

The Greater Manchester Palliative and End of Life Care SCN's Advisory Group in Partnership with Manchester Cancer Board

Date and time	Tuesday 14 July 2015
Meeting	The Greater Manchester Palliative and End of Life Care SCN's Advisory Group in Partnership with Manchester Cancer Board
Venue	Humphrey Booth Lecture Theatre 1, Mayo Building, Salford Royal NHS Foundation Trust

Present	
Name	
Carole Mula (Co Chair)	Pathway Director - Manchester Cancer / Consultant Macmillan Nurse in Palliative Care - The Christie
Dr David Waterman (Co Chair)	Strategic Clinical Networks Clinical Lead /Consultant in Palliative Medicine Stockport NHS Foundation Trust
Hodan Noor	Pathway Manager – Manchester Cancer
Elaine Parkin	Quality Improvement Programme Manager – Strategic Clinical Networks
Dr Trevor Rimmer	Macmillan Consultant Palliative Medicine/Medical Director - Central and Eastern Cheshire
Dr Sophie Harrison	Macmillan Consultant in Palliative Medicine –University Hospitals South Manchester NHS Foundation Trust
Cath Byrne	Macmillan Palliative Care Lead Nurse - Stockport NHS Foundation Trust
Julie Whitehead	Macmillan Pharmacist – East Cheshire
Dr Jenny Wiseman	Consultant in Palliative Medicine – Wrightington, Wigan and Leigh NHS Foundation Trust
Dr Ashique Ahamed	Consultant in Palliative Medicine – Central Manchester University Hospitals NHS Foundation Trust
Dr Iain Lawrie	Consultant & Honorary Clinical Senior Lecturer in Palliative Medicine – Pennine Acute Hospitals NHS Trust
Dr Philip Lomax	Consultant in Palliative Medicine – St Ann's Hospice
Sarah Gunshon	Commissioning Manager - NHS Trafford CCG
Anne-Marie Raftery	Team Leader and Clinical Nurse Specialist in Palliative Care – The Christie NHS Foundation Trust
Alice Davies	Macmillan Lead Cancer & Palliative Care Nurse – Pennine Acute Hospitals NHS Foundation Trust



Karen O'Connor	Community Macmillan Nurse – Pennine Acute Hospitals NHS Foundation Trust
Dr Katie Hobson	Consultant in Palliative Medicine – Salford Royal Foundation Trust
Debbie Hartley	Macmillan End of Life Care Clinical Lead - NHS Bury CCG
Fran Mellor	Macmillan Associate Development Manager - University Hospitals South Manchester NHS Foundation Trust
Steve Gene	Assistant Director of Nursing - Salford Royal Foundation Trust (SCN Transform SIG Co Chair)
Sarah Bullock	Deputy Director of Commissioning - NHS Bury CCG
Dr Helen Morgan	Consultant in Palliative Medicine - Springhill Hospice
Margaret Hayes	Macmillan Clinical Nurse Specialist/Team Leader – NHS Tameside and Glossop
Jennifer Gallagher	Hospice Nurse Specialist Team Manager – Wigan and Leigh Hospice
Mrs Wendy Allen	Patient/Carer Representative
Tanya Humphreys	Macmillan User Involvement Lead – Manchester Cancer
Philippa Robinson	Commissioner – Tameside and Glossop CCG
Mohammed Abas	Commissioning Manager – Central Manchester CCG
Apologies	
Stephen Burrows	North West EPaCCS Project Lead - SCN
Dr Robin Muir	Clinical Psychologist – Royal Bolton Hospitals NHS Foundation Trust
Corinna Edwards	Macmillan Palliative Care CNS
Ann Harrison	GP Lead - NHS Trafford CCG
Andrea Goodall	Commissioning Project Manager – NHS Heywood Middleton and Rochdale
Dr Samantha Kay	Consultant in Palliative Medicine – University Hospitals South Manchester NHS Foundation Trust
Alison Lewin	Commissioner – Tameside and Glossop CCG
Suzanne Lomax	Programme Manager End of life Care – Royal Bolton Hospitals NHS Foundation Trust

1. Welcome and Introductions

1.1 SCN and Manchester Cancer Partnership

Carole Mula welcomed the Group; attendance sheet with apologies documented was circulated.

1.2 Future Membership/TOR

Manchester Cancer and the SCN have worked to combine the TOR into a first draft which will be circulated for comments.

Carole opened a discussion regarding the membership of the group considering Manchester Cancer members/SCN members/peer review requirements and the function of the group.

ACTION – All members to discuss membership to the Greater Manchester Palliative and End of Life Care SCN's Advisory Group in Partnership with Manchester Cancer Board – feedback suggestions to Elaine.Parkin1@nhs.net before the 31/7/15.

