

Meeting of the *London Cancer* Rehabilitation Expert Reference Group

Date: **Tuesday 20th February 2018, 15:00-16:30**

Venue: **Ground Floor Central Meeting Room, 250 Euston Road, NW1 2PG**

Chair: **Sharon Cavanagh ERG Chair**

1. Introductions, Apologies and review minutes from last meeting

SC welcomed members of the ERG and read out apologies. The action log was checked from the last meeting and minutes of the last meeting were agreed.

2. UCLH Cancer Collaborative update (SC)

Nick Kirby has left his role as Divisional Manager and an internal candidate has been appointed, the start date is being negotiated. In the interim all Divisional Manager duties have been disseminated across Programme Leads.

Mairead Lyons joined the UCLH CC team this week, supporting the Clinical Leadership Early Diagnosis team on a six month contract.

UCLH CC will be holding a Recovery Package focused workshops between April/May 2018, coordinated by the Living With and Beyond Cancer ERG. SC will share this information with the group when available.

3. Rehabilitation Workplan (SC)

SC discussed the Rehabilitation Workplan. Main themes discussed:

- **Embedding physical activity into cancer pathways** – now complete and uploaded onto *London Cancer* service directory.
- **Embedding rehabilitation into cancer pathways** - Presented rehabilitation priorities to CCB on 28th April. Still awaiting confirmation of any cancer transformation funding release, subject to meeting 62 day wait targets. Local discussions occurring within NCL and NEL CCG's, SC will update the group in next meeting.
- **Consequences of Treatment – Improve Access to Services** – Lymphoedema audits across tumour sites almost complete. Melanoma audit is currently taking place with Head & Neck and Colorectal pending.

SC asked the group to feedback on about possible Rehabilitation work streams to focus on from April 2018 and to feedback so the 2018/19 workplan can be updated. Rehabilitation mapping carried out by TCST may bring up some themes that can be worked on; more information regarding this will be released from May. Developing resource packs of stock presentations for HWBE events with focus on rehabilitation may be a useful area to focus on.

ACTION:

- Circulate March Workplan
- Group to feedback to SC on Rehabilitation work stream themes for 2018/19

4. TCST Rehabilitation Update (KR/GW)

Karen Robb and Georgina Wiley provided an update on three main pieces of work being carried out by TCST;

Lymphoedema work

- Development of version two of the lymphoedema commissioning guidance will commence in September/October 2018 – will have an increased focus more on community services.
- A Pan-London Lymphoedema Community of Practice has been set up, working with LWBC Leads across three trusts and discussions are ongoing with Macmillan about funding to resource facilitation of this.
- Lymphoedema awareness week runs from 5th-10th March and TCST are holding an awareness event at Skipton house on 8th March at 1-2pm with presentations and stalls from Lymphoedema Society and Macmillan. All are welcome and they hope to attract a mix of service users, primary care staff and commissioners. The event information will be circulated to the group.

Rehabilitation Services Mapping

- TCST are mapping cancer rehabilitation services across London. A consultant, Shamsur Choudhury, has been appointed to take on the bulk of this work alongside support from a task and finish group including members of UCLH, RM Partners and Guys & St Thomas.
- Shamsur is contacting people to find out which rehabilitations services they refer to then finding out how they operate, how they are commissioned etc.
- If anyone has a list of services they regularly refer patients to for cancer rehabilitation please forward onto Georgina. The aim is for the mapping to be completed by end of March.

Benchmarking tool for cancer rehabilitation services

- Developing a tool to benchmark cancer rehabilitation services across London to see where services are doing well and where they need improvement.
- Looking at expectations of high quality rehabilitation and asking service users what this looks like. Held an event in January with twenty service users to find out what is important in cancer services, what went well/what didn't etc. The feedback matched up with expectations of high quality rehabilitation. People want individualised services and a clear view of which services are available.
- In process of drafting benchmarking tool. Aims to scope what services think are important. TCST are holding a Cancer Rehabilitation Consultation Event to discuss this on 1st March, event details have been circulated to the group.
- There will be a launch event in April and the tool will be refined after receiving feedback from the event.

KR also discussed the cancer rehabilitation minimum data set which has been piloted at four different services including Barts. There were lots of challenges which were presented at steering committee last week during data review. The team is now revisiting this to discuss the possibility of duplicate data collection with local systems, how they can work around this and whether it is the correct data that they should be collecting for every patient. KR invited any feedback on this minimal data set from the group.

TCST are working on commissioning guidance for Cancer Rehabilitation with a deadline of end of July and this will be published at end of Summer/Autumn.

- ACTION:**
- Circulate information on Lymphoedema Awareness Event 8th March
 - Group to feedback to KR any suggestion on minimal data set

5. HEE LWBC Primary Care Masterclasses (SC)

SC informed the group about a rehabilitation master class that will run in May and welcomed any suggestions on how to structure this master class, which will involve around 3 ½ hours of focus on rehabilitation. SC will send the date once confirmed to the group and if interested then members can come and talk about their speciality. It was agreed it would be useful to get a service user to come and discuss their experience.

