introductions, Apologies and review minutes from last meeting

SC welcomed members of the ERG and introductions were made.

SC read out apologies. The minutes of the last meeting were reviewed and accepted.

2. UCLH Cancer Collaborative update (SC)

SC updated the group on Health Education England Masterclasses that are currently underway for GP's and AHP's as part of a year-long LWBC Primary Care fellowship. SC and Anthony Cunliffe have developed and are running the cancer specific masterclasses – with support from the London LWBC community. There are four fellows in total; one pharmacist and three GP's. This is the first time these cancer specific masterclasses have been held. SC will circulate the latest version of the fellowship manual and masterclass session outlines. Of interest, Karen Robb will be presenting on the rehabilitation session scheduled for Spring 2018.

SC informed the group that UCLH CC submitted a successful bid to be a pilot site for the NHSE Quality of Life metric. Across the UK, five sites are taking part in this pilot, the aim is to produce a national QoL metric and help gather a picture of survival and quality of life after a cancer diagnosis. The QoL Pilot will run for fifteen months at UCLH and Barts. It will involve inviting people 12-24 months post treatment (individuals with breast, colorectal, prostate who were treated with curative intent) to complete a QoL questionnaire which can be followed up in clinic. Eligible individuals will be identified by the Project Support Manager a month prior to their follow-up appointment. They will receive a letter inviting them to fill in the questionnaire via an online patient portal. Monthly steering group meetings are taking place to discuss local implementation and recruitment of a Project Support Manager who will work across UCLH & Barts.

In April 2018, the UCLH Cancer Collaborative will transition into a Cancer Alliance. Discussions are ongoing about the changes this will entail and updates will be included on the UCLH CC website.

ACTION:

- Circulate master classes session outline
- Circulate updated manual for HEE London LWBC Fellowship

3. Pan-London Commissioning Priorities for London – Release of transformation funds (All)

Release of pan-London cancer transformation funds is not expected in the short term due to the recent coupling of the funding release with compliance with 62 day wait targets. London is not currently compliant with the targets. Next steps: continuing conversations with STP's about incorporating rehabilitation and finding out local rehabilitation needs and how this can be supported without the transformation funding.

4. TCST Rehabilitation Update (KR)

KR explained that one of her workplan aims is to develop London commissioning guidance for rehabilitation by June 2018. Within this guidance there will be a clear picture of what good rehabilitation looks like, and how it should be commissioned. The demand for services will be informed by some recent prevalence data for London which reports on tumour type, age, ethnicity and gender across all CCGs in London.

TCST have completed a detailed investigation of the data available on cancer rehabilitation services in London and collated the findings in a brief report. Led by a Cancer Information Analyst and supported by a task and finish group, this work included an examination of existing databases and interviews with system leaders and clinicians. As a result they have designed a minimum dataset (MDS) which will support the commissioning guidance for cancer rehabilitation services. The MDS will be piloted in four sites (two NHS, two non-NHS) within London, and published within the commissioning guidance in 2018.

The minimum dataset for cancer rehabilitation includes:

- Patient demographics
- Information on the type of cancer and cancer treatments
- Details about the provider of rehabilitation and reasons for referral
- Details on the type and amount of rehabilitation received by the patient and discharge status.

The aim is to roll this MDS pilot out to at least ten more sites, KR has requested members of the group to contact her if they are interested in becoming a pilot site and to share the blog post about this work widely.

This is the first stage in a collaborative process to develop a set of metrics that will demonstrate the impact of the full spectrum of cancer rehabilitation services, at both a patient and system level.

ACTION:

- Circulate the live link for TCST Scoping report
- Group to contact Karen Robb if interested in being a pilot site for minimum dataset

5. Cancer Transformation Fund Alliance Bid (SC)

Discussed in item 3 above.

6. Lymphoedema Audit (SC)

SC updated the group on the ongoing audits conducted to determine numbers of individuals presenting with lymphoedema symptoms, severity of symptoms at first presentation and information regarding referral pathways. Presently gynaecology, sarcoma and urology audits are running and the numbers of patients presenting with lymphoedema symptoms have been relatively low thus far. The next audits to be rolled out are in Head & Neck, Melanoma and Colorectal. The aim is for all audits to be conducted by April 2018.

