

**Greater Manchester & East Cheshire Palliative and End of Life Care Advisory Group
in Partnership with Manchester Cancer**

Date and Time	Tuesday 17 May 2016
Venue	Birchwood Conference Centre

Present	
Name	Organisation
Dr Dave Waterman (Co-Chair)	Greater Manchester & East Cheshire Strategic Clinical Network 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	Senior Programme Manager – Greater Manchester & East Cheshire Strategic Clinical Network
Christine Taylor	Quality Improvement Senior Project Manager – Greater Manchester & East Cheshire Strategic Clinical Network
Claire O'Rourke	Palliative Care Pathway Manager – Manchester Cancer
Dr Gillian Hirst	Associate Specialist - Central Manchester University Hospitals NHS Foundation Trust
Fran Mellor	Greater Manchester Macmillan Associate Development Manager
Delwyn Wray	Project Manager, Bury CCG
Dr Lesley Allsopp	Consultant in Palliative Medicine, East Cheshire NHS Trust
Mohammed Abas	Commissioning Manager – Central Manchester CCG
Anne-Marie Rafferty	Clinical Lead and Macmillan Clinical Nurse Specialist in Palliative Care – The Christie
Dr Chris J Pick	Medical Director , Springhill Hospice (attended on behalf of Dr Lippett)
Alice Davies	Macmillan Lead Cancer & Palliative Care Nurse – Pennine Acute Hospitals
Dr Tim Jackson	Consultant in Palliative Medicine, Salford Royal NHS Foundation Trust
Andrea Lightfoot	Service Improvement Manager (Long Term Conditions), Salford CCG
Cath Byrne	Macmillan Palliative Care Lead Nurse, Stockport NHS Foundation Trust
Dr Mariam George	Consultant in Palliative Medicine, Tameside Hospital NHS Foundation Trust
Margaret Hayes	Macmillan Clinical Nurse Specialist/Team Leader, NHS Tameside & Glossop
Dr Paul Cook	Medical Executive Director, Consultant in Palliative Care and Pain Medicine, Dr Kershaw's Hospice
Karen O'Connor	Community Macmillan Nurse, Pennine NHS Trust (Trafford Division)
Dr Aruna Hodgson	Consultant in Palliative Medicine, Wigan & Leigh Hospice
Lucy Lyon	Commissioning Manager – Cancer & End of Life Care, Wigan Borough CCG
Rev. Canon Anne Edwards	Chaplaincy & Spiritual Care Manager, Wrightington, Wigan and Leigh NHS Foundation Trust
Janette Sanders	Macmillan Palliative Care Nurse Specialist, Wrightington, Wigan and Leigh NHS Foundation Trust
Dr Liz Elliott	GP from Stockport leading on Enhanced Supportive Care, The Christie
Dr Kirsten Baron	SpR Palliative Medicine, Salford NHS Foundation Trust
Dr Gurs Purewal	SpR Palliative Medicine, Stockport NHS Foundation Trust

Apologies	
Stephen Burrows	North West EPaCCS Lead, Greater Manchester & East Cheshire Strategic Clinical Network
Shahid Mohammed	BME Health and Wellbeing
Michelle Leach	Macmillan User Involvement Manager, Manchester Cancer
Alison Walters	Patient/User Representative
Wendy Allen	Patient/User Representative
Dr Barbara Downes	Consultant in Palliative Medicine, Royal Bolton Hospitals NHS Foundation Trust
Sarah Bullock	Deputy Director of Commissioning, Bury CCG
Dr Debbie Hartley	GP Macmillan End of Life Care Lead
Ashique Ahamed	Consultant in Palliative Medicine
Dr Stephanie Lippett	Community Specialist Doctor, Springhill Hospice
Andrea Goodall	Commissioning Project Manager
Jennifer Gallagher	Hospice Nurse Specialist Team Manager, Wigan & Leigh Hospice
Dr Tin Aye	Salford CCG
Dr Jenny Wiseman	Consultant in Palliative Medicine, Wrightington, Wigan and Leigh NHS Foundation Trust

1. Welcome, Apologies and introductions

Carole Mula opened the meeting and introductions were made. Apologies were noted as above.

2. Conflict of Interest

Any conflict of interest forms should be submitted to the Strategic Clinical Network (SCN) office for filing. Those members who are attending on behalf of another member should declare any conflicts of interest at the beginning of the meeting.

Cath Byrne returned an audit form.

3. Notes and Actions from the Meeting held on 22 March 2016

Item 1 Karen O'Connor had given her apologies for this meeting.

