

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

Date and time	22 March 2016
Meeting	The Greater Manchester Palliative and End of Life Care SCN's Advisory Group in Partnership with Manchester Cancer Board
Venue	Frank Rifkin Lecture Theatre, Level 1, Mayo Building, Salford Royal NHS Foundation Trust

Present	
Dr Dave Waterman (Co-Chair)	Strategic Clinical Networks Clinical Lead /Consultant in Palliative Medicine Stockport NHS Foundation Trust
Carole Mula (Co-Chair)	Pathway Director - Manchester Cancer / Consultant Macmillan Nurse in Palliative Care - The Christie
Kim Wrigley	Quality Improvement Programme Lead – Strategic Clinical Network
Rachel Farrall	Quality Improvement Senior Project Manager – Strategic Clinical Network
Christine Taylor	Quality Improvement Senior Project Manager – Strategic Clinical Network
Wendy Allen	Patient/Carer Representative
Dr Philip Lomax	Consultant in Palliative Medicine – St Ann's Hospice
Ursula Haworth	Macmillan Occupational Therapist – AHP Representative
Dr Robin Muir	Clinical Psychologist – Royal Bolton Hospitals
Dr Trevor Rimmer	Macmillan Consultant Palliative Medicine/Medical Director – East Cheshire NHS Trust
Ashique Ahamed	Consultant in Palliative Medicine – Central Manchester University Hospitals NHS Foundation Trust
Anne-Marie Raftery	Team Leader and Clinical Nurse Specialist in Palliative Care – The Christie NHS Foundation Trust
Dr Stephanie Lippett	Community Speciality Doctor, Springhill Hospice
Alice Davies	Macmillan Lead Cancer & Palliative Care Nurse – Pennine Acute Hospitals NHS Foundation Trust
Dr Lindy Brooks	Palliative Care Consultant – North Manchester Community
Dr Tim Jackson	Consultant in Palliative Medicine – Salford Royal NHS Foundation Trust
Andrea Lightfoot	Service Improvement Manager – Salford CCG
Cath Byrne	Macmillan Palliative Care Lead Nurse – Stockport NHS Foundation Trust
Dr Mariam George	Consultant in Palliative Medicine
Samuel Eaton	Commissioning Business Partner – NHS Oldham CCG
Lucy Lyon	Commissioning Manager – Cancer & End of Life Care – Wigan Borough CCG
Dr Jenny Wiseman	Consultant in Palliative Medicine – Wrightington, Wigan and Leigh NHS Foundation Trust



Rev. Canon Anne Edwards	Chaplaincy & Spiritual Care Manager, Wrightington, Wigan and Leigh NHS Foundation Trust
Claire O'Rourke	Palliative Care Pathway Manager – Manchester Cancer
James Leighton	Acting Associate Director, Manchester Cancer
Michelle Leach	Macmillan User Involvement Manager, Manchester Cancer
Alison Walters	Patient/User Representative
Steve Gene	Assistant Director of Nursing Palliative & End of Life Care, Salford Royal NHS Foundation Trust
Dr John Ealing	Consultant Neurologist Salford NHS Foundation Trust
Apologies	
Stephen Burrows	North West EPaCCS Lead
Dr Gillian Hirst	Associate Specialist - Central Manchester University Hospitals NHS Foundation Trust
Fran Mellor	Macmillan Associate Development Manager - University Hospitals South Manchester NHS Foundation Trust
Sarah Bullock	Deputy Director of Commissioning – Bury CCG
Delwyn Wray	Project Manager – Bury CCG
Debbie Hartley	GP Macmillan End of Life Care Lead
Mohammed Abas	Commissioning Manager – Central Manchester CCG
Dr Samantha Kay	Macmillan Consultant in Palliative Medicine - University Hospitals South Manchester NHS Foundation Trust
Alison Roberts	Consultant in Palliative Medicine
Dr Iain Lawrie	Consultant & Honorary Clinical Senior Lecturer in Palliative Medicine
Dr Tin Aye	Clinical Work stream Lead for End of Life Care- Salford CCG
Margaret Hayes	Macmillan Clinical Nurse Specialist/Team Leader
Jennifer Gallagher	Hospice Nurse Specialist Team Manager

1. Welcome & Apologies

Dr Waterman opened the meeting and introductions were made.

