

**SUPPORTIVE, PALLIATIVE AND END OF LIFE CARE CORE GROUP**

1pm – 3.30pm on Tuesday 16 October 2018

Chester-le-Street Cricket Club, Ropery Lane, Chester-le-Street, DH3 3PF

<b>Present</b>	Alexa Clark, (Chair) Northern England Clinical Networks	<b>AC</b>
	Adrienne Moffett, Northern England Clinical Networks	<b>AM</b>
	Louise Watson, Northern England Clinical Networks	<b>LW</b>
	Jane Bentley, North Tees & Hartlepool NHS FT	<b>JB</b>
	Andrew Copland, Hartlepool and Stockton CCG	<b>AC</b>
	Ruth Frostwick, Sunderland CCG	<b>RF</b>
	Kathryn Hall, North Tyneside CCG	<b>KH</b>
	David Hand, North Durham/Durham Dales, Easington & Sedgefield CCG	<b>DH</b>
	Michelle Muir, Newcastle upon Tyne Hospitals NHS FT	<b>MM</b>
	David Oxenham, County Durham & Darlington NHS FT	<b>DO</b>
	Ann Paxton, South Tyneside NHS FT	<b>AP</b>
	Angela Ridley, Tees, Esk and Wear Valley NHS FT	<b>AR</b>
	Trish Sealy, South Tees Hospitals NHS FT	<b>TS</b>
	Sarah Turnbull, North East Ambulance Service	<b>ST</b>
	Christine Ward, South Tees NHS FT	<b>CW</b>
Kirsty Wright, Sunderland Locality	<b>KW</b>	
<b>Observers</b>	Rachel Kiltie, Palliative Medicine Specialty Trainee	<b>RK</b>
	Kerry Waterfield, Palliative Medicine Specialty Trainee	<b>KW</b>
<b>Invited Speakers</b>	James Ellam, St Oswalds Hospice / Hospices North East	<b>JE</b>
	Simon Gordon, St Oswalds Hospice / Hospices North East Lynne Barr, Advancing Potential	<b>SG</b> <b>LB</b>
<b>Apologies</b>	Nousha Ali, South Tyneside NHS FT	<b>NA</b>
	Sheila Brown, Patient Representative, NECN	<b>SB</b>
	Jayne Denney, Cumbria Partnership NHS FT	<b>JD</b>
	Alison Featherstone, Northern England Clinical Networks	<b>AF</b>
	Melanie Fogg, Gateshead Health NHS FT	<b>MF</b>
	John Hancock, Hambleton, Richmondshire & Whitby CCG	<b>JC</b>
	Keith Kocinski, Hambleton, Richmondshire & Whitby CCG	<b>KK</b>
	Alan Maguire, Northern Doctors Urgent Care	<b>AM</b>
	Alex Nicholson, South Tees NHS FT	<b>AN</b>
	Juliet O'Neill, Northern Doctors Urgent Care	<b>JON</b>
	Dawn Orr, Gateshead Health NHS FT	<b>DO</b>
	Julie Platten, North of England Critical Care Network	<b>JP</b>
	Kay Smith, Hambleton, Richmondshire & Whitby CCG	<b>KS</b>
	Teresa Storr, Cumbria NHS FT	<b>TS</b>
	Jocelyn Thompson, Childrens Palliative Care Forum	<b>JT</b>
Chris Walker, Patient Representative	<b>CW</b>	
<b>In attendance</b>	Naomi Tinnion, Northern England Clinical Networks	<b>NT</b>

