

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

Date and time	Thursday 24 September 2015
Meeting	The Greater Manchester Palliative and End of Life Care SCN's Advisory Group in Partnership with Manchester Cancer Board
Venue	Birchwood Business Park

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
Stephen Burrows	North West EPaCCS Project Lead - SCN
Jonathan Turnbull-Ross	Macmillan User Involvement Manager
Dr Trevor Rimmer	Macmillan Consultant Palliative Medicine/Medical Director - East Cheshire
Sue Dyde	NIHR Clinical Research Development Nurse
Dr Sophie Harrison	Macmillan Consultant in Palliative Medicine –University Hospitals South Manchester NHS Foundation Trust
Dr Mariam George	Consultant in Palliative Medicine - Tameside and Glossop
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
Raj Khuroya	GP End of Life Care Lead HMR CCG
Sarah Gunshon	Commissioning Manager - NHS Trafford CCG
Karen O'Connor	Community Macmillan Nurse – Pennine Care NHS Trust Trafford Division
Fran Mellor	Macmillan Associate Development Manager - University Hospitals South Manchester NHS Foundation Trust
Andrea Lightfoot	Salford CCG
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
Andrea Goodall	Commissioning Project Manager – NHS Heywood Middleton and Rochdale
Philippa Robinson	Commissioner – Tameside and Glossop CCG
Mohammed Abas	Commissioning Manager – Central Manchester CCG
Apologies	
Julie Whitehead	Macmillan Pharmacist
Dr Robin Muir	Clinical Psychologist – Royal Bolton Hospitals NHS Foundation Trust
Dr Gillian Hirst	Associate Specialist - Central Manchester University Hospitals NHS Foundation Trust
Alice Davies	Macmillan Lead Cancer & Palliative Care Nurse – Pennine Acute Hospitals NHS Foundation Trust
Dr Philip Lomax	Consultant in Palliative Medicine – St Ann’s Hospice
Dr Helen Morgan	Consultant in Palliative Medicine - Springhill Hospice
Dr Katie Hobson	Consultant in Palliative Medicine – Salford Royal Foundation Trust
Steve Gene	Assistant Director of Nursing - Salford Royal Foundation Trust (SCN Transform SIG Co-Chair)
Dr Jenny Wiseman	Consultant in Palliative Medicine – Wrightington, Wigan and Leigh NHS Foundation Trust
Anne-Marie Raftery	Team Leader and Clinical Nurse Specialist in Palliative Care – The Christie NHS Foundation Trust
Dr Samantha Kay	Consultant in Palliative Medicine – University Hospitals South Manchester NHS Foundation Trust
Ursula Haworth	Allied Health Professional
Kath Fisher	
Dr Aruna Hodgson	Consultant in Palliative Medicine - Wigan Hospice

1. Welcome and Introductions

SCN and Manchester Cancer Partnership

David Waterman welcomed the Group; attendance sheet with apologies documented was circulated.

David Waterman acknowledged the footprint between the SCN and Manchester Cancer does not fit together however members who sit on the border will hopefully be able to take information from the meeting for the elements they require.

Trevor Rimmer asked for it to be noted that it is only Cheshire who are included in the Manchester Cancer footprint.

2. Standing agenda item - Conflict of Interest

In order to comply with NHS England’s legislation in managing conflicts of interest and standards of business conduct Elaine Parkin introduced a process that will need to be followed by each group member. A document will be circulated for reading and completion of Appendix B.



This must be returned to the SCN to be logged on a main register which will be revisited at the beginning of each meeting.

ACTION: Managing conflicts of interest and standards of business conduct document to be distributed with completion guidance

3. Notes from the meeting held on the 14/7/15

Notes agreed as a true record with the following amendments

P1 Trevor Rimmer area – East Cheshire
P6 Survey Monkey - capital letters

Post meeting note – Amendments made on master document of saved notes available on request.

Freedom of information requests - Group members asked to share with this group any freedom of information requests regarding Palliative and end of life care. Details of how the requests are managed are not required.

4. Matters Arising

4.1 u DNACPR

ACTION: All Members please continue to inform the SCN of any U DNACPR implementation challenges faced by localities

Dr Waterman updated the group on discussions regarding the SCN, NWAS and NHS England. NWAS as the lead of the policy are clear they continue to require 1 single policy with 1 set of paperwork.

There is National work taking place which may influence future paperwork however the policy content and current paperwork will currently remain.

