NHS
Northern England
Clinical Networks

SUPPORTIVE, PALLIATIVE AND END OF LIFE CARE CORE GROUP

1pm – 3pm on Tuesday 24 April 2018
Evolve Business Centre, Houghton-le-Spring

Present	Nousha Ali, South Tyneside NHS FT	**NA**
	Jane Bentley, North Tees & Hartlepool NHS FT	**JB**
	Sheila Brown, Patient Representative, NECN	**SB**
	Alexa Clark, Northern England Clinical Networks	**AC**
	Kieran Conaty, Macmillan Cancer	**KC**
	Andrew Copland, HAST/Darlington CCG	**AC**
	Sheila Dawson, St Teresa's Hospice	**SD**
	Florence Gunn, Sunderland CCG	**FG**
	Kathryn Hall, North Tyneside CCG	**KH**
	John Hancock, Hambleton, Richmond & Whitby CCG	**JH**
	David Hand, North Durham/Durham Dales, Easington & Sedgefield CCG	**DH**
	Melvyn Laycock, Project Lead, Northern England Clinical Networks	**ML**
	Adrienne Moffett, Northern England Clinical Networks	**AM**
	Michelle Muir, Newcastle upon Tyne Hospitals NHS FT	**MM**
	Alex Nicholson, South Tees NHS FT	**AN**
	Juliet O'Neill, Northern Doctors Urgent Care	**JON**
	Vicki Pattinson, Association of Directors of Adult Social Services (ADASS)	**VP**
	Ann Paxton, South Tyneside NHS FT	**AP**
	Julie Platten, North of England Critical Care Network	**JP**
	Trish Sealy, South Tees Hospitals NHS FT	**TS**
	Jocelyn Thompson, Childrens Palliative Care Forum	**JT**
	Sarah Turnbull, North East Ambulance Service	**ST**
	Louise Watson, Northern England Clinical Networks	**LW**
	Kirsty Wright, Sunderland Locality	**KW**
Apologies	Matthew Beattie, North East Ambulance Service	**MB**
	Jayne Denney, Cumbria Partnership NHS FT	**JD**
	Alison Featherstone, Northern England Clinical Networks	**AF**
	Melanie Fogg, Gateshead Health NHS FT	**MF**
	Marc Herscovitz, Northern Doctors Urgent Care	**MH**
	David Oxenham, County Durham & Darlington NHS FT	**DO**
	Teresa Storr, Cumbria NHS FT	**TS**
	Chris Walker, Patient Representative	**CW**
In attendance	Naomi Tinnion, Northern England Clinical Networks	**NT**

M I N U T E S

Action

1 INTRODUCTION

1.1 Welcome and apologies

AC welcomed everyone to the meeting and introductions were made around the table. The above apologies were noted.

1.2 Declaration of interest

There were none to declare.

1.3 Minutes of previous meeting

These were agreed to be an accurate reflection of the meeting.

1.4 Action points from minutes of previous meeting

Electronic network documentation: AC advised that she had emailed the GP, advised that network documentation cannot be changed but can be completed and saved electronically. This must have a wet signature to be a legal document.

1.5 Locality Groups updated information and ToR

- **Group membership**
- **Accountability**

AC advised that the Terms of Reference had been updated to reflect discussions at the last meeting and was pleased to see almost all of the core membership at today's meeting.

AM advised that she had been in contact with Health Education England to discuss their representation to the SPEOL core group and it was agreed that the identified representative will attend these meetings twice a year.

LW confirmed that the Group is hosted by the Northern Cancer Alliance and accountable to the National End of Life Care Programme, North Regional Team.

