

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

Date and time	26 January 2016
Meeting	The Greater Manchester Palliative and End of Life Care SCN's Advisory Group in Partnership with Manchester Cancer Board
Venue	Seminar Room 12, Level 2, 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
Ursula Haworth	Macmillan Occupational Therapist – AHP Representative
Ashique Ahamed	Consultant in Palliative Medicine – Central Manchester University Hospitals NHS Foundation Trust
Jonathan Turnbull-Ross	Macmillan User Involvement Manager
Hodan Noor	Pathway Manager – Manchester Cancer
Dr Louise Hilton	NHS South Manchester CCG
Wendy Allen	Patient/Carer Representative
Dr Philip Lomax	Consultant in Palliative Medicine – St Ann's Hospice
Delwyn Wray	Macmillan Project Manager – NHS Bury CCG
Andrea Goodall	Commissioning Project Manager – NHS Heywood Middleton and Rochdale
Dr Iain Lawrie	Consultant & Honorary Clinical Senior Lecturer in Palliative Medicine
Lindy Brooks	Palliative Care Consultant – North Manchester Community
Andrea Lightfoot	Service Improvement Manager – Salford CCG
Cath Byrne	Macmillan Palliative Care Lead Nurse – Stockport NHS Foundation Trust
Margaret Hayes	Macmillan Clinical Nurse Specialist/Team Leader – NHS Tameside & Glossop
Karen O'Connor	Community Macmillan Nurse – Pennine Care NHS Trust Trafford Division
Sarah Gunshon	Commissioning Project Manager - Scheduled Care
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
Dr Tin Aye	Clinical Work stream Lead for End of Life Care



Apologies	
Dr Gillian Hirst	Associate Specialist - Central Manchester University Hospitals NHS Foundation Trust
Dr Robin Muir	Clinical Psychologist – Royal Bolton Hospitals NHS Foundation Trust
Fran Mellor	Macmillan Associate Development Manager - University Hospitals South Manchester NHS Foundation Trust
Dr Barbara Downes	Consultant/Medical – Royal Bolton Hospitals NHS Foundation Trust
Dr Trevor Rimmer	Macmillan Consultant Palliative Medicine/Medical Director – East Cheshire NHS Trust
Mohammed Abas	Commissioning Manager – Central Manchester CCG
Dr Sophie Harrison	Macmillan Consultant in Palliative Medicine –University Hospitals South Manchester NHS Foundation Trust
Anne-Marie Raftery	Team Leader and Clinical Nurse Specialist in Palliative Care – The Christie NHS Foundation Trust
Alison Roberts	Consultant in Palliative Medicine
Dr Stephanie Lippett	Community Speciality Doctor, Springhill Hospice
Alice Davies	Macmillan Lead Cancer & Palliative Care Nurse – Pennine Acute Hospitals NHS Foundation Trust
Tim Jackson	Consultant in Palliative Medicine
Dr Mariam George	Consultant in Palliative Medicine
Jennifer Gallagher	Hospice Nurse Specialist Team Manager
Stephen Burrows	North West EPaCCS Lead

1. Welcome & Apologies

Dr Waterman opened the meeting and introductions were made.

2. Standing agenda item – Conflict of Interest

Dr Waterman advised that all members should return their forms and send them back to Kim Wrigley at the Strategic Clinical Network (SCN).

Action: Members requiring another copy of the form to advise Rachel Farrall via email at rachelfarrall@nhs.net

3. Notes from the previous meeting held on 24.11.15

Actions from last meeting:

- (i) Jenny Gallagher had sent Wigan’s Statement of Intent prior to the previous meeting.
- (ii) Dr Waterman had received information from Phillippa Robinson at Tameside highlighting that within the Statement of Intent, some information was not up to date in terms of the content.

Action: Members to check with their localities re statement of intent and if it is used to communicate with Out of Hours services. Members to email Kim to comment on whether this document should be updated regionally or in local areas – if any updates are needed



Lung MDT

The lung MDT discussions have continued and all the sectors have been approached. A meeting is being held on 12 February 2016 so once this meeting has taken place further information will be fed back to the group.

4. Matters Arising

4.1 Liver disease and end of life care – next steps

A couple of responses had been received following Dr John O'Malley's presentation from the last meeting and subsequent letter. Dr Waterman advised that this work may become National rather than Regional.

Action: Anyone working with liver disease patients or those interested in being involved in this area of work on behalf of the advisory group should contact Dave Waterman at the SCN via email. Dave will follow-up with Dr John O'Malley

4.2 uDNACPR – update

There has been a National piece of work around emergency care and treatment plan as a potential national document to replace the uDNACPR documentation. We will continue to focus on education and training, implementation of the policy and governance and await any changes to the document. The National group involves the Resuscitation Council and other interested parties. The document is currently out for consultation.