2. Standing agenda item – Conflict of Interest

The group were reminded to return their conflict of interest forms to the SCN. The paperwork will be circulated again with the meeting notes. Wendy Allen had returned her form but this was not indicated on the attendance sheet.

Action: SCN to check if Wendy Allen's form and amend the attendance sheet (post meeting note: Wendy's form has been received and the attendance sheet amended)

Action: Conflict of interest papers to be circulated again with the meeting notes.



3. Notes from the previous meeting held on 26.01.2016

Dr Tin Aye did not attend the meeting but the notes indicated that she had attended.

Action: SCN to move Dr Tin Aye to apologies

Notes were agreed as a true record of the meeting.

4. Matters Arising

4.1 Action Summary from previous meeting (26.01.16)

- Statement of intent - some areas were using the statement of intent other areas were not. It was noted that some areas felt that the statement of intent needed updating. Discussion around whether this should be undertaken locally or regionally. Only received a response from Wigan. If there are no further responses, the SCN will be unable to undertake the work.

Action: Members to be given another opportunity to respond within the next 4 weeks regarding statement of intent review.

- Liver disease patients and end of life care - Dr Waterman has received a few responses. Dr John O'Malley is leading on this national piece of work. Responses received to date have been sent to Dr O'Malley. A meeting to be arranged in due course. Anyone wishing to be involved to contact Dr Waterman

Action: Members wishing to be involved to contact Dr Waterman who will forward to Dr O'Malley

- Emergency Care and Treatment Consultation – national documentation looking at a wider document rather than just DNACPR decision making. DNACPR would then form part of the wider document as part of a context in emergency care and treatments being led by the Resuscitation Council UK and other organisations. Consultation was open until 29 February 2016. Dr Waterman would like to know if any localities or individuals had responded to the consultation. Likely to be circulated for further consultation.

Action: Dr Waterman requested that members keep an eye out for any notification of any further consultation and encouraged them to participate

- Safeguarding issues – Kim Wrigley had not received any further information since the last meeting. A request had gone out in respect of DNACPR and any concerns around safeguarding through the Quality Surveillance Group at NHS England, but no responses had been received regarding this either. Kim stressed that it was important to understand what the local issues are in order to take back to NHS England.

Dr Waterman asked that in terms of auditing and monitoring the DNACPR usage, forms or decision making, there is a good opportunity as a group to try and collate the thoughts or how people are approaching it and how it may be undertaken.



Action: Collate any information on behalf of the group to help feed into the ongoing work and help to strengthen the audit and monitoring DNACPR advice going forward. Feedback to be sent to Christine Taylor at the SCN via email at christine.taylor41@nhs.net

- DOLS letter – Wendy Allen asked if there would be any objection to knowledge being shared that a letter has been sent from the SCNs to the Law Commission without divulging the content. The Group had no objections.
- Anticipatory/administration sheets – piece of work to start in April within the Education and Training SIG.

Action: Any information to be sent to Dr Waterman

- Letter to Greater Manchester Medicines Management – Not actioned as yet. Kim Wrigley waiting for work to start once an action plan has been devised.

4.2 Workplan for 2015/16 – piece of work being undertaken to highlight the elements that have been achieved or outstanding across both partnerships. Workplan will be shared prior to the next meeting so that members have the information.

Action: Workplan for 2015/16 to be circulated prior to the next meeting

4.3 uDNACPR Update

Christine Taylor gave an update on the North West DNACPR Policy which is due for review. Representatives from NWS, NHS England and each of the SCNs in the North West Region met to review the current policy. A survey monkey will be circulated to all organisations to look at the policy and comment on the sections. It is advised that each locality appoint a lead person to complete the survey. There is a mandatory field asking whether the lilac forms are being used or not and a section regarding the audit process. Once results are returned, a North West task and finish group will be set up in May with representatives from NWS and NHS England Safeguarding and each of the SCN's in the North West region, to make the changes. This will then go the legal team in June ready for publication in July. Following on from this, there will be a regional conference day incorporating education and training to make everyone aware of the changes.

The lilac forms are not always being used, partly due to the cost. The SCN is looking into possibly purchasing these forms and distributing them to the localities but will ask them to provide assurance that they are implementing the policy.