The SCN have begun to look at key building blocks that need to be in place to safely implement the policy following the network wide survey which demonstrated a variation of implementation.

1. Policy approved with governance and responsibilities outlined ideally at CCG level if used across the whole locality
2. Education and Training support for the implementation
3. Clarity on the recording of the audit and training and competencies of using the policy

Iain Lawrie commented it is important for trusts facing CQC visits to have this in order as the CQC will look at 20 of the DNACPR forms

Policy requires an update which has been delayed due to the outcome of the national work taking place. The policy will be reviewed in January with similar membership to those that initially reviewed the policy.

Statement of intents in Pennine is with the 4 coroners to request implementation also in hospital.



Wigan and South Manchester has also agreed this with the coroner.

ACTION: Jenny Gallagher to share Wigan Statement of intent with Iain Lawrie

4.2 Pain and Symptom Control App

Tameside and Glossop have developed a pain and symptom control app based on the network Pain and Symptom control Guidance

Philippa updated the group that the app is currently only available on Android. The Apple version is in development. Demonstration of the App given to group members.

The link will be circulated on completion.

ACTION: Philippa Robinson to confirm that the Pain and Symptom Control App will carry the SCN logo and a disclaimer that this is Network core rather than local guidance

Dr Waterman updated the group that he has been contacted by a drug rep regarding the information in the network guidance on tapentadol. Dr Waterman will meet with the representative to explore the query

Volunteers will be requested early next year for members to review the guidelines and bring them together with Lancashire and South Cumbria's guidance.

4.3 DoLS Consultation

New case law has changed the deprivation of liberty (DoLS) process which has increased the number of deprivation of liberty assessments, leading to more coroner's inquests. The Law commission are currently consulting on a review of the law for 2017.

ACTION: All members to access and input to the consultation
The consultation document can be accessed on the law commission website:
www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/

4.4 Terms of Reference

Terms of Reference to be circulated following Membership update to link membership to localities.

ACTION: Terms of Reference to be circulated for comments. None response from members will be acknowledged as agreement

5. Special Interest Group Work Programme Overview

5.1 Education and Training

Dr Waterman updated the group that the Education and Training SIG will meet next week. The group will be concentrating on principles of education and training, the last days of life NICE guidance, trainer's competencies and widening the competencies across the whole of the NW Model.

A questionnaire has been distributed to facilitators and clinical educators to gather information on the roles and impact on quality improving programmes.



Elaine Parkin requested that this group distribute the clinical educator's questionnaire to their teams. The deadline has been extended by 1 week.

Elaine Parkin and Dr Waterman have recently met with the GM Facilitators and encouraged facilitators membership to the SIG's and a nomination of a facilitator representative to this group

5.2 Research and Audit

Membership has been limited to a Core and Reference group to ensure consistency of members at group meetings and locality representatives via the reference group. Terms of Reference being finalised with the work programme. The next meeting will take place next week. The challenges regarding governance for hospices participating in research has been highlighted on the work programme

5.3 Care Coordination

Currently progressing well with the work programme. The next meeting will take place in November. Work taking place on an end of life care language directory. Also the group have agreed to try and coordinate a meeting with all the network coroners with a focus on DoLS. Currently the group is being chaired by Dr Salt whilst recruitment to the Co-Chair role is pursued.

5.4 Transforming Care

Three meetings have taken place which included a showcase event. There has been good representation from the Acute Hospitals across the network. The group have been linking with the National Transform work stream and locally sharing updates on implementation. Some Acute Trusts have not signed up to the National Transform programme but are welcome and linked into the group as they are delivering palliative and end of life initiatives care across their hospital.

6. Group Work Programme 2015/16

6.1 Locality Responses

A local lead has been requested from each locality group for the different objectives of the agreed work programme for this group

Elaine Parkin explained the purpose of identifying locality leads and updated the group that this is nearly complete. Outstanding areas will be contacted and support offered.

Carole asked the group how the work programme is being implemented locally. Group members it is being used as a guide. The document has been helpful to identify leads locally.



7. Patient and Carer Update

7.1 Patient Carer Manager for Specialist Palliative Care

Carole Mula introduced Jonathan Turnball–Ross jonathan.turnbullross@nhs.net who is the newly appointed as Macmillan User Involvement Manager for Manchester Cancer covering palliative and end of life care. Jonathan has been working closely with Wendy Allen. The User Involvement Managers are building user involvement across Manchester Cancer to the board groups and patient groups. They are also co-producing a model to increase the number of and offer support for user involvement. A programme is in development for patients and carers wishing to be involved in Manchester Cancer work.