Action: Emergency Care and Treatment consultation link to be circulated within the weekly run

Kim Wrigley reinforced that we are still using the uDNACPR policy and supporting documentation but a review of the content will be undertaken very soon. Steve Barnard will be leaving NWAS and confirmation is awaited as to a named person who will be taking over this work.

Action: Kim has suggested that the group forward to her any specific examples regarding any safeguarding issues

4.3 DOLS – Law Commission update

Wendy Allen has written a private letter re DOLS to Ms Ann Coffey, MP, but to date had received no acknowledgement or a response to her letter.

Dr Waterman advised that further correspondence from the North-West had been sent to the Law Commission consultation on behalf of the North West SCNs. No further response has been received from the Commission.

Action: Circulate a copy of this letter with the meeting notes



4.4 NICE Guidance – Care of the Dying Patient

Dr Waterman advised that this guidance has now been released as the final version. Dr Lawrie had written to Dr Waterman around the challenges of prescribing and administering anticipatory drugs particularly in the community and in line with the updated guidance.

Action:

- (i) **Members to forward their current electronic versions of their anticipatory/ administration sheets for medication in the last days of life to Kim Wrigley at the SCN for circulation and comments to the advisory group**
- (ii) **Dr Waterman will take the comments to the Training and Education Special Interest Group for them to look at collectively within that forum**
- (iii) **SCN to write to Greater Manchester Medicines Management to ask for their opinion and whether they would like to be involved in this work**

5. Cancer Vanguard

Carole Mula gave a presentation on the Greater Manchester Cancer Vanguard.

Action:

- (i) **Circulate a copy of the presentation with the meeting notes**
- (ii) **Members to feedback any thoughts and comments which they feel should be included within the Vanguard to Carole Mula via email as soon as possible**

6. Long Term Condition Trials

Dr Lawrie advised that a registration of interest had been circulated regarding a lung cancer trial.

7. Special Interest Groups

7.1 Education and Training – next meeting will be a WebEx which is scheduled for 10 February 2016 – The key areas to work on were outlined in the previous meeting.

Recent comments received:

- It has been noted that within the original Pain and Symptom Control Guidelines circulated by the SCN, the secretion algorithm section for medications in the last days of life may have an information box headed terminal agitation rather than secretions. The information within the box is correct. Please confirm that our local guidance is correct.

Action: Master copy to be amended on the SCN website

- The company who make Tapentadol have noted it is licensed for severe chronic back pain if this can't be improved with regular opioids. This will be updated in the next version of the Pain and Symptom Control Guidelines



7.2 Research and Audit

At the last meeting (14 December 2015) there was discussion around doing an audit research project.

Action:

- (i) Identify a project for the group going forward that can be delivered**
- (ii) Be mindful of the changes within the SCN - possibly identify work which could be supported beyond April 2016**

7.3 Care Co-ordination

Continuing to work on the Bereavement Directory – the group is not planning to undertake any further work prior to April 2016.

7.4 Transforming Care

Conference call took place on 26 November 2015. The meeting agreed to look at the key enablers and ask each area which parts of the key enablers within the transform they can take on and the lessons learnt around good practice and any challenges. Correspondence has gone out to the localities to respond to this request. Rachel Farrall from the SCN has pulled this information together.

8. Group – Work Programme 2015/16

Kim Wrigley advised that to date, no further comments have been received regarding the work programme. This programme is being implemented at locality level. In the near future, a review will be undertaken of the programme of work in line with the GM Heads of Commissioning who have agreed to a further years funding for 2016/2017 for the End of Life Care support team.

Kim Wrigley, Dave Waterman and Karen Proctor (Director of Commissioning) will be meeting up in due course to review the programme of work and the members of the advisory group will be involved in this consultation to discuss the priorities going forward. Kim advised that the relationship between the Commissioners and the Network has continued to improve over time. It is important to address the CCG priorities within the programme.

9. Patient Carer Update

Wendy Allen advised that the Manchester User Involvement team have recruited a further 80 people since March 2015. As the Manchester Cancer Provider Board has yet to agree future funding, unfortunately a couple of members will be leaving the group. Wendy expressed her thanks to Jonathan Turnbull-Ross for his help and involvement behind the scenes.

Jonathan advised that a lady with an interest in palliative care is interested in joining Wendy on the Board.

