

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

1pm – 3.30pm on Tuesday 11 July 2017

The Durham Centre, Belmont Industrial Estate, Durham, DH1 1TN

<b>Present</b>	Victoria Ashley, St Teresa's Hospice	<b>VA</b>
	Julie Barnsley, North Tees & Hartlepool NHS FT	<b>JB</b>
	Lynne Barr, Advancing Potential Un Limited	<b>LB</b>
	Jane Bentley, North Tees & Hartlepool NHS FT	<b>JBe</b>
	Sheila Brown, Patient Representative, NECN	<b>SB</b>
	Alexa Clark, Newcastle upon Tyne Hospitals NHS FT	<b>AC</b>
	Joe Cosgrove, Newcastle upon Tyne Hospitals NHS FT	<b>JC</b>
	Denise Crawford, Willow Burn Hospice	<b>DC</b>
	Sheila Dawson, St Teresa's Hospice	<b>SD</b>
	Maureen Evans, Northumbria Healthcare NHS FT	<b>ME</b>
	Alison Featherstone, Northern England Clinical Networks	<b>AF</b>
	Paul Frear, South Tyneside Foundation Trust	<b>PF</b>
	Lindsay Garcia, South Tees NHS FT	<b>LG</b>
	Maureen Gordon, North East Ambulance Service	<b>MG</b>
	Eleanor Grogan, Northumbria Healthcare NHS FT	<b>EG</b>
	Florence Gunn, Sunderland CCG	<b>FG</b>
	Kathryn Hall, North Tyneside CCG	<b>KH</b>
	Caroline Harper, Gateshead Health NHS FT	<b>CH</b>
	Mark Hodgson, Hambleton, Richmondshire & Whitby CCG	<b>MH</b>
	Marc Jones, Advancing Potential Un Limited	<b>MJ</b>
	Alison Kimber, North East Ambulance Service	<b>AK</b>
	Yifan Liang, Paediatric Palliative Care Network	<b>YL</b>
	Alison Marshall, St Teresa's Hospice	<b>AM</b>
	Robin Mitchell, Northern England Clinical Networks	<b>RM</b>
	Adrienne Moffett, Northern England Clinical Networks	<b>AMo</b>
	Diane Monkhouse, South Tees NHS FT	<b>DM</b>
	Michelle Muir, Newcastle Hospitals NHS FT	<b>MM</b>
	Alex Nicholson, South Tees NHS FT	<b>AN</b>
	Ann Paxton, South Tyneside Foundation Trust	<b>AP</b>
	Henry Pearce, St Oswalds Hospice	<b>HP</b>
	Julie Platten, North of England Critical Care Network	<b>JP</b>
	Rachel Quibell, Newcastle upon Tyne Hospitals NHS FT	<b>RQ</b>
	Isabel Quinn, Northumbria University	<b>IQ</b>
	Pam Ransom, Northumbria Healthcare NHS FT	<b>PR</b>
	Melanie Robertson, City Hospitals Sunderland NHS FT	<b>MR</b>
	Sharon Rooney, South Tyneside Foundation Trust	<b>SR</b>
	Trish Sealy, South Tees NHS FT	<b>TS</b>
	Yuki Smith, Hartlepool & Stockton CCG	<b>YS</b>
	Claire Stocks, County Durham & Darlington NHS FT	<b>CS</b>
	Cate Swift, North of England Commissioning Support	<b>CSw</b>
	Chris Walker, Patient Representative, NECN	<b>CW</b>
	Barbara Wells, North East Ambulance Service	<b>BW</b>
	Caroline Wade, Eden Valley Hospice	<b>CW</b>
	Louise Watson, Northern England Clinical Networks	<b>LW</b>

<b>Apologies</b>	Jayne Denney, Cumbria Partnership NHS FT	JD
	James Ellam, St Oswalds Hospice	JE
	Daniel Haworth, North East Ambulance Service	DH
	Keith Kocinski, Scarborough & Ryedale CCG/Hambleton, Richmondshire & Whitby CCG	KK
	Sarah Loudon, Newcastle Gateshead CCG	SL
	Matthew McCloskey, South Tyneside CCG	MMc
	Lucy Nicholson, County Durham & Darlington NHS FT	LN
	David Oxenham, County Durham & Darlington NHS FT	DO
	Jill Smith, HEE NE	JS
	Tina Thompson, Macmillan Cancer Support	TT
	Ruth Ting, Gateshead Health NHS FT	RT
<b>In attendance</b>	Naomi Tinnion, Northern England Clinical Networks	NT

## MINUTES

### 1. INTRODUCTION

#### 1.1 Welcome and apologies

RM Chaired this meeting in the absence of a current Clinical Lead for the group. RM assured the group there was progress with securing a Chair for the future and information will be shared once there is more news to report. RM welcomed everyone to the meeting and introductions were made around the room. 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.