Jonathan's work is specifically linked to Cancer; there is a requirement for this group to have a input from patients and carers from long term conditions.

Hodan Noor updated the group that Jonathan will be reviewing the outcomes if the work done in living with and beyond Cancer and will potentially be running focus groups in November to assess the needs of patients living with Cancer.

ACTION: All members to share any information on any work in their locality supporting people living with and beyond Cancer with Elaine.parkin1@nhs.net

7.2 SCN PCPE Steering Group event 23/9/15

There has been difficulty recruiting a PCPE member to the palliative and end of life care network. A presentation was delivered at the PCPE steering group event and we are hopeful that PCPE members may wish to become involved with the palliative and end of life care work programme

7.3 LTC representative

As discussed under 7.1 and 7.2

8 EPaCCS Update

8.1 Locality update

Stephen Burrows Updated the group that potentially we may have 7/8 localities with a live EPaCCS for the next meeting as there has been lots of developments over the last few months Stockport and Salford are currently live

Work is underway to pull together a meeting with Pennine group.

A letter will be circulated from Steve and NWS to the end of life care task group leads and via this group, regarding localities including NWS in their information sharing agreements.

The Christie will also be using the MIG and Graphnet to pull information into the Christie. Phase 2 will be work on sending data from the Christie.

8.2 Data Project Public Health England

Public Health England is planning for reporting from EPaCCS to be in place from February 2016. Stephen Burrows has agreed with Public Health England the North West (NW) will share NW reporting responsibilities



SB talked through the suggested draft list from Public Health England (PHE - EPaCCS data project paper circulated) of data that will be requested and reported against

As people are at different stages of implementation of EPaCCS across the NW it would be unreasonable to ask all areas to report on all of the data set initially, therefore Stephen Burrows has agreed that the North West will report as a region. Localities have been asked to report on a minimum of two from the list:

- Deaths - Number of % of deaths with EPaCCS record (analysis by age/gender/diagnosis)
- and at least 1 other from the list (locality choice - awaiting feedback from the locality task and finish EPaCCS leads)

ACTION: **Locality choice of questions to be shared with this group**

8.3 NW Proposed Data set

Data set displayed which has been colour coded. Feedback has been gathered from localities regarding suggestions from the Northwest. There is an ISB mandatory update due in January 2016 therefore Stephen intends to update the template so one set of changes can be made to the templates on the same date in December.

ACTION: **Feedback on the proposed data set to be sent to stephen.burows@nhs.net by 21/10/15**

8.4 Why EPaCCS DVD

Resource to be developed using film media to support the implementation of EPaCCS from a patient/professional user perspective not an IT perspective.

Dr Waterman thanked Stephen for his work on moving EPaCCS forward.

9 SCN Update

9.1 Showcase Event

Currently in the planning stages of the palliative and end of life care showcase event, on the 4/11/15, at the Bolton Holiday Inn. The aim of the event is to showcase the work from across the network especially where MPET funding has been used. There will be a call for posters from each locality group. The Special Interest Groups have also been asked to present their work programme and initiatives linked to the SIG.

9.2 MPET

2015/16 MPET funding is currently being transferred. An e mail will follow regarding the future MPET evaluation of funding

9.3 Facilitator/ Educators Scoping

Discussed under 5.1



10 Manchester Cancer Palliative Care Board Annual Report

Dashboard (attachment)

Dashboard created and distributed. At the back of the paper is a list of the Cancer Specific Boards which list palliative and end of life care. To be discussed under agenda item 14.

11 Specialist Palliative Care Services Scoping (Moved up from agenda item 14)

Previous mapping have taken place. A presentation has been given to the commissioner's for Manchester Cancer which has resulted in a request for a service specification for specialist palliative care. Dr Waterman and Carole Mula will be meeting with David Hackney – Lead commissioner for Cancer Services on the 6/10/15.

Dr Waterman presented a draft template of information that may help the commissioners. To date, there has been no specification outlining the minimum requirement per bed/population

The templates have been separated out by setting and service. Formulas will have to be agreed by the group.

Important to know how we can contextualise data.