Action: Meeting notes to be amended to reflect Karen's apologies

Item 4.1 Dr Waterman advised that in view of this level of response, it is up to local areas to take this forward as there is not enough interest.

Tameside had also provided a response to the Statement of Intent.

Action: Meeting notes to be amended

Subject to the above amendments, the meeting notes were agreed as a true record of the meeting.

Action Summary

4.1 No further statement of intent responses had been received. Dr Waterman advised that in view of this level of response, it is up to the local areas to take this forward if there is enough interest in this work on a GM footprint.

No additional replies apart from Wigan had been received regarding liver disease patients and end of life care – a meeting has been arranged, Dr Waterman will feedback at the next advisory group.

Emergency Care and Treatment Plan

Those people who have responded to the public consultation to the Emergency Care and Treatment Plan would have received an email summary from the consultation team.

Some of the feedback was:-

- Clearer messaging in communication on the form itself and in the supporting documents
- Some clarity around the legal status of the emergency care and treatment plan
- Compliance with Mental Capacity Legislation
- Design of the document
- Education materials and resources for health professionals

The National Plan is to amend the material and then present it to the working group in May 2016. Two patient focus groups have been arranged to review the revised material and then they will provide further information on the website after May 2016.

uDNACPR

The current North West unified guideline is due for a review and has been for 4 to 5 months. A meeting has been arranged for 27 May 2016 with NWAS and there is a pre-telephone conversation to discuss how to take this forward.

Items for further clarity are:

- How we frame the guidelines going forward, the implementation, education and training, the decision making itself and the monitoring and outcomes related to documented DNACPR
- Who is responsible for the policy/guidance?
- How NWAS may approach the emergency care and treatment plan when it is finalised towards the end of the year

Work Programme

There has been further discussion at the SCN – the work programme 2015/2016 has been updated and the status of each deliverable updated. The Greater Manchester and East Cheshire programme of work 2016/2017 is currently being reviewed by The Greater Manchester Heads of Commissioning.

Action: 2015/2016 Work programme to be circulated with the notes

Action: 2016/2017 Work programme (GMEC) to be discussed at the July meeting

4. Matters Arising

- 4.1 Liver Disease and End of Life Care – Next Steps – item covered as above.
- 4.2 uDNACPR update and emergency care treatment plan – item covered as above.
- 4.3 Work Plan 2015/2016 – item covered as above.
- 4.4 Statement of Intent – item covered as above.

5. North West Audit Group (NWAG) – Care of the Dying Audit

Item to be deferred to the next meeting in July 2016.

Action: To be included on the next meeting agenda in July 2016

6. Manchester Cancer

6.1 Annual Report

Carole Mula advised that Manchester Cancer had been asked to submit their Annual Report by the end of June 2016. This is a report on the activities that the Board has taken jointly with the SCN to influence the care and experience of patients with cancer across Greater Manchester. Claire O'Rourke had emailed group to ask for key themes from CQC visits and the National Care of the Dying Audit. The report needs to demonstrate the improvements made from the audit back in 2013/2014 compared to the recent National Care of the Dying Audit and show the impact that this Board has had to improve the care of dying patients.

Any key themes/challenges coming out of any local CQC inspections will help to inform Manchester Cancer in terms of resources going forward.

Pain services – useful to include an update in terms of how pain services are developing across Manchester Cancer.

Dr Waterman advised that in many areas their CQC report may not be available and the National audit results may not have been shared internally across the organisation, given the timing with the Annual Report, this is an opportunity to share general themes and learning of what is going well or is well supported. He advised that themes of the MDT involvement and the seven day working can also be included.

Action: Clare O'Rourke to circulate a further email to the group to ask for any themes/challenges to be included in the Annual Report

6.2 Enhanced Supportive Care

Carole Mula advised that at the last couple of meetings, a development at The Christie had been discussed around earlier integration of palliative care for patients with cancer. This is on the back of a 3-year CQUIN that was undertaken and was recognised by NHS England and has been developed into a National CQUIN for Cancer Centres. Other Cancer Centres around the country apart from Greater Manchester have been able to put forward interest in becoming a local site to take forward enhanced supportive care model and there is investment with this.

Phase 1 – background work undertaken at the Christie

Phase 2 – looking at setting up a daily outpatient area for palliative care and acute oncology where patients with complex symptoms are able to come to the clinic for review by a medic and palliative care specialists

Phase 3 – what the implications are across Greater Manchester in terms of implementation enhanced supportive care

Dr Liz Elliott, a GP from Stockport who is leading on the project with Richard Berman at The Christie, gave a presentation.