#### 1.4 Action points from minutes of previous meeting

Audit Group: to date there had only been one nomination received. LW encouraged others to nominate someone from their locality to join this Group and asked for names to be sent to her.

Locality Group roles and names template: as some of the Group had not received this for completion it was agreed to re-circulate it with a deadline for return.

Regional Directory: this had now been finalised and sent to NEAS who in turn had forwarded it onto NECS so that they have the appropriate up to date information to hand. LW thanked those around the table for their help to get this Directory up to date.

### 2. SPECIFIC ISSUES ARISING

#### 2.1 Regional Work Plan 2017-19 and update

LW explained that the work plan is written to reflect the national directive which covers 4 Key Deliverables for 2017-2019:

1. Support for STPs and Operational Plans
2. Electronic Sharing of EOL Information

Action

ALL

LW/NT

3. EoLC Commitment
4. Sharing Intelligence and sharing good practice

The Network are already working with the Emergency and Urgent Care Vanguard, the Cancer Alliance and locality groups but there is a need to look at how the Group can engage with STPs and link into the Mental Health Network.

Work continues on EPaCCs and Deciding Right across the region and discussions today will help determine the level of detail to be included in key deliverable 3 to further embed the EoLC commitment; where Deciding Right is intrinsic to the recommendations.

The Network will continue to encourage sharing of good practice across the region and continue to build on the good work and achievements of the Group.

LW asked for any comments on the workplan to be sent to LW/AM.

ALL

AM advised that she is still awaiting details of the national funding being provided to support the Network. It is likely that this funding will be increased which will enable the Network Lead to spend two days per week with the Network. AM asked the Group for agreement to allow LW/AM to decide how funding received can be used to the best advantage for the Group so that the funding can be allocated quickly to avoid losing it. This was agreed.

KH advised that a small element of this additional funding will be used to engage a second consultant to work on EPaCCs.

RM advised that it looked likely that the STPs will merge into one across the region. Their plans are currently at different stages – Cumbria's plan is currently out for public consultation; North Tyneside's plan will be going out for consultation this week and work remains ongoing on the Path to Excellence Programme in Sunderland and South Tyneside. It was suggested that the Group should invite STP representatives to a future meeting to give a more in-depth update.

LW/AM

## 2.2 EPaCCs update

KH provided an update. In March of this year the EpaCCS group applied for a bid from Connecting Health Cities, part of the Great North Care Record, to work within the region including North Cumbria to establish a regional solution with suitable intra-operable software for an EPaCCS.

The project was awarded the funding from Connected Health Cities from 1 June and the EPaCCs bid work has now started. There has been one core group meeting to date.

The EPaCCS bid is initially taking place within one trust site mostly across one CCG (North Tyneside) but with the intention of a very quick roll out across the region. The Bid is being hosted by Northumbria University who is doing a health economic evaluation of the work which will end in December 2018.

The work done to date with the regional Digital Programme and other digital work going on within the region regarding intra-operability including the MIG and the group is now part of this programme. This has included integration with the frailty programme work, the urgent and emergency care work on special patient notes for NEAS and OOH providers and primary care integrated programmes. The

project is working with the regional care home programme work to ensure it is embedded within this too. This work is ongoing.

Volunteers will be sought to move forward the workstreams currently being established.

KH agreed to keep the Group updated on progress. If anyone would like more information please contact her at [kathryn.hall@nhs.net](mailto:kathryn.hall@nhs.net)

**KH /  
ALL**

### **2.3 Deciding right – Regional Education Group update**

LW advised the group of the background information for this work to date. Deciding Right was implemented across the North East in March 2012 with each locality taking their own stance on its implementation.

Acknowledging that a lot of great work is happening across the region and that there is much more to do, St Benedict's Hospice education team were tasked from the Northern Clinical Networks (in April 2016) with bringing together a group of likeminded professionals to drive a standard approach to training and education for Deciding Right. The Regional Deciding Right Education Group began meeting in July 2016 and proposed the following:

- Developing a workbook in line with the eLearning resource: accessible electronically for health and social care staff;
- Develop a power point for use by the general public to increase their knowledge and understanding of Deciding Right;
- Facilitate a Deciding Right education group, which allows those who have responsibility for delivering Deciding Right education and training in their locality / organisation to come together;
- Where organisations / localities didn't have anyone delivering this, then this is a great opportunity and time to identify people who can lead on this work in the knowledge that the group will support those less experienced.