1.6 NEAS – Special Patient Notes Form

ST introduced herself as the new End of Life Care Facilitator at NEAS. She advised that two versions of the Special Patient Notes Form had been created, one of which focused on palliative care whilst the other encompassed all special patients. This was discussed and the Group agreed that ST should liaise with GPs on the group to create a single form for special patient, including palliative patients. It was agreed that the existing Special Patient Form should remain on the website until the new form is agreed and available. **ST/KH**

A discussion also took place about submitting these forms as they can no longer be faxed to NEAS. NEAS request that they are emailed using an NHS.net address. AC asked those around the table to ask who, in their locality groups, had NHS.net addresses and send this information to naomitinnion@nhs.net to help the Network try and identify where there may be issues submitting these forms. **Group**

ST advised there had been several cases recently where a DNACPR form had been misplaced by a family member which had caused some issues as the patients involved had been resuscitated. KH advised that the EPaCCs Group were looking at how DNACPR information can be shared to avoid this happening in the future. She will keep the Group updated on any progress. **KH**

1.7 Regional Telephone Advice Line Task and Finish Group

AP advised that Ellie Grogan was leading a Task and Finish Group to look at provision of telephone advice in each locality. Some scoping work had been done and the results collated into a grid which AP agreed to share with the Core Group. Findings included:

- Many areas are too small to develop their own advice lines without working collaboratively with other areas.
- Many areas are offering some sort of advice line, but few are commissioned or funded.
- Advice lines may be better run locally a local knowledge of services is invaluable, but this only works for larger services

Further discussions ensued including:

- Durham does have a commissioned service in place;
- Sunderland has a commissioned service in place which provides consultant level advice;
- Although most Trusts have some form of advice line in place, very few are available to the public.
- It is difficult for small localities to fulfil the NICE requirements;
- North and South Tees have a joint rota in place which provides cover by two professionals and is accessible by District Nurses.
- It would be good for NEAS to have better and more detailed information on the services available to avoid being called out
- Whether any network leverage which can be used to try and find a solution
- Whether Macmillan funding could be used to fund this service
- Is there any information on the amount of calls made to services already in place

NICE guidelines state that timely advice should be available day and night. This was discussed and the following observations made:

AC advised that as provision varies so much across localities there is a need to identify what is actually provided, where there may be gaps in service, how much it would cost to plug these gaps and what the benefits would be of providing an advice line. There was agreement around the table that it would be good to work collaboratively and develop this across the Network. To move this forward it was agreed that the Network should write out to each locality group to ask:

- Are there plans to develop an advice line?
- Are there any gaps in services currently being provided?
- Is there any interest in collaborating with neighbouring areas to help reduce the cost of setting up this service?

KH requested that a question be included in the letter around how CCGs would approach linking into clinical hubs and whether they would prefer a locality or network helpline. It might also be helpful to inform the CCGs that they have a requirement to meet the NICE guideline on providing this service.

ST advised that NEAS had been awarded the 111 contract for the next five years and would therefore appreciate a regional approach on this.

ACTION: AC/LW to draft a letter to locality groups for approval by the Group before sending. **AC/LW**

1.8 National Audit for Care at End of Life – update

LW advised that she had fed back to the national team regarding the Group's concerns about this audit being extended out to community and mental health

providers. The March briefing paper from the national team had since advised that mental health providers are not required to take part in the clinical element of this audit but do have to take part in the organisational and workforce element. Briefing paper 1 from March 2018 to be shared with the group. **LW**

MM advised that during a recent webinar it had been confirmed that 67% of mental health trusts had signed up to this audit. She also commented that three weeks into the process of doing this audit the tools and helpline were still not available.

AN suggested that, as all localities are engaged in this audit, that it would be good to hold a regional event to share good practice, experience and challenges around the audit and findings. The Group agreed that as the survey results are expected in May 2019 a network event should be held in September 2019.

The link to the national audit can be found here

1.9 Locality Group visits

LW advised that these are ongoing. She had visited four groups to date and will have completed eight visits by the end of May 2018. This was proving to be a very worthwhile piece of work to help determine a recommended model for a locality meeting. She will feedback to the group once she has attended the meetings.