Action: Attach a copy of the presentation with the meeting notes
Action: Comments re: Enhanced Supportive Care to be sent to Dr Waterman

7. Cancer Vanguard – Living with and beyond and palliative care work stream

7.1 Goals of Care Initiative

Carole Mula advised that an overview of what cancer Vanguard is trying to achieve has been discussed at previous meetings. It has now been agreed that living with and beyond and palliative care will be a work stream for the cancer Vanguard and within that work stream there are 3 projects:

- i) Transformation of follow-ups – links in with living with and beyond.
- ii) Goals of care - ensuring that all patients embarking on treatment are moving on in their disease trajectory and although they may not be for further treatment, ensuring that their goals of care are understood and these match the goals of treatment.
- iii) Seven day working.

7.2 Seven Day Working

Dr Waterman updated the meeting. This is an element of the living with and beyond Cancer Vanguard Workstream. Over the last year, Manchester Cancer and the SCN have been looking at seven day provision and the current position. Also looked at Palliative Care involvement within tumour specific MDT's. The work needs some more resource behind it to take it forward. Cancer Vanguard provides an opportunity to drive this workforce planning. Need to think what the seven day provision position would look like.

The project work and the pilot both need resources and this is what is being asked for.

Seven day working is an area which everyone is continuing to struggle with.

General discussion around other models in different localities.

Carole Mula and Dr Waterman have agreed that they would like to have project time clinically to support this project work and will keep the group up to date on progress.

8. Special Interest Groups (SIGs)

Although the SCN footprint is changing, the SIG's will continue to support Greater Manchester and East Cheshire. The LSC work will be taken forward through the North West Coast SCN. Some of the transition will happen over June 2016 but the group membership is from both areas.

8.1 Education and Training inc. facilitators scoping

Meeting took place on 1 April 2016 and also met with facilitators and those educating as part of the clinical role and took this opportunity to look at competency framework for trainers. This document has been updated and is currently in draft form. Also looked at scope of a facilitator role and looking

at documentation in further depth. It is hoped that these two elements dovetail each other. The third element is that the group will look at education and training competencies around wider palliative care. The London SCN produced a competency document which covers this wider framework and they have agreed that this can be adopted locally. Aim of the group is to focus on completing this work by June 2016.

In the future the group will look at anticipatory prescribing and the documentation around the last days of life both for prescribing and administering the drugs particularly in the community. There are discussions on-going across a wider north-west footprint.

The Greater Manchester guidelines will remain currently although discussions continue across the North West.

8.2 Research and Audit

The group are moving forward and have agreed to investigate undertaking a clinical trial. The details will be presented at the meeting in early July 2016.

The two areas to be covered are:

- Early drug intervention for presence of respiratory tract secretions in end of life care patients
- New anti-emetic drug for patients having chemotherapy treatment

A bid for funding for these trials is being looked at.

In conjunction with CLARC, a provisional date of 5 October 2016 is being considered to hold a full-day conference which will be an opportunity for medical staff and registrars to present audit work that has been undertaken. They are looking to split the day in two halves. Half the day dedicated to audit and the second part of the day will be research.

Kim Wrigley advised that discussions are still underway to look at how the group will progress going forward in the context of the SCN reconfiguration. Cheshire and Merseyside do have an audit group so conversations are underway between the two areas.

8.3 Care Co-ordination

Kim Wrigley advised that this group was rested some months ago. The main piece of work from this group is the Greater Manchester, Lancashire and Cumbria Bereavement Directory which is in now in a final draft. This directory will be placed on the website when complete. There are no further plans to continue with this group.

8.4 Transforming Care

Dr Waterman advised that this was presented at the last meeting as an overview with regards to transform for acute hospitals. The group has clearly taken a view that there are limited sites that deliver transform in its entirety within acute trusts and need to identify for each element what the key enablers and blockers are and how can this information be shared. This work is being pulled together and hopefully will be finalised very soon. This work will then sit under the education and training special interest group so the transforming care group will no longer meet.

8.5 EPaCCS and Locality Update

Kim Wrigley advised that Steve Burrows was unable to attend this meeting but she understood that the current dashboard had not changed significantly since the last meeting.

Steve will continue to work for the SCN at least until the end of September 2016 and members are encouraged to utilise his expertise and capitalise on this time with the SCN

Steve is currently looking to have a Suppliers Event in July 2016 which members will be invited to.

9. Innovation Programmes

- 9.1 Early lung cancer support – enhanced supportive care
- 9.2 Palliative and EoLC 16-18 years
- 9.3 Neurology - update

The group agreed to look to creating a new special interest group which focuses on elements of service innovations.

