

SUPPORTIVE, PALLIATIVE AND END OF LIFE CARE CORE GROUP

1pm – 3pm on Tuesday 17 October 2017

Emirates Stadium, Chester-Le-Street ,County Durham. DH3 3QR

Present	Alexa Clark, Northern England Clinical Networks	AC
	Andrew Copland, HAST/Darlington CCG	ACo
	James Ellam, St Oswald's Hospice	JE
	Florence Gunn, Sunderland CCG	FG
	Kathryn Hall, North Tyneside CCG	KH
	Keith Kocinski, Scarborough & Ryedale CCG	KK
	Adrienne Moffett, Northern England Clinical Networks	AM
	Alex Nicholson, South Tees NHS FT	AN
	David Oxenham, County Durham & Darlington NHS FT	DO
	Julie Patten, North of England Critical Care Network	JP
	Teresa Storr, Cumbria NHS FT	TS
	Chris Walker, Patient Representative	CW
	Louise Watson, Northern England Clinical Networks	LW
	Kirsty Wright, South Tyneside NHS FT	KW
Apologies	Jane Bentley, North Tees & Hartlepool NHS FT	JB
	Sheila Brown, Patient Representative, NECN	SB
	Maureen Evans, Northumbria Healthcare NHS FT	ME
	Eleanor Grogan, Northumbria Healthcare NHS FT	EG
	Alison Featherstone, Northern England Clinical Networks	AF
	Daniel Haworth, NEAS	DH
	Alison Kimber, NEAS	AK
	Matthew McCloskey, South Tyneside CCG	MMc
	Michelle McKidd, Northumbria Healthcare NHS FT	MMcK
	Michelle Muir, Newcastle upon Tyne Hospitals NHS FT	MM
	Pam Ransom, Northumbria Healthcare NHS FT	PR
	Kay Smith, Hambleton, Richmondshire & Whitby CCG	KS
	Paula Swindale, Hartlepool & Stockton CCG	PS
	Barbara Wells, NEAS	BW
In attendance	Naomi Tinnion, Northern England Clinical Networks	NT

MINUTES

	Action
1. INTRODUCTION	
1.1 Welcome and apologies	
AC welcomed everyone to the meeting and introduced herself as the new End of Life Clinical Lead for the Network. The above apologies were noted.	
1.2 Declaration of interest	
There were none to declare.	
1.3 Minutes of previous meeting	

These were accepted to be a true reflection of the meeting. The outcome from the discussions in the meeting regarding the ReSPECT document and Deciding Right has led to the Northern Clinical Networks producing the following position statement: Deciding Right will continue to be used across the region.

1.4 Action points from minutes of previous meeting

Audit Group: as only one volunteer had so far come forward it was agreed to put this on hold for the time being due to pending projects discussed in agenda item 2.1.

NEAS EoL ambulance service flyer: this had now been updated to include the times during which this service is available.

1.5 Locality Groups/Model and Terms of Reference

AC advised that the purpose of this agenda item is to ensure the right people are coming along to these meetings and that information is being shared with locality groups.

Locality Groups: a discussion took place around how these vary across the region. Information from these meetings is fed into the groups however it was noted that:

- Attendance and representation at some is very robust whilst attendance at others is inconsistent;
- Some Groups are not as proactive as others when it comes to implementing change.
- More providers than commissioners attend which means fewer commissioning issues are discussed;
- Some providers are using funding to resolve issues (eg staffing) themselves because of their frustration at the lack of action by CCG locality groups.

It was agreed by the Group that it would be good for LW to undertake a series of visits to the locality groups to explain the role of this Group and the importance of working together and sharing good practice and information. AN suggested that it would be good for her to take examples with her of what a robust group looks like, what they are achieving and some examples of the work and achievements of this Group.

Terms of Reference: LW advised that these had been written in 2016 and needed to be updated to reflect the changes which had happened since then.

It was agreed that membership should be extended to include a wider range of grades and organisations including:

- Voluntary Sector – Hospice UK, Marie Curie, Macmillan, Help the Aged etc
- Paediatrics
- NECS
- Critical Care Network
- Commissioning and locality representative

LW/NT

ALL

- Learning Disability Network
- IT Group

It was agreed that the contact information for this Group be recirculated for updating where appropriate.

NT
ALL

It was also agreed to keep both the Core and Network Groups in place until the locality groups are operating more effectively.

1.6 Regional Deciding Right Education Group – update

LW advised that the Group continues to meet. They have signed off the public facing powerpoint which has been uploaded onto the NECN website. This has been tested with patients and carers and one area have proposed this may be used in GP Practices. The Group are looking at providing some example advance statement documents from across the region to located on the Deciding Right website. The group suggested having good example documents as a useful resource. LW agreed to take this suggestion back to the Group for discussion.