General discussion around the review of elements of the policy. Dr Waterman advised that having gone through the legal process previously it is unlikely to change substantially but following conversations with NHS England, it may be useful within the policy to look at the implementation, governance, training and education elements.

NWS are also surveying their paramedic staff for feedback which will prove useful.

Dr Waterman advised that an attempt will be made to track the changes between the current policy and the new policy to help localities see where the changes are. Changes may be required due to the national emergency care and treatment plan but the focus on



training, education and governance will still be relevant even if documentation needs changing.

There is a separate policy and form for children.

Action: Circulate a copy of the policy for children to the group –

www.cypacp.nhs.uk<http://www.cypacp.nhs.uk>

5. Cancer Vanguard

Carole Mula welcomed James Leighton, Acting Pathway Associate Director for Manchester Cancer, to the meeting who gave an update on the Vanguard and the implications for the group. At the last meeting Carole gave a presentation regarding what the Vanguard is trying to achieve for Palliative and End of Life Care and discussed the six work streams being developed. One of those is living with and beyond and palliative care. This work stream is chaired by Wendy Makin and potentially will focus on the following three areas;

- Enhanced shared decision making and support in progressing cancer to include Goals of care Initiative (GOCI)
- Transformation of follow up (lung gynae, colorectal)
- 7 day specialist palliative care access

James advised that the Vanguard is identified by three work programmes

- Clinical transformation
- Cancer intelligence
- Commissioning and finance

Clinical transformation is split into five work streams:- improved diagnostics, prevention screening and early detection, clinical standards, cancer education, living with and beyond – work streams have appointed leads who are clinically based they will work with the Vanguard around emerging themes and priorities. Clinical networks or pathway boards will work with the work stream leads to deliver each piece of work and integrate the work of Manchester Cancer into the work of the Vanguard over the next 6-8 months.

All the investment from the Vanguard is for transformation there is no extra money for delivery.

The ambition of the Vanguard is to deliver a single point of commissioning for cancer care and services.

Dr Waterman advised that the challenge and opportunity for this group is to support how to commission single services that provide that both cancer and non-cancer work in a coherent way. Need to make sure all the transformation work is the same and clear that there are no competing aspects across all the providers.

General discussion around the challenges of the Vanguard going forward and the need to use our partnerships to influence conversations going forward.

Devolution Manchester – Dr Waterman advised that the SCN is planning to respond formally to the strategy document. Any comments to be sent to Kim Wrigley or Dave Waterman within the next 3 weeks in order to produce a final response in April 2016.



Action: Comments to be sent via email to Kim Wrigley or Dave Waterman within the next 3 weeks

Trevor Rimmer advised that although East Cheshire is not involved with Devolution Manchester, the tertiary services will be. Dr Waterman advised that comments from East Cheshire will be captured through the SCN .

Carole Mula updated on enhanced supportive care originally a 3 year CQUIN project at the Christie which is now a NHS England CQUIN for cancer centres. Palliative care for cancer patients to be introduced earlier but concerns are not just cancer but rolling the model out into the wider provider services. NHS England say cancer patients should have earlier referral in palliative care.

Pennine Acute are looking at lung cancer although this is still very early work.

Tameside; there are concerns that services are already stretched and it is important to manage expectations before running 7 day service.

Members who have an interest in being involved in any workforce work to let Dave or Carole know.

Action: Anyone with an interest in the workforce work stream to contact Dr Waterman or Carole Mula

There is a blog on the NHS England website about the enhanced supportive care and how the model is perceived to be working for cancer care nationally. There is a space for comments so any feedback would be helpful.

Action: Carole Mula to forward link to Rachel Farrall for inclusion in the notes:

NHS England blog re Enhanced Supportive Care:
<https://www.england.nhs.uk/2016/03/richard-berman/>

Joint education events between palliative care services and other disease groups. The first conference between palliative care and acute oncology was very well evaluated. Further 6 monthly half-day conferences to be arranged with each of the disease groups.

Manchester Cancer website - currently being updated and is not accessible. Video for the other Pathway Boards to get a greater understanding of palliative care and when to refer has been produced. This is not online at the moment.

Survey money – asking about the impact of the board and leadership.