She had also found that there had been no input from mental health trusts into locality meetings she had attended. This was discussed and it was agreed that there should be mechanisms in place to feed appropriate information to the mental health Trusts. AC agreed to approach the mental health trusts – NTW, TEWV and Cumbria – to ask if they would like to join this Group. It was agreed that the Terms of Reference could be adapted to reflect this. **AC/LW**

1.10 Engagement with STPs

AC advised that the STPs have now merged into one Accountable Care Partnership (ACP) and that AC and LW are establishing links with relevant work streams in order to ensure palliative and end of life care is included as apriority on their agenda. The meetings include:

- Clinical Network Managers of the various work streams
- Dr Rajesh Nadkarni and Anne Moore, Mental Health STP leads.
- Attended and contributed to the regional Mental Health STP event
- Stephen Childs, Senior Responsible Officer for Cancer work stream
- Joanne Dobson, Urgent and Emergency Care Lead.

1.11 Bereavement Survey

This had been circulated to localities to cascade to GP practice end of life leads. The purpose is to look at the current provision and gaps in bereavement services. To date 62 replies had been received. To help calculate the level of response, AC asked those around the table to let her know the total number of GP practices in their locality. **Locality reps**

2 AGENDA ITEMS

2.1 Project update

- **Deciding Right project**
- **Care for the Dying Patient Regional Documentation**

ML thanked those around the table for helping him to gather information and evidence for these projects although he was still planning to meet others. He advised that some common themes were starting to emerge.

He is currently planning Focus Groups involving community, district and ward nurses and he advised that he may be back in touch with the Group to ask for contact information for the appropriate people.

He still needs to get feedback from social care. VP offered to help with this and agreed to have a conversation with ML outside of the meeting to move this forward. He is also attending the care home provider forum to engage care homes in the project.

AC advised that the outcomes of both projects will be shared at the sharing good practice event being held on 17 July and thanked Mel for today's informative update.

2.2 National and Regional Work Plan update

See section 2.6

2.3 EPaCCs update

KH advised that contracts with BlackPear IT Solution had been signed recently. A standardised dataset is now in place but constraints mean that the data must be condensed more than originally intended. Although no results are available yet, she confirmed that good progress has been made.

Project BlackPear has requested the title EPaCCs continues to be used; however there is a view regionally that it should be called Palliative Care Plan. KH asked for views on this. This was discussed and it was agreed that as patients will not know what EPaCCs is that it should be called Palliative Care Plan.

Standardisation of data set: KH asked about the long term review of this data set. She would prefer it to sit with the Network rather than with any one individual. The Group discussed this and agreed that it should sit with the Network and be reviewed biannually.

2.4 Paediatric Palliative Care

JT advised that she had taken over from Yifan Liang as the Paediatric Palliative Care representative on the Group. She advised that a national scoping exercise is being undertaken to address gaps and variation in service and the outcome of the recent bid for financial support is still being considered. Adult palliative care services continue to support paediatric palliative care colleagues as per local informal agreements and until a substantive arrangement has been reached; however it was recognised that this is not a long term solution.

2.5 End of Life Care Profiles – NHS

AM advised that the data being shared with the Group today can be found on the Public Health Fingertips website. The most current data available is from 2016 (published in February 2018). AM advised that the data could be used to do some benchmarking of deaths in hospitals/at home/in residential and nursing homes.
It was also agreed that, as the figures are dependent on the number of homes, hospices and beds in each locality therefore there is a need to understand the locality well to get a true reflection of the figures. It was agreed that this information be shared at one of the Group's twice yearly sharing of information events to locality and

CCG areas in order to share best practice.

A copy of AM's presentation will be circulated with the minutes of this meeting. **AM**

2.6 NHSE update from face to face meeting on 8 February 2018

LW advised that although there had been some structural changes at NHS England, the regional work plan and deliverables will remain in place. There is a proposal to add additional deliverables around increasing the numbers of people who have a Personalised Health Budget, and reducing the number of people who have had three or more admissions to hospital in the last 90 days of life.