2. Notes from the meeting held on the 21/5/15

Notes agreed as a true and accurate record of the meeting



3. Matters Arising

3.1 u DNACPR Survey

Elaine Parkin updated on a brief summary of the results from the SCN unified DNACPR survey conducted in June 2015: 66 responses, 59 will be used in the report (others were duplicate or incomplete surveys). There is at least one response from each locality within the network. The following organisations are represented:

Acute
CCG
Primary Care
Hospice
Care homes
Community Trust

The final report will be circulated on completion and used to inform discussions regarding safe implementation across the network.

Dr Waterman thanked members for completing the survey and asked for locality facilitator's feedback to be shared with this group.

Discussions continue with NHS England regarding ownership of the policy

National work due to be released in September which appears to combine advance care planning and DNACPR.

Steve Gene reported numbers have increased for Salford in GP training as it is a local commissioned service around end of life care.

Trevor Rimmer reported the Cheshire Partnership lead on the unified DNACPR with a high success rate; Anne-Marie Challinor is the contact.

The challenge of whose responsibility to deliver care home training was raised and the high staff turnover with a lack of organisational responsibilities.

ACTION all members to feed back issues being raised to the SCN Elaine.parkin1@nhs.net ideally pre the NHS England and joint SCN and NWAS Meeting on the 20/7/15 but ongoing information welcome.

3.2 Symptom Control App

Philippa Robinson and Margaret Hayes provided feedback on a smart phone App which is in development and holds the pain and Symptom Control Guidelines. A disclaimer will be added to the App to state this is a guideline.

Dr Waterman asked that the SCN badge is present and the NHS Kite mark process is followed.

ACTION Philippa and Margaret to update the group at the next meeting.

ACTION Pain and Symptom Control Guidance to be placed on the SCN and Manchester Cancer website.



3.3 Scoping of Palliative Care Services – feedback following the presentation to the Manchester Cancer Provider Board

Carole Mula gave a presentation at the Provider Board of an overview of the work of the Palliative Care Board including the mapping of 7 day services, MDT working and highlighting the lack of medical and nursing capacity for SPC. Carole linked the lacking capacity to the deaths in usual place of residence data highlighting Greater Manchester are one of the national lowest in achieving death in usual place of residence. A strong message was delivered that it is not just about survival. Commissioners agreed to start work on a service specification with clinical input for Greater Manchester. Carole is currently in discussion about taking this work forward. Commissioners want to reduce variation. Once the specification is developed a gap analysis will be undertaken.

Discussion was held on the danger of focusing on deaths at home. Iain Lawrie highlighted Baroness Finlay's Bill which acknowledges the quality of care.

Dr Waterman raised the national work that is taking place on service specification on Palliative Care.

Locally we have the Dearden 2005 and 2012 needs assessment report and the current work Hilary Compston has just completed which highlights service capacity and structures as well as gaps.

3.4 MDT/SPC Mapping

Discussion held on Freedom of information (FOI) requests for whole time equivalent (WTE) posts, which has come from the House of Lords and appears to support the Access to Palliative Care Bill, Baroness Finley is presenting.

Phil Lomax raised the concern that services could be double counted as each organisation responds individually.

Dr Waterman advised the network data would not be able to give the information required for the FOI requests.

ACTION - Dr Waterman asked if future FOI requests are made, for members to update the group

4. Special Interest Group Work Programme Overview

4.1 Education and Training

Dr Waterman updated the group that the next meeting will be in August with meeting dates booked in for the year. Work priorities are being worked through.

4.2 Research and Audit

Dr Sophie Harrison updated the group the next meeting will be at the end of July with meeting dates set for the rest of the year. The work programme is ongoing. The end of life care plan audit is progressing.

4.3 Care Coordination

Elaine Parkin updated the group that the next meeting will be on the 29 July 2015. The work programme focusses on bereavement, local strategy groups, pain and symptom control guidelines (2016), facilitation models and improvement programmes, coroner's equity across the network with issues that arise and common language between different services.



4.4 Transforming Care

Steve Gene updated the group the next meeting will be on the 30 July 2015. There will be a launch event at South Manchester in July who are joining phase 3 of the national Transform Programme. There is an emphasis on metrics through the work programme.

5. Group Work Programme 2015/16

Carole Mula presented the final document, with the aim that this document is now cascaded to local strategy groups to highlight the priority areas and where the Special Interest groups can support the work.

Locality Leads - responses received from Central Manchester, Salford, Tameside and Glossop, Stockport, Wigan Borough and the Christie.

ACTION – Outstanding areas to send a response to Elaine.parkin1@nhs.net this will inform the SIG for specific pieces of work

6. Patient and Carer Update

6.1 Update

Work starting to move forward with patient involvement recruitment for Manchester Cancer.