## MINUTES

	Action
<p><b>1 INTRODUCTION</b></p> <p><b>1.1 Welcome and apologies</b> AC welcomed everyone to the meeting and introductions were made around the table. The above apologies were noted.</p> <p><b>1.2 Declaration of interest</b> There were none to declare.</p> <p><b>1.3 Minutes of previous meeting</b> These were agreed to be an accurate reflection of the meeting. AC advised that draft minutes will be circulated within two weeks of each meeting for comment. A nil response will be taken as agreement that the minutes are correct. The final version will then be circulated within a month of each meeting for distribution to localities.</p>	
<p><b>2 ACTION POINTS FROM PREVIOUS MEETING</b></p> <p><b>a. Advice Line letter to locality groups</b> AC stated that a letter has been sent to CCGs to ask if any commissioned services were in place. AC will bring responses received to a future meeting. She asked those around the table to encourage their locality group to respond to her letter. A subsequent Survey Monkey has been created to capture the feedback from all localities.</p>	<b>Group</b>
<p><b>b. NEAS – Special Patient Notes form V2 (August 2018)</b> LW advised that the Clinical Networks had worked collaboratively with NEAS on updating the form. The form has been circulated widely and should be used to inform NEAS about all special patients, including palliative care patients. ST advised that some forms are being received by NEAS but that it would be good to do a comparison across localities in six months to find out if more forms had been received.</p>	<b>ST</b>
<p>KH advised that NEAS is happy to share data on number of forms received as part of the EPaCCS project.</p>	<b>KH</b>
<p><b>c. Mental Health Trust invitations to join SP&amp;EOL Regional Group</b> AC advised that she had written to both Mental Health Trusts to invite them to become members of the Group. She thanked AR from TEWV trust for attending today’s meeting and informed the Group that she is in touch with NTW trust about their representation.</p>	
<p><b>d. Deciding right update</b> AC advised that she had received some concerns that the wording on the NECN website and Deciding right app around Deprivation of Liberty Safeguards (DoLS) and Lasting Power of Attorney is incorrect although this could be due to the information being open to misinterpretation. AC advised that the Network is in contact informally with legal representation to seek advice on this.</p>	<b>NECN</b>

MM advised that there are some legal companies touting for business to help with the completion of forms and that efforts are being made to let people know free help is available from NHS staff to complete the form. It was discussed that patients/families can use online resources to complete LPAs, without the need to get legal assistance.

The app will have to be updated when the Mental Health Capacity Act is updated and DoLS amended in 2020.

**e. Sage and Thyme**

LW confirmed that there is no formal expectation from the Network to support Sage and Thyme as Macmillan hold the regional licence. There were some informal arrangements in place to support organisations across the region to facilitate S&T training; this continues with more organisations getting their own licences as well. The Network is hoping that these informal arrangements can continue to ensure the smaller organisations would not be disadvantaged to deliver the S&T training. LW shared an example from South of Tyne patch where, over time, Macmillan has supported additional facilitators to be trained to maintain the ability to fulfil the requirement of sessions within the licence.

MM advised that although this training is facilitated by palliative care within her organisation, it would be good to encourage cancer nurses to facilitate training too.

**f. DNACPR forms – urgent bulletin June 2018**

LW reiterated the information contained in the June Urgent bulletin about the latest versions of the DNACPR forms. She explained that the e.fillable form remains the same version 17 and that the printable form is version 17a. There is also now an updated copy document available (also version 17a) which has a ‘copy’ watermark (rather than the previous ‘invalid’ watermark) and an updated strapline.

The Group advised that NEAS had recently challenged DNACPR documents in practice. ST agreed to look into these issues and providing education to paramedics. ST will feedback to the Group any ongoing issues.

ST

Version control remains an issue as versions 15 and 16 are still being used in some places, despite version 17 being introduced in 2015. NEAS have asked for the tightening up of version control and will therefore only accept Version 17 and 17A after the end of December 2018. Group to affirm in localities

Group

LW also confirmed that NEAS will not accept version 16 with a GMC number added as version 17 and 17a also includes wording which fulfils the requirement of the Tracey ruling from 2014.

AR asked for a copy of this bulletin to be sent to her so that she can cascade the information to the appropriate people in TEWV. NT agreed to send this to her.