ACTION: Request for any evidence base to support the building of the templates. Ian Lawrie suggested the Macmillan calculation of contacts per year and there may be evidence from the North Manchester model

ACTION: Iain to send the North Manchester modelling to Dr Waterman

12 Future development of specialised services in Greater Manchester

Briefing paper (attachment)

Briefing paper distributed to the group. Carole to continue to send the group briefings as they are received. Any group members with questions to contact Carole.Mula@christie.nhs.uk

13 Research NIHR Clinical Research Nurse

Carole welcomed Sue Dyde - Research Delivery Manager for the Greater Manchester Clinical Research Network and the National Institute for Health Research. Sue talked to the paper distributed regarding research in Cancer. Information regarding other trials in LTC can be added. Foot print does include East Cheshire and Blackburn. Each Trust has a research nurse and work is underway to create GP federations with Research Nurses that can in reach to nursing homes/hospices and community.

Sue is happy to be contacted if members wish for further details Sue.Dyde@cmft.nhs.uk

ACTION: Sue Dyde to list all the other Specialities and share with Hodan Noor so the updates can be shared



14 Recent Documents

14.1 NICE Consultation

Consultation is now closed. Await updated document

14.2 One Chance to Get it Right: One Year on Report

Highlights areas of good practice and development

14.3 Ambitions for palliative and end of life care - A national framework for local action 2015-2020

Slide pack available endoflifecareambitions.org.uk

Dr Waterman asked the group how localities are approaching the implementation of the document
Tameside plan to conduct a gap analysis

Pennine are planning to use the document to develop the next 2 year strategy

Useful document for planning strategies.

The document could be used to put palliative and end of life care on the agenda of the
Manchester Cancer Pathway Boards as discussed in agenda item 10.1

ACTION: All members to share any information on the implementation of the document
with Elaine.parkin1@nhs.net

15 Any Other Business

Stephen Burrows updated the group it is hoped the next National EPaCCS Conference can be
held in the North West early next year

Andrea Goodall asked how the work of this group feeds into the commissioning group. Dr
Waterman responded to say there is a formal reporting line from the SCN into the Heads of
Commissioning Greater Manchester and each locality should be feeding back to their
commissioning lead. Manchester Cancer also have formal reporting to the commissioners.

Support offered to any locality where feedback and discussion from this group is not reaching
commissioners members to contact Elaine.parkin1@nhs.net

Sarah Gunshon wished to formally thank Dr Waterman, Stephen Burrows and Kim Wrigley for the
support that has been given to Trafford.

16 Date and Time of Next Meeting

**Tuesday 24 November 2015, 2.30pm to 4.30pm (Seminar Room 1, Mayo Building, Salford
Royal Foundation NHS Trust)**



Action summary				
Initial discussion date	Agenda item	Action	Action to be taken by	Date for completion
24/9/15	2	Managing conflicts of interest and standards of business conduct document to be distributed with completion guidance	Elaine Parkin	16/10/15
		All members to return Appendix B to the SCN	All Members	24/11/15
24/9/15	4.1	All Members please continue to inform the SCN of any DNACPR Implementation challenges faced by localities	All Members	Ongoing
24/9/15	4.1	Jenny Gallagher to share Wigan's Statement of intent with Iain Lawrie	Jenny Gallagher	16/10/15
24/9/15	4.2	Philippa Robinson to confirm that the Pain and Symptom Control App will carry the SCN logo and a disclaimer that this is Network core rather than local guidance	Philippa Robinson	24/11/15
24/9/15	4.3	All members to access and input to the DoLS consultation The consultation document can be accessed on the law commission website: www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/	All Members	2/11/15
24/9/15	4.4	Terms of reference to be circulated for comments. None response from members will be acknowledged as agreement	Elaine Parkin	31/10/15
24/9/15	7.1	all members to share any information on any work in their locality supporting people living with and beyond Cancer with Elaine.parkin1@nhs.net	All members	24/11/15
24/9/15	8.3	EPaCCS locality choices of data to report on to be shared with this group	Stephen Burrows	31/10/15
24/9/15	11	All members to send any comments and supporting evidence base regarding the development of a service specification to Dr Waterman	All Members	24/11/15



Initial discussion date	Agenda item	Action	Action to be taken by	Date for completion
24/9/15	13	Sue Dyde to list all the Specialities on which she reports and share with Hodan Noor so the updates can be shared with the group	Sue Dyde	31/10/15
24/9/15	14.3	All members to share any information on the implementation of the Ambitions for palliative and end of life care - A national framework for local action 2015-2020 with Elaine.parkin1@nhs.net	All Members	Ongoing