6.2 Tanya Humphreys, Manchester Cancer User Involvement Lead

Tanya will manage four Patient/ Carer Managers, who will work with the Boards and support Wendy Allen. A manager will be allocated to the Palliative and End of Life Care Board and will hopefully be able to attend the next meeting. A discussion was held on the requirement for somebody to represent long term conditions (LTC) who could work alongside Wendy which is outside the remit of Manchester Cancer. Tanya will be building a wider community of people affected by cancer who may wish to be involved with projects.

ACTION All to contact tanya.humphreys@nhs.net with any contacts for people affected by cancer who may wish to be involved with projects.

Iain requested that any volunteers could be linked with the universities to deliver on training and education programmes.

Hodan Noor requested a database of patient stories that could support the work programme.

The group identified good patient/carers input to local groups.

7. SCN Update

Elaine Parkin updated the group, that there is no further update on the National Improvement Architecture Review and SCN; structures are awaited. A band 7 advert will go onto NHS Jobs for a Senior Project Manager within the Palliative and End of Life Care Network, closing on the 31/7/15; the post will run between now and May 2016.

7.1 National Feedback

Elaine Parkin updated the group on information from the National Clinical Lead meeting held on the 13/7/15. Dr Bee Wee National Clinical Director, gave feedback that end of life care continues to sit under the priorities of the Medical Directorate and is highlighted in the NHS England Business plan 2015, under 'Harnessing the information revolution' (EPaCCS), and 'Redesigning urgent and emergency care services' (Highlighting ACP although can be expanded). There are strong links



with the Mental Health and Cancer National Clinical Directors and work underway with the other National Clinical Directors to raise the profile of end of life care.

The voices survey 2014 (at national level) has been released and will be circulated.

ACTION Voices survey 2014 to be circulated

A discussion was held on data collection and getting this right for palliative and end of life care not just focussing on place of death but capturing quality and preferences.

The Ambitions for end of life care has been distributed to the group for a 'sense check' NB this is not a formal consultation.

ACTION Members to respond on behalf of their own organisations to the sense check response via the survey monkey – Closing date 27/7/2015

There was a presentation from CQC regarding the thematic review focusing on end of life care and inequalities. Four key lines of enquiry were highlighted:-

1. Identification and Communication
2. Coordination
3. Access to good care
4. Care in the last days

Localities across the country have been identified by CQC to be part of the thematic review.

Specialist palliative care funding review is currently piloting the currencies. A briefing has been circulated to the group.

Peer review was discussed and clarity is still being sought nationally on the way forward for specialist palliative care. It is thought going forward there will be a reliance on the service specification and less reliance on measures, structures and process. The inspection cycle will run January-July and if areas are ready to bid to go forward with peer review, the earliest this can be done will be 2017. Specialist palliative care will not be included in 2016. There is also a separate movement led by the Royal Colleges of 'clinical services accreditation'. Work on the service specification is due to take place in September 2015.

EPaCCS - The personalised health 2020 document was highlighted and gives support to EPaCCS with some key dates. 2018 – All individuals able to record comments and preferences on their care record and by 2020 - All care records to be digital, real time and interoperable.

Interoperable EPaCCS systems were highlighted as good practice given the requirements to work with long term conditions.

Dr Waterman updated the group on the regional work, that Stephen Burrows is leading, hoping to pull together information to provide localities with a helpful guide for implementation and to identify the gaps overall from across the network to work with commissioners. Dr Waterman also highlighted the SCNs are aware of the challenges of interoperability and are working towards solutions.

ACTION Stephen Burrows to update at the next meeting



Phase 3 of the National Transform Programme is due to begin and South Manchester has signed onto this from Greater Manchester.

E-elca - Now on a new platform which is more intuitive and easier to coordinate. It also allows people with NHS emails to sign up individually rather than organisationally. A training needs analysis is now on the site, which highlights modules linked to one chance to get it right. Core modules are due to be released which are aimed at specific professional groups i.e. Doctors, nurses and HCA's. These core modules could form the basis of localities core training programmes.

Unified DNACPR - National work to be released in September 2015 and will incorporate an element of advance care planning (ACP).

7.2 GM Devolution

Elaine Parkin highlighted the early implementation projects of devolution Manchester:

- 7 day access to general practice
- Public Health Campaign
- Academic Health Science System
- Healthier Together
- Dementia Pilot
- Mental Health and Work
- Workforce policy alignment

More information can be found at www.gmhealthandsocialcaredevo.org.uk

7.3 Advisory Group Showcase event

Early thinking is developing, to hold a palliative and end of life care Advisory Group showcase event in November 2015, which will hopefully showcase some of the innovation and good practice from the MPET investment.

7.4 MPET process for 15/16 allocation

Dr Waterman fed back the MPET process is underway and returns are being collated and reviewed. Correspondence will be sent to commissioning leads in August.