NT

**3 AGENDA ITEMS**

**3.1 Network update**

- **Project Report and Executive Summary**
  - **Feedback from Localities – next steps**
  - **Regional Advance Statement**
  - **Caring for the Dying Patient Guidance v2**

- **Locality Group visit summary**

Project Report and Executive Summary: LW advised that the main report contains a breakdown of results and RAG ratings by locality of the work undertaken by Mel Laycock. This had been discussed at the July event where localities were asked to look at their next steps and actions in September 2018, November 2018 and January 2019. LW then asked each locality to give an update on these:

### **Durham and Darlington**

Deciding right:

- Still awaiting metrics from their business information team.
- Quality Lead is looking to take the six steps approach – this will be discussed at meeting later in the week
- Other benchmarks will be progressed as planned

Caring for the Dying Patient document:

- An event is being held on 12 November where feedback will be received from the Family Voices survey. This will be used to inform the approach they will take with regard to this documentation.
- The Trust is looking at prescribing on SystmOne of drugs prescribed at end of life

### **South Tees**

Deciding right:

- Locality work had halted but is starting to move again and the Trust is resuming again in regard to embedding Deciding right.

Caring for the Dying Patient document:

- The ARDENS system in South Tees allows GPs to prescribe from SystmOne and allows links to templates which contain the Caring for the Dying Patient documentation.
- Community nurses are on SystmOne so have a paperless system in place although they still need to complete paper documents when out and about.
- The Trust has completed the national audit so there may be something from these results that they can use to achieve their milestones.
- Hambleton, Richmondshire & Whitby don't have an End of Life Group in place or electronic prescribing which means staff working across these Trust areas and South Tees do have some issues.

### **Newcastle**

Deciding right:

- They have a Deciding right Steering Group in place, membership of which includes Newcastle Hospital staff, patient representatives and CCG representation.

- Work is being done to finalise education packages for staff. They also have a patient video (adapted from the Network Deciding right video) which is to be shown on a loop in the out-patients to help encourage people to ask questions of their professionals. They are also raising staff and public awareness of Deciding right.

Caring for the Dying Patient document:

- Trust M&M meetings have been used to make staff think more about Caring for the Dying Patient and ensuring a person has a 'good death'.
- The team have been asked if they can get involved in reviews of Learning Disability deaths to determine whether the quality of death could have been better. A joint NTW/NUTH quality meeting has been set up to discuss shared care. End of Life care is a standard agenda item for these meetings.
- Caring for the Dying Patient document is now used in the hospital and community. However the Trust is going 'paper-lite' so are looking to make end of life documents available electronically whilst ensuring they are printable and recognisable for those who do not share electronic records – half of GPs are on EMIS, half on SystmOne; all community nurses, palliative care teams and hospices on SystmOne.

KH suggested there be some quality control over these documents to ensure they are no longer than four pages long and are writable to encourage them to be completed.

**North Tees & Hartlepool**

Deciding right:

- The Trust has been unable to look at the detail of Deciding right as they have been focusing on other priorities.
- DNACPR forms can now be signed by nurses and senior AHPs (acting as senior clinicians) rather than just by doctors. ST confirmed that NEAS are happy for nurses and AHPs to sign forms provided they have details of who these staff are and trust policies are in place to support this practice.

Caring for the Dying Patient document:

- It is Trust policy to use the CDP document for patients in the last days of life. It is not used by all GP practices in the community. It is used by Alice House Hospice and the Butterwick Hospice is planning to start using the document. During the recent NACEL audit it has been highlighted that for those patients for which the document was used it is much more likely for the details of care to be documented than for those in which the document is not used.

**South Tyneside**

Deciding right:

- As part of their strategic development plans they have now got four work streams in place, which includes education and Deciding right.
- Some rolling education has taken place and more is planned for November.

- Primary Care has accepted Deciding right well and are also completing EHCPs, although the quality of these does vary.
- The Trust has been awarded some funding to undertake further primary care training; a programme is currently being agreed.