6. Special Interest Groups

6.1 Education and Training – running a half day training event on 1 April 2016 for clinical and non-clinical educators in palliative and end of life care to include update around the recent guidance including NICE, also will share information about the scoping exercise currently being undertaken by Hilary Compston. Trainer competencies will also be reviewed



within a workshop to discuss their level of skills and competencies when training others. The special interest group will meet in the afternoon.

6.2 Research and Audit – previous meeting (22 February 2016) discussed research opportunities and challenges. There was a recognition of the need to work together.

Update from Dr Andrew Fletcher - Plan to develop a research proposal – broad idea is to look at the effectiveness of drug intervention at end of life for excessive respiratory secretions. Literature search being undertaken and research question to be formulated.

1. It is planned for PRiMA to be incorporated into the research and Audit SIG. PRiMA previously organised a full day conference and it was agreed that this should continue. To hold full day Conference later in the year. Topic currently under discussion.
2. To develop a survey looking at care in the last days of life including knowledge of clinicians with a focus on the care delivered rather than the documentation. It was confirmed that Dr Iain Lawrie attends the Research and Audit SIG on behalf of Manchester Cancer as Palliative Care Research Lead.

6.3 Care Co-ordination – the group has not had a meeting for a while. However the bereavement directory is almost complete and once finalised the details of the link will be circulated.

6.4 Transform – written to localities and asked about key enablers and which elements they have been able to deliver. Next meeting (Webex) on 20 April 2016.

Action: Anyone wishing to chair or support any of the special interest groups going forward beyond April 2016, to contact Dr Waterman

7. Innovation Programmes

7.1 Early lung cancer support

Carole Mula advised that there had previously been a request from the lung pathway board for representation on their pathway group and also to look at the low attendance at Lung MDT meetings. A palliative and end of life care scoping exercise was undertaken on all the MDT groups as part of peer review. Working with Neil Bayman to look at better integration between lung and palliative care. Neil has delegated some of the work programme to one of the consultants who works between the Christie and North Manchester to look at this. Meeting arranged with lung oncologist from Greater Manchester and Palliative Care Consultants to look at the triggers for referrals may be. Outcomes may inform a future business case.

7.2 Palliative and EoLC 16-18 years

Rachel Farrall advised that following the last meeting a questionnaire was circulated to the localities. Eight responses have been received. There were three localities where no response had been received from either the community or providers. The SCN is working



on a short report which will be circulated in due course. Rachel thanked those who have submitted their data.

Kim Wrigley advised that a joint commissioning palliative care for children and young people paper had recently been received. Details will be circulated on the weekly run.

Action: Report re palliative and EOLC 16-18 years to be circulated once completed.

Action: Joint commissioning report re palliative care, children and young people to be circulated on the weekly run

Action: Item for next meeting – link the Manchester Cancer and SCN conversations together

7.3 Neurology

Kim Wrigley, Dr Waterman and other colleagues from the SCN along with two consultant neurologists from Salford Royal had met due to previous conversations around supporting patients diagnosed with Motor Neurone disease (MND) including the provision of services particularly at the end of life. A number of areas were raised including access to aids and adaptations and worrying stories regarding the length of time people had to wait for life changing equipment. Variation of access to specialist services to support people with the disease and provision of neurology services along with and impact of increase in numbers and service reconfiguration was having. Rachel Farrall has started to explore data and a Public Health Register (Dr Emily Parry-Harries) is now working with us will be pulling together a project plan. The information will be brought back to the group for consultation and discussion.

Dr Waterman advised that the discussion with the neurologists was a Greater Manchester conversation. PSP and MSA patients with short progressive neurological conditions are a similar group to the MND patients and should be included within that work stream.

Action: Any thoughts and ideas re MND provision to be emailed to Dr Dave Waterman or Kim Wrigley

8. Patient Carer Update

8.1 Manchester Cancer User Involvement Progress Review Report

Michelle Leach updated the meeting. Quarter 2 report to be circulated with the meeting notes although it is a little out of date. Funding is secured for a further year.

Highlights from report:

- Pathway boards at the time of release - of the 17 functioning, 12 were represented with user involvement. Further work has been undertaken with recruiters and co-produced a learning and development programme for people affected by cancer to get involved.