Action: Members wishing to express an interest in being involved in this group to contact Christine Taylor at the SCN via email at christine.taylor41@nhs.net

Action: The Palliative and EoLC 16-18 years summary report will be circulated with the meeting notes for information

10. Patient Carer Update

10.1 Welcome to Shahid Mohammed from BME Health and Wellbeing.

Shahid is unable to attend the meeting today though he has been co-opted onto the membership of the group following a successful workshop with predominantly BME communities in Rochdale which was supported by the SCN and Springhill Hospice in Pennine Acute Trust. He has produced a report with some recommendations which the SCN need to discuss going forward.

10.2 Welcome to Alison Walters – Patient/User Representative

Neither Alison Walters, the new patient user representative, or Wendy Allen were available to attend this meeting. A copy of the Manchester Cancer User Involvement final report had been circulated with the meeting agenda. The key findings from this work are that across Greater Manchester there has been a culture shift in terms of user involvement particularly in service developments. Professionals seem to be more engaged in terms of working with users.

11. CQC

11. Thematic review report

This report has now been published on 11 May 2016. The report is encouraging from a Greater Manchester perspective that three localities are featured in one of the documents which is

highlighting best practice. The Through our Eyes work undertaken by the SCN is also featured. The report covers 11 specific groups within the context of end of life care.

Action Circulate the link on the SCNs weekly run

11.2 Locality reports and shared learning

This highlights the key challenges and gaps in the local areas.

12. Commissioning Advice and EoLC

12.1 NHS England

12.2 Specialist Palliative Care

12.3 SCN London

Dr Waterman advised that all these documents have been circulated via the SCN weekly run. Commissioners and Providers to review these documents and consider how they are sharing and using them as part of on-going commissioning discussions. Dr Waterman also asked for the providers to consider how they are sharing these documents as part of ongoing commissioning discussions.

Action Circulate the documents/links on the SCNs weekly run.

13. SCN Update

13.1 National review of SCN's and Senates/team update

Kim Wrigley advised that the SCN are part of NHS England and are fortunate in the north-west to have palliative and end of life care as part of this activity. The SCN is currently in the final stages of separation from Lancashire and South Cumbria who will be moving to the North West Coast SCN along with Cheshire and Merseyside.

The SCN will now be a Greater Manchester and East Cheshire function and is fortunate to have a further year's funding until the end of March 2017.

13.2 Greater Manchester/East Cheshire Programme of work 2016/2017 (HOCS)

Kim Wrigley, Carole Mula and Dr Waterman have been working with Karen Proctor, Director of Commissioning at NHS Salford CCG re: Heads of Commissioning work programme. Heads of Commissioning have supported the Palliative and EOLC team to continue for a further 12 months. A case will be made in due course to hopefully continue beyond March 2017. It is also important to note that we are part of the new Health and Social Care Partnership for Greater Manchester previously known as Devolution Manchester. This creates challenges in navigating the new systems but work is continuing to keep palliative and end of life care on the agenda. The HOCS programme has now been signed off which is testament to all the hard work which has been undertaken.

13.3 National Clinical Leads Meeting feedback and NCD Appointment

Professor Bee Wee who was the National Clinical Director has been re-appointed to this role and she will work on long term conditions of older people and end of life care. The SCN will continue to have contact with the National team to receive information in a timely manner. Dr Waterman wanted to highlight that we are fortunate in Greater Manchester that the Heads of Commissioning are funding this work stream as other SCN's are not that fortunate and not every area has ongoing funding. This does not diminish the work done in each locality in GMEC, but to have this group enables us to share good practice and common work.

13.4 Regional call feedback

Dr Waterman advised that there is some potential funding which NHS England nationally has identified for end of life care. This funding will come through the Regional Medical Directors which will then be spent across a region. This is currently an ongoing conversation. The money is for clinical and programme support across the north region.

13.5 North West Operational Group Meeting feedback

Nothing to add to this item which has not already been covered during the meeting.

13.6 Finance

Kim Wrigley advised that we are now in a new financial year. Money from the 2015/2016 slippage has been invested in additional support for EPaCCS via Stephen Burrows. Funding has also been invested in DNACPR documentation along with the Dying Matters materials from the NCPC.

13.7 MPET 2016/2017 and MPET Evaluations 2015/2016

Dr Waterman advised that he was grateful for local groups, organisations and individuals for using the MPET evaluation forms and for submitting them back to the SCN. This is helpful to collate evidence and forward to Health Education North West which has allowed the SCN to make the case for more funding.