Caring for the Dying Patient document:

- An audit of the use of this document is underway. Some GPs are reluctant to use this documentation so it will be interesting to see the outcome of the audit as, although patients are cared for, this care is not always being recorded in a standardised way without use of this documentation.

**Sunderland**

Deciding right:

- A lot of education has been done in the past and the Trust is now looking at ways of doing this differently.
- Their Business Intelligence team is gathering information from EMIS to determine how many GPs complete the Deciding right documentation. The Trust has some underspend so are hoping to do some further GP education around Deciding right.

Caring for the Dying Patient:

- The Trust is hoping to go paperless but have the same issue as other Trusts that their community nurses cannot access the electronic system. However they have a new GP in place who is keen on IT and having an electronic system in place. It was suggested that he link up with NUTH, Northumbria and Sunderland to move forward on this.

The action plans from Cumbria and Gateshead were available but not presented or discussed in the meeting as there was no representation from these localities. The Northern England Clinical Networks have not received completed action plans and next steps from North Tyneside and Northumberland localities therefore these could not be presented at the meeting.

LW thanked everyone for their updates and the progress made by each locality. It was agreed that this be included on the agenda for the January meeting for further updates.

Network Advance Statement (AS): this was discussed and the Group agreed that there was an appetite to have a Network AS in place. LW advised that the Deciding right Education Group will be working on developing this and, as this work develops, progress will be shared with the Group.

Network Caring for the Dying Patient Guidance v2: the 2015 Network guidance sheet has been updated and is available on the website. DO advised that he has updated the guidance for Durham and Darlington which he is happy to share with the Group.

Locality Group visits summary: LW advised that this summary highlighted the good practice of each group which will be used to develop a model that localities can adopt. The format and discussion topics of these meetings did vary quite widely

**Group**

**LW**

**DO**

although LW would like to see more translation of national priorities into these meetings. She agreed to share this summary with the Group and confirmed that she is happy to continue to attend locality group meetings.

Group

### **3.2 National and Regional work Plan update**

AC had attended the most recent national meeting and advised that some of the key points were:

- there continues to be a focus on groups with special needs including LGBT, homeless, gypsies and travellers;
- work has commenced on looking at commissioning models for TYP; this work will hopefully be published in March 2019.
- imminent survey (?Oct 2018) looking at availability and delivery of medicines out of hours
- NHS Improvement offering and providing support to trusts who were identified by CQC as inadequate or requiring improvement. Discussion ensued that this should be available to all trusts to help improve their care or maintain their high standard of care.
- NHS England is developing a 10 year plan, the main focus of which will be prevention through identification, planning, sharing of information, and integrated services wrapped around the patient. It is hoped that this will lead to more planned and less reactive personalised care for patients. They are also looking to achieve this by an increase in Personalised Care Plan, but currently discussing how outcomes will be measured.

AP asked if there were any plans to have a future regional event to share good practice. It was confirmed that a future event will be planned to look at results of the National audit (sharing methods of achieving success but also recognising and overcoming challenge faced). It was also suggested that it might be useful to have an event on recording and sharing information electronically. It was agreed that the Network would discuss options and confirm to the Group at a future date.

Regional workplan: LW advised that there are three national deliverables in place and that the regional workplan is to be updated in line with these deliverables. The draft will be shared with the Group for comment.

Group

### **3.3 St Oswalds Hospice Education Hub**

JE and SG delivered a presentation to update the Network on 3 strategic developments they are leading/involved with.

JE advised that three years ago the Hospice celebrated its 30<sup>th</sup> birthday by putting a 10 year vision in place. It decided that the best way forward was through collaboration with other hospices across the region.

#### Hospices North East

A collaborative has been established called Hospices North East which consists of ten hospices (St Benedicts and Marie Curie are not included) and is led by St Oswalds as they already have operational and governance structures in place.



This is not a merger or a legal body but it does have Terms of Reference. Their focus is to have consistent patient care and services across the region.

A training and education consortium has been set up so that one set of training takes place rather than ten.

HR has always been a single group across all of the hospices but they too are now looking to have one set of standards in place.