The group:

- Discuss and share good practice;
- Identify the educational methods which enhance the learning and development for 'Deciding Right';
- Agree a set of training materials;
- Consult on teaching and facilitator notes to support the training material;
- Receive an electronic teaching pack;
- Facilitate the implementation of Deciding Right education and training across their area of responsibility;

Completed educational resources had now been uploaded onto the new NECN website [here](#) :

- 1 hour awareness training pack is available with lesson plan, power point presentation and additional resources;
- The ELearning Module is also available and is being hosted by the North of England Commissioning Support (NECS);
- A workbook replicating the eLearning resource can be downloaded from the NECN website;
- A public facing PowerPoint on disc (with audio) is also available from members of the Education Group.

Pending is a 3 hour workshop and supporting case studies and a supportive approach for training for trainers.

## 2.4 OOHs Advice Line

EG raised the attention of the group to the locality changes in one area in the region and the current challenges. The purpose of this item is to find out about any examples of good practice across the region.

EG advised that, despite not having any funding available, Northumbria do continue to have an advice line in place for professionals but not patients.

AN advised that Wales has a Single Point of Contact (SPoC) in place which she suggested could be considered for our region given its similarity in size.

It was agreed that this should be discussed in more depth at a future meeting to determine whether a Task and Finish Group should be put in place to undertake a scoping exercise to inform Commissioners about what is currently in place, the volume of calls being taken and what should be in place.

LW/AM

## 2.5 Network Documents

AM advised that the Northern Clinical Networks now have a central coordinator in place that will be responsible for keeping the website up to date and monitoring its usage.

# 3. Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

## 3.1 Background information

LW explained the background to the development of Deciding Right and how far this had progressed across the Network. LW also explained the work done nationally on ReSPECT and the aims of this project. ReSPECT was published 28<sup>th</sup> February 2017 and since this isn't a nationally mandated tool as a region there is a choice to decide what would be the way forward acknowledging that the Northern Region is in a different position than other regions in the country where a standard approach through Deciding Right.

The purpose of this part of the meeting is for the Group to discuss whether ReSPECT should be adopted across the Network.

Earlier in 2017 Supportive and Palliative Care and End of Life Care (SP&EOLC) Core Group representatives had been tasked to engage with their locality groups and gather, as broadly as possible, a consensus of opinion regarding ReSPECT. Locality group representatives were also offered the opportunity to invite additional representatives from their locality to the Summer meeting to ensure a balanced representation was in attendance. The gathered opinions were asked to be shared with the Network and thanks to those who achieved this. Those opinions could be used to enrich the table top discussion in the room ensuring that the decision in the room was representative from a wider group than SP&EoLC.

## 3.2 Critical Care Network perspective

JP explained the resources currently in place to help those families going through a very difficult time including a suite of documents entitled 'Dignified Death' which have proven to be very useful for new staff inexperienced in dealing with the death of patients. The work of the Network has been shared with Wales, Southampton, Isle of Man and Northern Ireland.

<http://www.respectprocess.org.uk/pdfs/ReSPECT-Introduction-slides.pdf>

### 3.3 Table top focused discussion

LW explained that the three topics of discussion for today were:

What are the benefits for the region of adopting ReSPECT?

What are the risks for the region of adopting ReSPECT?

What are the challenges?

Discussions took place in five groups, the notes from which are attached to these minutes.

### 3.4 Feedback

Each Group was asked to feedback on their top two benefits, risks and challenges. These included:

#### Benefits:

- National document so no border issues;
- ReSPECT document has scope to discuss all treatments, not just DNACPR;
- Empowers patients to have discussions about what they want;
- Includes information on all discussions;
- Allows a person to say what they want to do rather than what they don't want to do;
- Fits in with Compassionate Communities

#### Risks:

- Boxes are too small on the form to include appropriate information;
- Version control;
- The need to get everyone behind to drive it forward;
- Negative public opinion;
- Decrease credibility of palliative care – another form;
- Deciding right not yet evaluated;
- Region will fall behind others when used to being leaders;
- Education / resources to train staff in the use of new form;
- Lack of wider engagement (already in place with Deciding right)

#### Challenges:

- Need to learn first of the benefits of Deciding right and any lessons learnt;
- May become another LCP and therefore not completed fully;
- Getting full engagement across the region;
- Who will lead re implementation?
- Funding and time need to implement;
- Why not tweak what is already in place?
- Not as visible as the DNACPR form;
- Simpler is better especially for the patient

#### Additional Comments:

The Group advised that they had anticipated a decision being made today on the adoption (or not) of the ReSPECT documentation but acknowledged that such a decision could not be made without full agreement across services which would be difficult today as some services were not represented eg elderly medicine, acute medicine, GPs and some CCGs.



KH advised that other Networks were starting to get interested in Deciding right and there could be a real risk of losing what has been achieved over the last five years if ReSPECT is implemented without proper discussion.

AN advised that he had asked for opinions on this and most of his colleagues had replied to say they had reservations about the document and how it would be used.