LW

DO advised that one of the outcomes from a recent CQC visit was that “best interest” was the least understood phrase within CDDFT. There is an assumption that Trusts do their own mental health capacity and DoLS training but as this doesn’t happen he asked if the Deciding Right resources could be used to design something more specific for best interest conversations. Perhaps this could include a worked example and/or a case scenario. KH advised that mandatory training does now cover best interest conversations as these are not just relative to palliative care.

LW agreed to take this back to the Education Group to discuss how to have more robust arrangements in place.

LW

2. SPECIFIC ISSUES ARISING

2.1 Network Update New Clinical Lead Delivery Team Lead uplift in resources Project focused work x 2 secondments

AC advised that she is the new Network Clinical Lead for End of Life Care and that she will be devoting half a day per week to this role. LW advised that the Network had received some additional funding which meant she can now spend two days per week in her role, allowing her to take on some additional tasks.

Two project focused lead posts have been advertised. One is to scope out how the Deciding Right documentation has been embedded across the region. The second post is to look at the Regional Care for the Dying Patient documentation and scope out where this is being used in the region and, where it is not being used why, and what is being used in its place. Both projects are time limited, one day per week posts. Interviews for these posts are being held at the end of October. There will be an update on these projects at the January meeting and sharing of learning from both at the half day event planned for April 2018.

2.2 National and Regional Work Plan update

STP workstream alignment work is underway. A meeting has been held with the Network's Associate Director to discuss the way forward for End of Life Care and how to engage with the STPs. Some national support will be made available to help with this engagement work.

The Northern Region has been invited to offer suggestions for an event on 31 January 2018 to engage with STP leads. There will also be an opportunity at this event to showcase some examples of good work. Two examples suggested so far include the NEAS End of Life Service and the EPaCCs project. If anyone has any other suggestions can they please send them to LW at louise.watson@stft.nhs.uk

ALL

LW advised that a bi-monthly update has to be submitted to the national team which provides the opportunity to share information based on the 4 key deliverables set by NHS England National End of Life Care Team. However as no information had been received from Cumbria TS asked for Cate Swift be included on the distribution list for any requests for information.

LW

Agreement was reached to share the key deliverables with all representatives.

LW agreed to circulate a request for information ahead of each bi-monthly report. submission dates for and a template of the Regional report is provided below:

Any information from localities is welcome in line with the 4 Key Deliverables which includes the sharing of good practice.

Regional Report Submission Dates:
Week Beginning 13th November 2017
Week Beginning 15th January 2018
Week Beginning 12th March 2018
Week Beginning 14th May 2018
Week Beginning 9th July 2018
Week Beginning 10th September 2018
Week Beginning 12th November 2018

2.3 EPaCCs update

KH advised that funding had been secured to help support the EPaCCs work. The Steering Group had met twice and identified a couple of workstreams – Data and Comms and Engagement. The Data Group had developed a refreshed dataset and all IT codes will have a commonality from April 2018. The Group are also looking at who should input this data.

The Group have also been looking at an issue that Northern Doctors Urgent Care (NDUC) and NEAS have around having the ability to know if a GP will certify the death of a patient and how this can be captured as an EPaCCs requirement. Information on this will be circulated once the issue has been resolved.

KH advised that EPaCCs had commenced in North Tyneside and hopes that it will be rolled out across the region. The Group are working on how to standardise the way data is collected. Governance issues are also being looked at. Both Groups are on track to meet their quarterly outcomes for the EPaCCS project.

KH offered to come out to individual Trusts to discuss the implementation of EPaCCs across the region. If anyone would like a visit please contact her at kathryn.hall@nhs.net

KH advised that the EPaCCs project is being showcased at the Great North Care Record event on 28 November at Newcastle Racecourse. Tickets, if they are still available, can be obtained via the following link:
<https://www.eventbrite.com/e/great-north-care-record-network-launch-tickets-36482719797>

2.4 NEAS

- **Macmillan End of Life Care Service Launch**
- **Special Patient Notes form**

Macmillan end of Life Care Service Launch: AC advised that NEAS have received Macmillan funding to fund the service. There are three posts – admin support, an engagement officer and a Macmillan Nurse Facilitator (hosted by Gateshead Health NHS FT). A lot of engagement work has been undertaken by NEAS to improve their services and thanks from the Group go to Dawn Orr for her contribution to this piece of work; Dawn's secondment opportunity to NEAS has now finished.

Special Patient Notes form: as comments had been received that the current document on the Deciding right website is not fit for purpose for palliative care, NEAS have asked for it to be removed and replaced with a new special patients notes form.

KH advised that the Great North Care Record team are working with NEAS on the Special Patient Notes form to ensure the information on this is consistent. Another issue is that the current paper document has to be completed and then emailed so completion is not happening. However this will continue to be used until a new system is in place.