Action: Agreed that Jonathan would forward her contact details to Carole Mula and involve Wendy in any further discussions to take this forward



10. CQC Locality Visit Feedback

Dr Waterman advised that a number of Trusts have or will be visited by CQC over the next few weeks. General discussion as members fed back their experiences within their own localities and shared advice for colleagues.

- Dr Lawrie has been part of CQC inspection team for other areas of the country. He emphasised that the end of life care inspection includes palliative and end of life care services, but also mortuary and bereavement services as well as focusing on other areas such as DNACPR.
- CQC inspection and reports can be a driver to improve resources locally.
- Evidence is required for each inspection and preparation can take some time.
- It is important to make sure you know what information/ data is being sent to CQC by the Trust on behalf of your team.
- Free up time in your diary for the duration of the inspection.
- If you are aware of areas locally that require improvement, then have an action plan in place.
- CQC visits will focus on the provider of the services being inspected and whatever services they provide within the local area.

Dr Lawrie advised that if Trusts needed any help or guidance to prepare for inspections he would be happy to assist.

Kim Wrigley advised that the SCN had responded to the CQC's request for contacts for the thematic reviews and although they didn't pursue this offer of potential contacts, they did acknowledge the work undertaken around End of Life Care and Black and Minority Ethnic Groups as an example of best practice from a CQC perspective.

11. EPaCCS Update

Rachel Farrall provided an update as Stephen Burrows had sent his apologies.

11.1 Locality update

- Apart from Tameside & Glossop no other localities have provided their 8 key areas update. If these are not received, Stephen cannot provide a report.

Action: Reminder email to be circulated again to ask for all local areas to supply their update on the 8 key areas of EPaCCS

- Bolton EPaCCS have a Project Manager in post and he has met with Stephen.
- North East sector are trying to arrange a meeting for March 2016.

11.2 Data Project Public Health England

- Everyone has been asked for baseline data. Stephen circulated an email recently. This is baseline data and as far as he is aware this is not going to be ongoing. The data requests will go from the CCG's to the CSU.



11.3 NW Proposed dataset

- The templates will all be updated on 1 March 2016.

11.4 Why EPaCCS Video

- Going to be an online film. The filming is going to be in Tameside and Glossop and Blackpool. Looking to film on the 9th February in Blackpool and 10th February in Tameside and Glossop (T&G). Stephen has a list of volunteers.

Tameside and Glossop to film in the hospital and a GP Practice. Blackpool to film in Trinity Hospice.

Each area will have two different locations. Slot times will be set out and those volunteers asked to fill these slots for about an hour in any of the three areas. All the questions will be gone through prior to filming.

11.5 EPaCCS National Conference - 17 March 2016

- Already 50% booked and it has yet to be advertised. Stephen will speak to the National team and ask if the numbers can be increased.

Action: Details of the national conference to be circulated as soon as possible

12. SCN Update

Kim Wrigley updated the meeting. With effect from the 1 April 2016, the Strategic Clinical Network will split. Greater Manchester and East Cheshire will join and be integrated with the Greater Manchester Academic Health Science Network and Devolution Manchester programme. The Network will be moving premises to offices on Oxford Road, Manchester. The consultation process is still open. New information has necessitated the need to review the proposed structures.

The Lancashire and South Cumbria part of our current organisation will move across to the Cheshire and Merseyside Strategic Clinical Network and be aligned with the North West Coast Academic Health Science Network.

Palliative and End of Life Care is a priority. The North West Operational Group is to be reinstated and for Greater Manchester funding is available for a further 12 months.

12.1 Finance and MPET

MPET funding – a telephone call is arranged with Mike Farrall, Health Education North West, to confirm the position of funding for 2016/2017.

Other areas have not had Palliative and EoLC monies which is ring-fenced so there may or may not be an opportunity for funding for this year and the SCN is awaiting confirmation of any amounts.



MPET Evaluation – forms have been circulated to evaluate the training related to MPET funding. Forms should be returned when the training is completed in localities. No space to add qualitative comments data on the form so Rachel Farrall has updated this work and it will be circulated in due course. To date, no forms have been returned from Greater Manchester.

Action: Reminder MPET email will be circulated with all the existing forms for completion

12.2 National Clinical Leads Meeting feedback

Dr Waterman advised he had nothing to add from this meeting except that the uncertainty felt in Greater Manchester remains the same nationally and within all the SCNs across the country. Apart from Greater Manchester not every SCN will have a Palliative and End of Life Care resource beyond April 2016. Grateful to the GM Commissioners in providing that support.

Dr Waterman and Kim Wrigley expressed their thanks to the members of the group for their continued valuable support.