Health Education England are keen to run master class again next year, which may be open to AHP's. SC will keep the group updated about this.

- ACTION:**
- Send date of rehabilitation master class and group members to contact SC if would like to present

6. Lymphoedema Audit (RP)

Discussed in item 3 above.

7. Service Updates (All)

Louise Platt - National Hospital for Neurology and Neurosurgery

- Molly Fox Brain Tumour Unit has now moved and doubled the numbers of patient.
- In process of implementing electronic health records for all documentation on the wards.

Kassie Montanheiro - UCLH

- Therapies team due to meet to discuss any changes to staffing required to serve proton beam service.
- Dietitians have been conducting a benchmarking exercise – to address needs for ambulatory care in paediatrics and young adults.

Supriya Nerlekar - Royal National Orthopaedic Hospital

- Attended Recovery Package steering group meeting at UCLH, plan to scope their role and local changes required to deliver locally.
- New sarcoma surgeon starting soon.
- OT band 6 role has been vacant for a year- still no success in recruiting
- Cancer ward will move into new building in October 2018.

Lindsay Farthing - Barts Health

- Maggie Centre at Barts is open and Oncology Therapies team are working closely with them to deliver rehabilitation
- Barts are running 3x Teachable Moments sessions in March for people with a near miss of cancer, to highlight awareness of screening, healthy eating and acting early on symptoms.
- A lung Pre-habilitation app is in development.

Nicola Raine – UCLH

- Developing a bid to Macmillan for funding for an OT and PT within the cancer centre
- Had second Induction day in October with the Cancer Academy. There was positive feedback and next one will be in May. Discussions occurring to open these sessions up to multi professionals i.e. dietitians, speech and language therapists in the future.

8. AOB

SC in process of recruiting a patient/carer rep. to the group.

Workforce mapping will be carried out in May. SC will send information gathered from teams two years ago and request them to be updated with any changes in directory.

Next Meeting: Tuesday 1st May 2018 15:00-16:30- 250 Euston Road, Ground Floor Central Meeting Room, London, NW1 2PG

ACTION LOG

Action	Owner	Date Agreed	Status
Circulate March Workplan	SC	20.02.18	Complete
Group to feedback to SC on Rehabilitation work stream themes for 2018/19	All	20.02.18	In progress
Circulate information on Lymphoedema Awareness Event 8 th March.	KR	20.02.18	Complete
Group to feedback to KR any suggestion on minimal data set	All	20.02.18	All
Send date of rehabilitation master class and group members to contact SC if would like to present	SC/All	20.02.18	Complete

Attendees

Name	Role	Trust/Organisation
Georgina Wiley (GW)	Macmillan Project Facilitator	TCST
Jenny Parker (JP)	Neuro-oncology Physiotherapist	NHNN
Karen Robb (KR)	Macmillan Rehabilitation Clinical Lead	TCST

Name	Role	Trust/Organisation
Kassie Montanheiro (KM)	Clinical Lead Dietician	UCLH
Lindsay Farthing (LF)	Clinical Lead for Oncology Therapies	Barts
Louise Platt (LP)	Therapy Lead – Neurosurgery	NHNN
Nicola Raine (NR)	Haematology Physiotherapist	UCLH
Roxanne Payne (RP)	Macmillan Project Co-ordinator	UCLH CC
Sharon Cavanagh (SC)	Living With and Beyond Cancer and AHP Lead	UCLH CC
Supriya Nerlekar (SN)	Clinical Specialist Manager	RNOH

Apologies

Name	Role	Trust/Organisation
Caroline Quilty	Specialist Dietitian in Palliative Care & Oncology	Homerton
Adrian Gilson	Community Nutrition Support Dietitian	Barts
Clare McEwen	Team Lead Occupational Therapist for Oncology	UCLH
Claire Axton	Speech and language Therapist	UCLH
Diana Markham	Site Lead for Dietetics	Barts
Charlene Walters	Senior Physiotherapist	Barts
Kay Eaton	Clinical Lead for Lymphoedema Service	UCLH
Jennifer Gilbert	Lymphoedema CNS	UCLH
Jennifer Hart	Macmillan Community Dietitian	NELFT
Sarah Hodgson	Team Lead Physiotherapist for Oncology	UCLH
Abi Fisher	Lecturer in Physical Activity and Health	UCL
Carla Zanichelli	Lymphoedema Physiotherapist	UCLH
Emily Stowe	Day Therapy Manager	St Clare Hospice
Fiona Kelly	Head of Adult Therapies	Homerton
Gemma Lindsell	Team Lead Occupational Therapist	UCLH
Jayne Morton	Macmillan Specialist Palliative OT	NELFT
Kathy Wisbey	Community Specialist Palliative Care	Homerton
Susan Hourihan	Clinical Specialist OT in outpatients	UCLH

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