All volunteers are being kept informed of developments and what the collaborative wants to achieve.

Plans are being put into place to seek statutory funding for all hospices.

Great North Palliative Care Research Centre: SG explained that, as there isn't a Palliative Care research team between Leeds and Edinburgh, it has been decided to develop a research centre in the region. This should help retain staff within the region, improve patient care and enable local people to take part in research and development.

A regional Palliative Care Steering Group has been established and will be chaired by James Ellam. A new Research Associate will take up post in November. Their role will be to look at what is in place in other parts of the country and help develop a regional centre.

Northern Palliative Care Partnership: this currently includes Newcastle Hospitals, Northumbria Healthcare, Gateshead Health, Marie Curie and St Oswalds. As a charity, St Oswalds are considered best placed to get charitable funding to form a wider partnership. There will however be a need to agree how best to use any funding to move forward collaboratively.

Four programmes have been put in place to address the six ambitions of the NHS England framework. These are:

- Communication
- Service
- Prepared Professionals
- Prepared Communities

Prepared Professionals: this programme is about training staff at all levels, including care workers, staff nurses etc who may need upskilling if they don't often get involved in palliative care.

Prepared Communities: work is being done with Kath Mannix on this. Professor Julia Newton is also working with the team. As the work develops it is hoped to get more organisations involved. The team will ensure that there is no duplication of effort with other organisations across the region as their work progresses.

There has been engagement with senior representatives from the regional Intergrated Care Systems to share their work and visions.

JE confirmed that he is happy for his slides to be shared with all locality groups across the Network, whether or not they are involved in Hospice North East, as



regular conversations are held with St Benedicts and Marie Curie to keep them updated on the project.

AC and LW thanked JE and SG for joining today's meeting and for a very interesting presentation. It was agreed that they should be invited to a future meeting to keep the Group updated on progress.

### **3.4 EPaCCs update**

KH advised that the name of this project had been changed to The Palliative Care Plan. In North Tyneside over 1,000 patients are now on primary care palliative care registers and an integrated system is now in place which can be accessed 24/7 by professionals.

The Black Pear Electronic system is in place which allows data to be pushed and pulled through primary and secondary care systems and sends reports to NEAS and VOCARE. The standardised data share set has been updated so that all EMIS codes are compliant. Three weeks ago this system was tested in primary care where patient data was successfully inputted, amended and saved across two Trusts. The system isn't perfect but it is a massive step forward for the project. KH agreed to demonstrate the system at a future meeting of the Group.

LB explained that she had been appointed as Project Manager to keep the project moving and on time. The project included funding for formal evaluation to take place. This will focus on the effect and impact of staff pre and post project and what difference the new system has made.

LB has written a draft report which sets out the challenges, risks and experiences of those involved in the project. It also contains information on the role of the citizen focus groups and the consent challenges faced by the project. An information sharing agreement is in place for the pilot but a further information sharing agreement will be needed when the system expands into other Trust areas.

KH advised that this project has highlighted the strengths and weaknesses of various systems across the region and that there had been some difficult conversations along the way but that some good outcomes had been achieved.

LB advised that they have begun to future proof the project before both timing and funding runs out.

KH will be arranging a meeting of the EPaCCS reference Group and will advise members of the date once this has been agreed.

### **3.5 NECN Community Prescription Sheet**

AC advised that there is some uncertainty around whether and where the Network Community Prescription chart is used. It has therefore been agreed that a survey using Survey Monkey will be sent around the Group to map current usage of this chart. The Group will be informed of the results of this survey.

### **3.6 NECN website changes**

AM advised that it has been agreed NHS England will host all of the Clinical Network websites including Northern England and that these will transfer across in the near future. This means that any website updates will have to be done via the national team.

**Group**

However as the largest number of hits on the Northern England website are for Deciding right and Caring for the Dying Patient, the Northern Cancer Alliance (NCA) have agreed to host both on their website and include a page for this Group so that agendas and minutes can be uploaded. This will ensure that information can be updated as and when appropriate. The Group confirmed that they were happy for this to happen. The new website address will be communicated to the Group as soon as it is known.