The Group agreed that the new form needed to be electronic, short, concise, easy to complete and pre-populated where possible to ensure it is used effectively. It is hoped that it will be linked up with the palliative care register. KH advised that NEAS have a time restriction of one year for keeping forms on their system.

The issue with the two versions of SPN forms requires further discussion and LW agreed to contact NEAS to offer the opportunity to share the comments with the group as NEAS weren't represented at this meeting.

LW

2.5 STP Regional Event January 2018 led by NHSE Regional STP data packs – NHSE

Discussed under item 2.2

2.6 Deciding Right App NHS Digital ReSPECT

AC advised that the Deciding right app is currently jointly owned by St Oswald's Hospice and the Network (who own the digital rights). NHS Scotland has

expressed an interest in taking over the ownership rights and to make appropriate changes to make it applicable to Scotland. AC advised that St Oswald's are happy to change ownership and asked the Group for their views on this. After a discussion it was agreed that the Group is happy for St Oswald's to change ownership but that joint ownership must remain between NHS Scotland and the Network.

2.7 National Audit for Care at End of Life

LW advised that an audit will be undertaken of Care at End of Life of hospital patients. This contract has been given to NHS Benchmark and awarded for three years. For the first time carers and staff will be included in the audit. This is currently for hospitals only but may be extended to the community. The Clinical Networks are encouraging Trusts to get involved.

Once the results are known of this audit a learning and sharing event will be held to discuss the outcome. The Care for the Dying Patient project will precede this piece of work.

AN advised that the data from the South Tees audit is to be shared with consultants to inform them of the progress made from 2013-2015. KH advised that Northumbria Healthcare are about to start their audit.

2.8 Death in Usual Place of Residence (DIUPR) data

LW advised that this data is now available on the national EoL intelligence network website and can be found via the following link: http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

2.9 OOHs advice line

A 24 hour advice line for patients with a single point of contact was raised as an issue in the Summer meeting and has been raised again as an issue. AC asked the Group for their views on this. The Group discussed this and agreed that it would work for the larger Trusts where there are sufficient consultants in place to provide 24 hour advice but that smaller Trusts would struggle. It would therefore be better to have one properly commissioned system in place across the whole network - the Gold Line in Airedale is a good example of a successful service, details of which can be found [here](#)

It was agreed that LW would ask for volunteers to join a Task and Finish Group to scope out what is already in place, what is required and what the costs would be to set up and run an advice line. This could then be taken to the Northern CCG Forum for discussion. DO, TS, JP and AP agreed to help take this piece of work forward. KH agreed to contact Eleanor Grogan to ask if she would be happy to get involved too. CW advised that he would be happy to get involved from a patient's point of view at an appropriate point in the project. AC and LW agreed to discuss how to progress this outside of the meeting and come back to the Group.

LW

KH

AC/LW

3. STANDING ITEMS

3.1 Clinical Governance Issues

There were none.

3.2 LW provided an update from face to face meeting NHSE on 20 September 2017

- Care after Death scoping work ongoing
- NICE quality standard for end of life care for infants, children and young people – <https://www.nice.org.uk/guidance/qs160>
- Age UK and Malnutrition Task Force (MTF) booklet and accompanying animation – <http://www.ageuk.org.uk/latest-news/dying-wishes/>
- Consultation guidance for CCGs: items which should not be routinely prescribed. Consultation period closes on 21 October 2017 <https://www.engage.england.nhs.uk/consultation/items-routinely-prescribed/>

LW advised that she had included these links on the agenda for information and interest.

3.3 Any Other Business

AC advised that the Network had been alerted to a shortage of 10mg per ml of morphine and were asked for advice on how this is being dealt with across the Network as this affects more than palliative care patients. KH advised that Northumbria Healthcare had drafted some guidelines on this which she is happy to share once finalised. NECS pharmacy team had prepared some guidelines which will also be circulated around the Group as soon as they become available.

KH/AM

KK asked for advice on a combined Child and Young Person's Advance Care Plan and ReSPECT Form which is being developed by the National Child and Young Person's Advance Care Plan Collaborative and promoted within Yorkshire and Humber by the Yorkshire and Humber Children's Palliative Care Network. He expressed concern about this as, by combining the two, it implies that organisations may be able sign up to ReSPECT for children only. When in fact, if an organisation signs up to adopt the ReSPECT Process it covers both Children and Adults. He asked if anyone in the North is aware of this a combined Child and Young Person's Advance Care Plan and ReSPECT Form and whether the CYP network had agreed to adopt it.

AC confirmed that the Group had agreed not to adopt ReSPECT at their summer meeting and that only the local documentation be used. KK agreed to send an electronic copy of the document to AM so that she could discuss this with Yifan Liang and ask for advice. LW to share.

**KK
AM**

3.4 Date and time of next meeting

Tuesday 16 January 2018 at Evolve (1-3pm)

Tuesday 24 April 2018 at Evolve (full afternoon event)

4. MEETING CLOSE