Evaluation of 14/15 funding has been requested.

(Moved up the agenda) Agenda item 10 MPET Funding and Evaluation

Correspondence will be sent in the next couple of weeks regarding the MPET ongoing evaluation with full guidance. This will provide a new system of collating information pre and post courses, across the North West and also generate immediate local graphs and data.

8. Manchester Cancer Palliative Care Board Annual Report

Carole Mula has circulated the Annual Report and thanked members for their comments.

Hodan explained a final version is now available on the Manchester Cancer website.

A dashboard will be developed in September 2015, to identify what objectives the other cancer pathway boards have in their annual plans with regards to palliative and end of life care.



9. Research

Sue Dyde has sent apologies for this meeting but hopes to attend the next meeting.

Iain Lawrie updated the group that a repeat baseline has not taken place, however discussions are underway regarding how best to share information of trials taking place across the network. A newsletter may be developed but information will need to be submitted to populate this. Iain will follow up on Stephanie Gomm's suggestion to contact Jason Boland from the APM to explore how hospices can be more linked in.

ACTION Iain to contact Jason Boland

10. MPET Funding and Evaluation (Moved up the agenda)

11. Palliative Care Funding Review Update

Dr Waterman highlighted the development initially towards a currency prior to any tariff is produced. Dr Waterman urged localities to give thought to how they would capture the data. Pennine Acute Hospitals are a pilot site and are feeding back nationally.

12. Any Other Business

Dr Waterman brought a question to the group regarding any transition strategies for young Adults Elaine Parkin highlighted the work of Together for Short Lives - 'Stepping up'.

ACTION to circulate 'Stepping Up'

Elaine Parkin highlighted an event on the 16/7/15 which will be held in Sheffield on Deprivations of Liberty Safeguarding (DoLS). The event will contribute to Law Society's national consultation on reviewing the law that regulates DoLS. Elaine Parkin will attend the event and feedback to the group. The consultation document can be accessed on the law commission website:

www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/

ACTION Feedback at the next meeting on the event

Carole Mula updated the group that the concerns raised regarding the lack of focus on palliative care and only on end of life care in the Cancer Strategy for England, have been raised by Carole Mula to Harpel Kumar the chair of the National Cancer Strategy Taskforce.

13. Date and Time of Next Meeting

24/9/15 (Venue to be confirmed) 2.30-4.30pm (agreed)

Future Dates:

24/11/15 (Seminar Room 1, Mayo Building)



Action summary				
Initial discussion date	Agenda item	Action	Action to be taken by	Date for completion
14/5/17	1	TOR to be circulated for comments	Elaine Parkin	31/7/15
14/7/15	1	Discuss membership at the Greater Manchester Palliative and End of Life Care SCN's Advisory Group in Partnership with Manchester Cancer Board – feedback suggestions to Elaine.Parkin1@nhs.net	All	31/7/15
14/7/15	3	Feedback issues being raised regarding unified DNACPR to the SCN Elaine.parkin1@nhs.net ideally pre the NHS England and joint SCN and NWAS Meeting on the 20/7/15 but ongoing information welcome	ALL	20/7/15 (preferable) Ongoing
14/7/15	3.2	Feedback on progress of the pain and symptom control App at the next meeting	Philippa Robinson and Margaret Hayes	24/9/15
14/7/15	3.2	Pain and Symptom Control Guidance to be on the SCN and Manchester Cancer website	Elaine Parkin Carole Mula	31/7/15
14/7/15	3.4	Members to update the group of FOI requests that are received	All	Ongoing
14/7/15	5	Localities to send a response to Elaine.parkin1@nhs.net informing of who will be the locality lead for each area of the work programme	All	31/7/15
14/7/15	6	To contact tanya.humphreys@nhs.net with any contacts for people affected by cancer who may wish to be involved with projects.	All	24/9/15
14/7/15	7.1	Voices survey 2014 to be circulated	Elaine Parkin	20/7/15
14/7/15	7.1	Members to respond on behalf of their own organisations to the Ambitions in end of life care 'sense check' response via the survey monkey – Closing date 27/7/15	All	27/7/15
14/7/15	7.1	Stephen Burrows to provide EPaCCS update at the next meeting	Stephen Burrows	24/9/15
14/7/15	9	Iain Lawrie to contact Jason Boland at the APM, regarding hospice engagement to research trials	Iain Lawrie	24/9/15



Initial discussion date	Agenda item	Action	Action to be taken by	Date for completion
14/7/15	12	Circulate the Together for Short Lives - 'Steeping up' guide	Elaine Parkin	31/7/15
14/7/15	12	Feedback at the next meeting on the DoLS consultation event	Elaine Parkin	24/9/15
14/7/15	13	Next meeting to be 2.30-4.30pm. Venue to be confirmed	Elaine Parkin	24/9/15