This information will assist us to improve patient experience and outcomes by identifying any gaps in lymphoedema service provision or informing us where pressures exist on current lymphoedema services within our London Cancer footprint.

SC, KR and their equivalents from SEL and RM Partners are liaising with lymphoedema colleagues re. convening a Pan-London Strategic Lymphoedema Group.

7. Rehabilitation plan (SC)

SC opened up discussion regarding the workplan for the Rehabilitation ERG and asked for ideas regarding future focus. One piece of work currently on the plan is to explore is a standardised rehabilitation plan for development and implementation within the UCLH CC geography. Discussion ensued about the pros and cons of moving forward with this piece of work. It was agreed that the availability and quality of information received from community services is the primary concern and the rehabilitation plan would not resolve this. It would be difficult to verify how up to date information is or rely on patients to have the relevant papers on them.

KR informed the group that there is a NHSE AHP Discharge Learning Session meeting on 20th November, in which communications between different services will be a central theme and key issues will be summarised to consider at the end of the meeting. KR will circulate the link to the workshop and will bring feedback from the meeting to the next Rehabilitation ERG meeting.

ACTION:

- Circulate information for AHP Discharge Learning Session
- KR to feedback from AHP Discharge Learning Session

8. Service Updates (All)

Louise Platt - National Hospital for Neurology and Neurosurgery

- Redevelopment of the NHNN theatres continues with work due to finish next year.
- Bid was put in to increase staff as the ward will double in size in November; however this has been turned down due to financial restraints.
- LP discussed a Neuro-Oncology Therapy Screening Tool document which she will share with the group.

Supriya Nerlekar - Royal National Orthopaedic Hospital

- New hospital site will be ready to move into in August 2018. Cancer patients will be moving into the new building which will have high quality gym facilities.
- Referrals to RNOH's cancer services have seen a vast increase.
- Recruiting a new Sarcoma surgeon as well as a Band 6 OT.

Zenab Ahmad – Barking Havering and Redbridge University Trust

- BHRUT have received the country's first Varian Halcyon radiotherapy machine. It is anticipated that, once in place, this will have an impact on cutting treatment times while still delivering state-of-the-art cancer care.

Lindsay Farthing - Barts Health

- Neuro-Oncology Rehabilitation services – significant number of referrals currently being received. Thus far there has been positive patient feedback and outcomes reported. A scoping report is being worked on and will be presented to the ERG when complete.
- Macmillan funding for Outpatient physiotherapy role ends in November 2018. It has been agreed that the trust will pick up the funding post this date.
- Work is taking place to create a Lung Prehabilitation app.

Claire O' Herlihy – Royal Free London

- Claire's team are working on getting an a band 6 OT post funded and have approached Macmillan to support this.

Anthony Perryman – University College of London Hospital

- Nicola Raine (physiotherapist) has joined the Haematology team.
- A service review has been completed for adult oncology and haematology services. The team has been running a cancer programme of presentations over the past six months, where key topics and areas that have evolved are discussed; this has now turned into two study days for internal staff. The first took place in July to coincide with band 5 rotations; the second one is taking place at present. Moving forward this could potentially be offered externally, focusing on AHP's working in cancer. It is tailored for OTs and Physios but dietitians have attended to observe and establish if relevant to them.
- AP and NR are to begin working with the myeloma team in a pilot tele clinic study. Patients who are 3-6 months post stem cell transplant will be offered a tele clinic via a conference call. Individuals will receive a questionnaire to complete prior to the clinic. It is aimed at patients who can be put onto a supported self-management follow-up pathway and will have their bloods done locally (and results will be discussed in the clinic). The pilot will be funded until April 2018 by Myeloma UK.
- Currently reviewing their exercise physiotherapy role as it is currently focussed on treating transplant patients – scope for this to be more generic.
- OT and Physio posts at Teenage Cancer Service have been put on hold for now. Paediatric OT Band 7 post vacant at moment.

Victoria Todd - Maggie's at Cancerkin

- Royal Free have now granted permission to start building new Maggie's centre. Cancerkin will move into this once complete.