12.3 Facilitators Scoping Exercise – 21 January 2016

Very well represented event by Greater Manchester – questions were put out to the facilitators. Really useful session from each care setting with good learning and exchange of ideas. All the information has been captured from the day and Hilary Compston will be including this in her report. Another email will be circulated to those who could not attend on the day to add any extra information. This piece of work to be completed by the end of March 2016 and then presented to the GM Commissioners.

12.4 Deaths in Usual Place of Residence (DiUPR)

Rachel Farrall presented the data to the meeting. It had previously been circulated quarterly but in future, members can request this data in any form. Contact Rachel via email rachelfarrall@nhs.net

Action: Generic version to be circulated with the meeting notes and members to ask what particular information/data they would like to have. Any further thoughts contact Rachel

13. Any other Business

Special Patient Notes/ NHS111

- NHS 111 are undertaking a piece of work following a small number of significant incidents in terms of responses to patients in the last days of life. This work has been taken on by Magnus Hird. Internal guide for NHS 111 staff within the context of whether or not there are special notes and other documentation to ask for should a call come through. This has been sent back to NWAS for further information. The communication appears to be local.

Action: Information to be circulated

Action: Members to bring to the next meeting any key themes re: NHS 111 input for localities to be shared with SCN at the next meeting



- MPET Monies and delivery of training programmes – discussion re: revalidation of training in care home in Trafford. Snap shot training available to obtain evidence.
- Link to mydecisions.org on the recent weekly update – Members to be aware that this is set up by a sister charity of Compassion in Dying - hospices cannot be seen to support this.
- Palliative Care and Acute Oncology Afternoon for CNS's & AHP's is being held on 29th February 2016. Flyer attached.
- Presentation and thanks to Hodan Noor, Pathway Manager, who is leaving for a new role in education
- Palliative and EoLC 16-18 years – email to be circulated to the group due to lack of time

14. Date and Time of Next Meeting(s)

Tuesday 22 March 2016, 3.30pm to 5.30pm, Frank Rifkin Lecture Theatre, Level 1, Mayo Building, Salford Royal NHS Foundation Trust



Action summary				
Agenda item	Action	Action to be Taken by	Date for completion	
2	Members requiring another copy of the form to advise Rachel Farrall via email at rachelfarrall@nhs.net	All		
3	Members to check with their localities re statement of intent and if it is used to communicate with Out of Hours services. Members to email Kim to comment on whether this document should be updated regionally or in local areas – if any updates are needed	All		
4.1	Anyone working with liver disease patients or those interested in being involved in this area of work on behalf of the advisory group should contact Dave Waterman at the SCN via email. Dave will follow-up with Dr John O'Malley	DW		
4.2	(i) Emergency Care and Treatment consultation link to be circulated within the weekly run (ii) Kim has suggested that the group forward to her any specific examples regarding any safeguarding issues	Denise (SCN) KW	28.01.16	
4.3	Circulate a copy of this letter with the meeting notes	Denise (SCN)	Attached	
4.4	(i) Members to forward their current electronic versions of their anticipatory/ administration sheets for medication in the last days of life to Kim Wrigley at the SCN for circulation and comments to the advisory group (ii) Dr Waterman will take the comments to the Training and Education Special Interest Group for them to look at collectively within that forum (iii) SCN to write to Greater Manchester Medicines Management to ask for their opinion and whether they would like to be involved in this work	All DW KW		



Agenda item	Action	Action to be taken by	Date for completion
5	(i) Circulate a copy of the presentation with the meeting notes (ii) Members to feedback any thoughts and comments which they feel should be included within the Vanguard to Carole Mula via email as soon as possible	Denise (SCN) All	03.02.16
7.1	Master copy to be amended on the SCN website	Denise (SCN)	16.02.16
7.2	(i) Identify a project for the group going forward that can be delivered (ii) Be mindful of the changes within the SCN - possibly identify work which could be supported beyond April 2016	Research & Audit Group	
9	Agreed that Jonathan would forward her contact details to Carole Mula and involve Wendy in any further discussions to take this forward	JT-R	
11.1	Reminder email to be circulated again to ask for all local areas to supply their update on the 8 key areas of EPaCCS	Denise (SCN)	28.01.16
11.5	Details of the national conference to be circulated as soon as possible	Denise (SCN)	28.01.16
12.1	Reminder MPET email will be circulated with all the existing forms for completion	Rachael	27.01.16
12.4	Generic version to be circulated with the meeting notes and members to ask what particular information/data they would like to have. Any further thoughts contact Rachel Farrall	Rachael	Attached
13	(i) Information to be circulated (ii) Members to bring to the next meeting any key themes re: NHS 111 input for localities to be shared with SCN	Denise (SCN)	Attached