She advised that funding for End of Life work remains in place through to end March 2019 but that no information is available on funding from April 2019 onwards.

She thanked the Group for their contributions to the last regional report which had been submitted to the national team.

2.7 Dying Matters

AM explained that there had been a small budget made available to get Dying Matters packs printed for each locality and hospices. AM/LW will be putting the packs together and distributing them to Group members. It will then be for the localities to decide how this information is disseminated.

2.8 Impact of financial constraints on palliative care services

AN suggested that the network advise the national team about financial constraints and the challenges they cause across localities. AC/LW agreed to do this and asked the localities to let them know of any financial challenges in order to feed back to the national team. **AC/LW**

2.9 e-ELCA
https://www.e-lfh.org.uk/wp-content/uploads/2018/02/Social-Care-Access-FINAL.pdf

LW advised that this is a good educational resource although recently published national data indicated that the northern region is one of poorest users of e-ELCA resources, especially care homes.

VP agreed to share this link with the Local Authority regional network. **VP**

2.10 End of Life Diabetes Care
Clinical Care Recommendations 3rd Edition March 2018

JB advised that these new guidelines had now been published. They are a useful resource and include some good algorithms including around nutrition and feeding. This guidance still reflect the information in the NECN Palliative and End of Life Care Guidelines 4th Edition 2016; Diabetes management at end of life Page 21. These have been uploaded on to the Network website, the link to which is here

3 STANDING ITEMS

3.1 Clinical Governance Issues:

- **Midazolam**
- **Items which should not be routinely prescribed guidance**

Midazolam: the Group were advised of a clinical incident in Cumbria that arose because different strengths of the drug are available. Discussion ensued and it suggested that Trusts could be contacted individually to share clinical governance and safe practice arrangements around this issue.

Items which should not be routinely prescribed guidance: This guidance to CCGs was published in December 2017 to support them to fulfil their duties regarding appropriate use of prescribing resources. Localities were asked to cascade the recommendations in this report. It was noted

- Immediate release Fentanyl – maybe prescribed for palliative patients if SPC MDT/Palliative care specialist supports decision.
- Lidocaine plasters – only for refractory post herpetic neuralgia
- Oxycodone/naloxone combination (targinact) – not supported.

3.2 Any Other Business

AP advised that she is struggling to make progress in establishing the use of SC sodium valproate and SC levetiracetam (Keppra) in the rare occasions where these are preferable to SC midazolam in managing seizures at the end of life. AC suggested taking this issue to the next meeting of the Northern Region Palliative Care Physicians Group for further discussion. **AC**

Sage and Thyme: MM advised that Newcastle Hospitals currently have four facilitators who are providing training both in-house and across the Network. As this is now causing issues with regard to the time taken to do external training it was agreed that LW would explore the history of Sage and Thyme in the region and the Clinical Networks expectations for the future. **LW**

DNACPR forms: ST informed the Group that following a paramedic clinical incident, Dr Matthew Beattie, NEAS had now issued a letter which confirms that Frailty, Dementia or Old Age can be written on a DNACPR document as appropriate reasons why CPR would not be successful. It was agreed that a copy of his letter would be circulated with these minutes. **AC/LW**

RCGP Webinar 16/05/18 13:00 -14:00:

- How practices can use the patient online record access to support end of life care
- How it can help family members or carers support the patient's end of life.
- Understand where patient online record can complement EPaCCs.

My Future Wishes: This was published April 2018 by NHS England and Alzheimer's Society. The link to this publication can be found here

3.3 Date and time of next meeting

17 July 2018 – Sharing Good Practice event full afternoon

LW proposed that the Network would like to hold two sharing good practice events – the first held on the afternoon of 17 July and a full day event later in the year; the group agreed this proposal.

4 MEETING CLOSE