ACTION:

- LP to circulate Neuro-Oncology Therapy Screening Tool document

9. AOB (All)

- SC has become an AHP representative on the clinical advisory for London CCB. SC will collaborate with AHP community to decide how to best to feedback and report to the pan-London cancer AHP workforce, taking into consideration that this ERG is the only Rehabilitation ERG who meet up across the patch.
- SC attended the London Cancer Nurse Lead forum held in October. It had a focus on sharing learning to implement the Recovery Package. One idea which was successful at Imperial to support implementation of HWBEs was the creation of stock presentations that served as a resource for services wanting to establish their own events. If the ERG supported this idea, agreed rehabilitation focussed presentations could be held centrally locally for use by all. The ERG agreed that this would be helpful. SC asked the group to forward any presentations they want to put forward for consideration into the resource.

ACTION:

- Group to send health and wellbeing focussed presentations to SC. These will then be brought to the ERG for consideration for inclusion in a HWBE resource pack

Next Meeting: Tues 20th February 2018, 15:00 – 16:30 at Ground Floor Central Meeting Room, 250 Euston Road, London, NW1 2PG.

ACTION LOG

Action	Owner	Date Agreed	Status
Circulate master classes session outline	SC	01.11.17	
Circulate updated manual for HEE London LWBC Fellowship	SC	01.11.17	
Circulate the live link for TCST Scoping report	KR	01.11.17	Completed
Group to contact Karen Robb if interested in being a pilot site for minimum dataset	All	01.11.17	Ongoing
Circulate information for AHP Discharge Learning Session	SC	01.11.17	Completed
KR to feedback from AHP Discharge Learning Session	KR	01.11.17	At next meeting

LP to circulate Neuro-Oncology Therapy Screening Tool document	LP	01.11.17	Completed
Group to send health and wellbeing focussed presentations to SC. These will then be brought to the ERG for consideration for inclusion in a HWBE resource pack	All	01.11.17	Ongoing

Attendees

Name	Role	Trust/Organisation
Sharon Cavanagh (SC)	Macmillan Living With and Beyond Cancer and AHP Lead	London Cancer/UCLH CC
Anthony Perryman (AP)	Haematology OT	UCLH
Claire O' Herlihy (CO)	Highly Specialist Oncology Occupational Therapist	RFL
Claire Wells (CW)	Neuro OT	NHNN
Karen Robb (KR)	Macmillan Rehabilitation Lead	TCST
Lindsay Farthing (LF)	Clinical Lead for Oncology Therapies	BH
Louise Platt (LP)	Therapy Lead – Neurosurgery	NHNN
Nicola Raine (NR)	Haematology PT	UCLH
Roxanne Payne (RP)	Project Co-ordinator	London Cancer/UCLH CC
Supriya Nerlekar (SN)	Clinical Specialist Manager	RNOH
Victoria Todd (VT)	Breast Cancer Lymphoedema Clinic Director	Maggie's at Cancerkin
Zenab Ahmad (ZA)	Macmillan Dietitian	BHRUT

Apologies

Name	Role	Trust/Organisation
Jayne Morton	Macmillan Specialist Palliative OT	NELFT
Adrian Gilson	Community Nutrition Support Dietitian	BH
Carla Zanichelli	Lymphoedema Physiotherapist	UCLH
Diana Markham	Site Lead for Dietetics	BH
Sally Greig	Senior Physiotherapist	BHRUT
Kay Eaton	Clinical Lead for Lymphoedema Service	UCLH
Roisin Barr	Physiotherapist	HUH
Joshna Hirani	Orthopaedic Oncology Team	RNOH

Name	Role	Trust/Organisation
Fiona Kelly	Head of Adult Therapies	HUH
Suzette Ferreira	Clinical Lead OT	BHRUT
Freya Hickey	Clinical Lead SALT	BH
Caroline Quilty	Therapies Services Manager	HUH
Rebecca Tiberini	Therapies Service Manager	St Joseph's Hospice
Teresa Hill	Lymphoedema Nurse Consultant	Enfield
Kassandra Montanheiro	Clinical Lead Dietitian	UCLH
Abi Fisher	Lecturer in Physical Activity and Health	UCL
Kathy Wisbey	Occupational Therapist	HUH
Christina Moore	Lymphoedema CNS	UCLH

The UCLH Cancer Collaborative is a part of the national Cancer Vanguard, working with Greater Manchester Cancer Vanguard Innovation and RM Partners