The MPET money for 2016/2017 has now been agreed at £500,000 which will be across Greater Manchester, Lancashire & South Cumbria, Merseyside and Cheshire. This has been a substantial reduction on money received in previous years but there would have been a further reduction if the evidence wasn't available to explain how funding has been spent.

The view from the North West group is that although since 2008 there has been an allocation of MPET money every year for localities to bid for and fund education and training etc, the money will now be invested in a more central way to support specific education and training needs across the localities, rather than individual CCG allocations. This decision has not been taken lightly. An action plan will be produced to highlight how the money will be invested regionally and circulated for comments.

Action: Any suggestions or core messages on how best to spend this money should be sent Dr Waterman

14. Palliative Care Data

14.1 Public Health England Data Set and DIURP

Dr Waterman advised that the DIURP data is regularly being produced indicating where the trends are locally.

Public Health England has sent out some information regarding the National End of Life Care Intelligence Network and potential data and templates to be collected in future. This is not going to be mandated data. Dr Waterman asked for any thoughts on how localities can incorporate that dataset within the data they are currently collecting.

Action: Any general views can be discussed again at the next meeting. Place item on the next agenda for the meeting on 19 July 2016

15. Any other Business

15.1 Cordotomy services

Dr Paul Cook gave some background to this service and advised that everyone has a small percentage of patients who struggle with pain issues. Dr Cook is one of four people in the country who carry out cordotomies. There was previously a National service at Pennine Acute which has now ceased. Since this time he has been trying with a colleague at Christie to try to engage in National commissioning for a vision of interventional cancer services that are going to be fit for purpose for patients. This vision would also include a variety of interventions for approximately 5% of patients but hopes that this percentage will increase.

In summary, he is trying to engage with NHS England and has the support of Professor George and the Association of Palliative Medicine. Dr Cook asked for any thoughts and opinions to be directed to Dr Waterman to engage with potential services and support him in this business case.

Action: Any thoughts or opinions from the local areas to be directed to Dr Waterman via email who will then collate them

16. Date and Time of Next Meetings

Tuesday 19 July 2016 – 3pm to 5pm – Humphrey Booth Lecture Theatre, Room 1, Salford Royal NHS Foundation Trust

Tuesday 20 September 2016 – 3pm to 5pm – Birchwood Conference Centre – Room to be advised

Tuesday 15 November 2016 – 3pm to 5pm – Seminar Room 6, Mayo Building, Salford Royal NHS Foundation Trust

Action summary				
	Agenda item	Action	Action to be taken by	Date for completion
	3	Meeting notes to be amended to reflect Karen's apologies	Denise (SCN)	Actioned
	3	<p>Item 4.1 Dr Waterman advised that in view of this level of response, it is up to local areas to take this forward as there is not enough interest.</p> <p>Tameside had also provided a response to the Statement of Intent.</p> <p>Meeting notes to be amended to reflect above</p>	Denise (SCN)	Actioned
	4.1	2015/2016 Work programme to be circulated with the notes 2016/2017 Work programme (GMEC) to be discussed at the July meeting	Denise (SCN) SCN	Attached
	5	North West Audit Group (NWAG) – Care of the Dying Audit To be included on the next meeting agenda in July 2016	SCN	
	6.1	Clare O'Rourke to circulate a further email to the group to ask for any themes/challenges to be included in the Annual Report	CO'R	

Agenda item	Action	Action to be taken by	Date for completion
6.2	Attach a copy of the presentation with the meeting notes Comments re: Enhanced Supportive Care to be sent to Dr Waterman	Denise (SCN) All	Attached
9	Members wishing to express an interest in being involved in this group to contact Christine Taylor at the SCN via email at christine.taylor41@nhs.net The Palliative and EoLC 16-18 years summary report will be circulated with the meeting notes for information	All Denise (SCN)	Attached
11	Thematic review report - circulate this report with the meeting notes	Denise (SCN)	Weekly run 20.05.16
12	Re-circulate these documents. 12.1 NHS England 12.2 Specialist Palliative Care 12.3 SCN London	Denise (SCN)	Weekly run 05.05.16 Weekly run 07.04.16 Weekly run 14.05.16
13	MPET 2016/2017 - Any suggestions or core messages on how best to spend this money should be sent Dr Waterman	All	
14	Public Health England Data Set and DIUPR - Any general views can be discussed again at the next meeting. Place item on the next agenda for the meeting on 19 July 2016	SCN	
15	Cordotomy services - Any thoughts or opinions from the local areas to be directed to Dr Waterman via email who will then collate them	All	