- Patient experience surveys with two of the boards (Urology and Lung Pathway). Teenage and Young adult event took place which was very successful.
- Targets- tasked with having a least a single user representation on every pathway board. Out of 17 functioning, 15 have user representation on the board. Campaign has exceeded target by 43% for recruitment

This resource is available to anyone who wishes to use it from the group and locally.

Michelle welcomed Alison Walters to the group. Alison was observing the meeting today and in the future will become a member.

Wendy Allen wanted to congratulate the team for achieving 99/100 of the deliverables and was hopeful that this would make a positive impact going forward.

Michelle asked that the group be mindful that there are only two contact managers in post at present.

Action: Re-circulate Michelle's contact details with the meeting notes (post meeting note) email is michelle.leach1@nhs.net

9. CQC Locality Visit Feedback

Carole Mula raised the question of how we can use the CQC local reports to support Manchester Cancer palliative care developments. General discussion around safety and effectiveness and issues and around keeping inspection on the agenda. Key themes to be picked up from the reports and determine which actions are deliverable.

Dr Waterman asked if anonymised key themes could be sent to Carole Mula in order that they can be collated.

Action: Key themes to be sent to Carole Mula for anonymous collation

10. EPaCCS Update

10.1 Rachel Farrall reported back to the meeting as Stephen Burrows was unable to attend. A National EPaCCS Conference took place on 17 March 2016 which was very successful. There was a lot of representation from North West. Good to showcase the work that has been done locally. The EPaCCS Film was shown, Tameside and Glossop had agreed to host. Rachel thanked all the people who came along to be filmed. The film will be available very soon and the link to the website will be sent out on the weekly run. The film is very moving with people talking about their experiences

Action: EPaCCS film link to be included on the weekly run when available

Rachel presented a dashboard to share the submitted reports on progress so far. Only one had been received so far. It is hoped that more sites will provide a report for the next update with is due 1 April 2016.

Action: Reminder to be sent out by the SCN to sites re EPaCCS dashboard reports



Rachel has asked to confirm with the local task and finish group lead for dates for their future meetings so that the SCN can attend when required and so far half the localities have responded. The Greater Manchester Network Implementation Group meeting will be held on 30 March 2016.

Action: Any localities experiencing problems with the dashboard or who have any questions, to contact the SCN

11. SCN Update

11.1 National review of SCN's and Senates/Team Update

Kim updated the meeting. SCN has been under review for approximately 18 months. New structures have been drafted. HR discussions are taking place regarding voluntary redundancies and staff changes. With effect from 1 April 2016, the SCN will no longer exist in its present form geographically. There will be a Greater Manchester Network to include East Cheshire and will include palliative and end of life care as we have a resource for the work for a further 12 months. Lancashire and South Cumbria will be with the Cheshire and Merseyside Strategic Clinical Network and each of the networks will be aligned with the local Academic Health Sciences Network. The structures for all of the networks (dementia, mental health etc.) are being finalised. The implementation of the new way of working will be complete by the end of June 2016.

Kim stressed that the whole process has been extremely difficult to manage for all staff particularly those who have had so much uncertainty hanging over them.

Dr Waterman added that the aim and intention of the group is to continue as it is following the re-structure.

11.2 National Clinical Leads meeting feedback

Dr Waterman and Rachel Farrall had attended recently. A lot of areas continue to remain a national focus, certainly transform and EPaCSS remain high on the agenda particularly with the digital road map. A number of new documents are likely to come out in the next few weeks, these include the specialist palliative care service specification and the commissioning documentation. As soon as anything is available, it will be shared with the group.

11.3 Finance

Confirmation from Health Education North West (HENW) regarding MPET Funding for 2016/17 is still awaited. It is hoped that funding will be available but no further news regarding the amounts are available at the moment.



11.4 MPET Evaluation – update

New process for submitting evaluation for MPET training, so far only received one return for Greater Manchester. Evaluation forms have been updated to include a free text box for additional feedback comments. Rachel is in the process of producing the Q4 and end of year report to be sent back to HENW.

Action: Please ensure all MPET returns are sent to Rachel Farrell

11.5 Facilitator/Educators scoping

Covered in agenda item 6.1 – education and training special interest group.