### 3.7 NEAS End of Life Care Services

NEAS End of Life Care Services: ST advised that the Department for Health's End of Life Strategy published in 2008 had identified key roles for ambulance services. More guidance has since been published in 2012. ST has been appointed as the Macmillan End of Life Lead in NEAS and will be working as part of a small team to:

- Continue to develop and embed regional guidance with the aim of ensuring staff have the appropriate level of knowledge
- Ensure their Directory of Services is kept up to date
- Implement call handler training along with an EoL algorithm to help avoid hospital admissions. ST agreed to bring this algorithm to the next meeting of the Group
- Look at EoL transport and updating the whole booking process. Once updated the service will be relaunched
- Develop audits to ensure information gathered is both informative and of good quality
- Undertake a piece of work on complaints v compliments.

ST will continue to keep the Group updated on a regular basis on progress made in these various areas of work.

ST

Administration of s/c medication by NEAS: JB asked ST about EHCPs where District Nurses and paramedics are asked to give subcutaneous medication, and whether the paramedics would do so. ST stated that many paramedics are not trained to give SC medication so would be unable to administer this (although they are trained to give IM meds). She stated that current advice is that if there is an urgent need to give a subcutaneous injection then it is for staff to decide if they have the skills to administer.

ST

ST was requested to look at education for paramedics so that they were able to administer SC meds.

CW has delivered training on administration of SC end of life medication for YAS paramedics in H&R. This is now being cascaded throughout North Yorkshire

Instructions on DNACPR form of where patient should be transferred to if they die on route: JB described an incident related to a challenge for the patient, family and ambulance crew regarding information on the DNACPR form relating to transferring to their preferred place of care in case of deterioration. This was discussed and it

Group

was agreed that there needed to be better education on the completion of these forms.

**3.8 Patient use of non-prescribed Cannabinoil and hospice admission policy**  
To be added to the agenda for the next meeting of the Group.

## 4 STANDING AGENDA ITEMS

### 4.1 Clinical Governance Issues

Prescribing CSCIs in advance and prescribing ranges for CSCIs:

Prescribing of CSCIs in advance of being needed and prescribing of ranges for CSCIs was highlighted and criticised in the recently published Gosport Memorial Hospital report.

AC stated that she was aware that some localities in the Network discontinued this practice several years ago, but is not aware of current practice across the whole Network. In order to get a picture of current practice, AC will be sending out a survey using Survey Monkey to include prescribing across the Network and requested that all services within each locality complete individually and return to Naomi – [naomitinnion@nhs.net](mailto:naomitinnion@nhs.net) (see item 3.5). The results will be presented at a future meeting.

Group

Prescribing drugs to be mixed in syringe driver: AP took the opportunity to ask the group about the practice in each locality regarding mixing of medicines in syringe drivers. This has become an issue in South Tyneside as they have been informed that all prescribed infusions need specific instructions on mixing written on drug kardex, which has implications for current practice. AP would like to know what the practice is in other localities and, if there were any issues with this, how they were overcome.

It was agreed that this question should be included in the proposed survey on current prescribing (see item 3.5).

AC

**4.2 NHSE Update from face to face meeting on 13 September**  
Covered by item 3.2

## 5 ANY OTHER BUSINESS

Legacare conference: AC reminded everyone of this free event which is being held at St James Park on 8 November. Places can be booked via Meg Kirby - [mkirby@legacare.org](mailto:mkirby@legacare.org)

Fingertips data: AM advised that this included information on a range of topics and agreed to circulate a copy with the minutes of this meeting.

## 6 DATE, TIME AND VENUE OF NEXT MEETINGS

13.00-15.00 on 8th January 2019 at Evolve Business Centre

13.00-15.00 on 5th March 2019 at Evolve Business Centre

## 7 MEETING CLOSE