12. Any other Business

12.1 Special notes/111

Kim thanked all the localities that had submitted information which is currently being collated. Still trying to gauge the picture across Greater Manchester and Lancashire & South Cumbria. Kim has a direct contact with Magnus Herd, Director of NHS 11, and has asked him to keep the group updated on any developments within the context of palliative and end of life care. Agreed to invite Magnus to a meeting in the future to have a specific session on progress and development.

Action: Invite Magus Herd re NHS 111 to a future meeting

Action: Localities to continue to submit information re NHS 111 particularly any areas of concern to Kim Wrigley

12.2 Wendy Allen raised the difficulty in completing the conflict of interest form so had sent it direct to Denise. Kim will check if it has been received. (Post note: Wendy's form has been received).

12.3 BMA and End of Life Care report

Kim highlighted this report. The link to be circulated with the meeting notes

Action: Circulate BMA & EOLC report with notes

13. Date and Time of Next Meeting(s)

Venues to be confirmed

- Tuesday 17 May 2016, 3pm to 5pm – Birchwood Conference Centre, Mulberry/Cedar Rooms
- Tuesday 19 July 2016, 3pm to 5pm
- Tuesday 20 September 2016, 3pm to 5pm
- Tuesday 15 November 2016, 3pm to 5pm



Action summary				
	Agenda item	Action	Action to be Taken by	Date for completion
	2	SCN to check if Wendy Allen's form and amend the attendance sheet (post meeting note: Wendy's form has been received and the attendance sheet amended)	SCN	Actioned
	2	Conflict of interest papers to be circulated again with the meeting notes	Denise	Attached
	3	SCN to move Dr Tin Aye to apologies	SCN	Actioned
	4.1	Members to be given another opportunity to respond within the next 4 weeks regarding statement of intent review	All	
	4.1	Members wishing to be involved to contact Dr Waterman who will forward to Dr O'Malley	All	
	4.1	Dr Waterman requested that members keep an eye out for any notification of any further consultation and encouraged them to participate	All	
	4.1	Collate any information on behalf of the group to help feed into the ongoing work and help to strengthen the audit and monitoring DNACPR advice going forward. Feedback to be sent to Christine Taylor at the SCN via email at christine.taylor41@nhs.net	All	
	4.1	Any information to be sent to Dr Waterman	All	
	4.2	Workplan for 2015/16 to be circulated prior to the next meeting	SCN	
	4.3	Circulate a copy of the policy for children to the group – www.cypacp.nhs.uk	SCN	Link attached
	5	Comments to be sent via email to Kim Wrigley or Dave Waterman within the next 3 weeks	All	
	5	Anyone with an interest in the workforce work stream to contact Dr Waterman or Carole Mula	All	



Agenda item	Action	Action to be taken by	Date for completion
	Carole Mula to forward link to Rachel Farrall for inclusion in the notes: NHS England blog re Enhanced Supportive Care: https://www.england.nhs.uk/2016/03/richard-berman/	SCN	Link attached
6	Anyone wishing to chair or support any of the special interest groups going forward beyond April 2016, to contact Dr Waterman	All	
7	Report re palliative and EOLC 16-18 years to be circulated once completed Joint commissioning report re palliative care, children and young people to be circulated on the weekly run Item for next meeting – link the Manchester Cancer and SCN conversations together	SCN SCN SCN	To follow Actioned 31.03.16
7.3	Any thoughts and ideas re MND provision to be emailed to Dr Dave Waterman or Kim Wrigley	All	
8.1	Re-circulate Michelle's contact details with the meeting notes (post meeting note) email is michelle.leach1@nhs.net	SCN	Email attached
9	Key themes to be sent to Carole Mula for anonymous collation	All	
10.1	EPaCCS film link to be included on the weekly run when available	SCN	When available
10.1	Reminder to be sent out by the SCN to sites re EPaCCS dashboard reports	SCN	Actioned (01.04.16)
10.1	Any localities experiencing problems with the dashboard or who have any questions, to contact the SCN	All	
11.4	Please ensure all MPET returns are sent to Rachel Farrell	All	



	Agenda item	Action	Action to be taken by	Date for completion
	12.1	<p>Invite Magus Herd re NHS 111 to a future meeting</p> <p>Localities to continue to submit information re NHS 111 particularly any areas of concern to Kim Wrigley</p>	<p>SCN</p> <p>All</p>	
	12.3	Circulate BMA & EOLC report with notes	SCN	Attached