PR advised that as Trusts have been putting off revising their documents because of ReSPECT, a decision needs to be made soon on how to move forward.

MG advised that NEAS need a document which enables time critical decisions to be made and that the ReSPECT document currently doesn't allow that.

RQ suggested we learn from the regions in the country where ReSPECT is being used from the ongoing evaluation that is happening.

It was agreed that before the Group considers implementing ReSPECT that there should be a focus on evaluating Deciding right and whether having a DNACPR in place has made a difference for patients. There was also agreement that there is a requirement for more nurturing of Deciding right and DNACPR before putting new documentation in place.

**It was therefore agreed that everyone should continue using the current Deciding Right documentation until the Northern Clinical Network had been able to assess the impact of Deciding Right. ReSPECT will remain on the radar of the Clinical Networks and will be keen to learn from the areas where it has been implemented and evaluated. Therefore a regional position on the adoption of ReSPECT is currently *No-Not Now* rather than *No-Never*.**

### 3.5 The Way Forward

Notes from today's discussions will be typed up and shared with the Group to take back to their organisations and localities to help inform discussions on this topic. The Northern Clinical Network will look at the additional funding being made available to determine whether this can be used to help fund this project work going forward.

LW/AM

## 4. STANDING ITEMS

### 4.1 Clinical Governance Issues

NEAS End of Life Ambulance service: MM informed the Group that there had been several incidents at weekends where families had expected this ambulance service to be available only to find that this service operates Monday - Friday. DO agreed to update the NEAS flyer to reflect this.

DO

### 4.2 Any Other Business

LW advised that the advanced statement document is not available on the NECN website as the Network had been advised that by having only one version on their website this would be seen as favouring one organisation. It was therefore agreed that a selection of example Advance statement documents should be made available on the NECN website; group members are welcome to share their example documents to LW. The example documents will be located on the NECN website with the education resources.

LW/AM

ALL  
LW

**4.3 Date and time of next meeting**

Tuesday 17 October at Evolve Business Centre, Houghton-le-Spring  
1-3pm : Core Group

**5. MEETING CLOSE**



## ReSPECT Group Discussion Notes

**Table 1**

### **Benefits:**

- Linking resuscitation decision with plan of care – “not leaving decision behind”
- DNACPR = can be sts meaningless
- Lack of border issues
- Resources already available
- Some lack of clarity with Dr
- Not simple
- Paeds – good: what to do and what not to do
- More positive conversation
- Can guide discussion
- Will help documentation of decisions made

### **Risks:**

- Piecemeal - ReSPECT v Deciding right
- Why not mandated
- Decisions not made – lack of clarity
- Not as visible as DNACPR “not black and white”
- Resources – engagement not tools.
- “Simpler the better”
- Reconisability
- Understanding from patient and carer perspective
- Teams not recognising documentation
- Capturing transport discussion

### **Challenges:**

- Time resources to implement
- Could we not embed EHCP
- Use template of TEP, stepped template
- Ongoing education
- Parents feel the risk of ambiguity of documentation
- Engagement with other groups – LMC, care homes
- Regional decision – buy in

**Table 2**

**Benefits:**

- Not just DNACPR – start of further conversation
- Feedback: support for principles and concept but see risks\*\*
- Could be summarised for patient
- Emergency situations / quick documentation
- ‘Nationally recognised approach – public awareness / profile
- Unification of the advance care planning process so less documents which can be confusion for patients.

**For patients:**

- Will facilitate discussion for patients but hard to see what advantage this has over existing documents;
- Could benefit from conversations being framed in terms of their preferences for life prolonging treatment versus comfort. National document should mean it is recognised if patients present acutely away from home;
- Unification of the advance care planning process so less documents which can be confusing for patients.

**For professionals:**

- It may facilitate discussions and contextualise them for professional and patients;
- Encourages DNACPR to be part of wider advance care planning conversations and so promoting best practice.

**Risks and challenges:**

- Potential distraction from Deciding right;
- Time – for conversation; to educate/raise awareness/coordination;
- Resources – who can do the training / facilitators?
- Lessons from Deciding right (5yrs) and resources required;
- Follow on from conversation/layout encourages ‘tick box’ approach;
- \*\*Clarity needed – is this legally binding? DNACPR/DNR;
- Form not always filled in in one go – process;
- Performance measures – secondary care hospital – first conversation with RLB (all patients). Maybe junior staff having conversation;
- Concern about primary care resources;
- Which form to go with – new patient / planned;
- Needs regional or national mandate to achieve consistency;
- Needs to work with Deciding right;
- ADRT needs to be separate to be legally binding;
- Interpretation alongside EHCP;
- Needs review dates (or do a new form?);
- “New way of working” – should assume going to resuscitate / recommendation;
- Concern that ReSPECT has been developed primarily for those areas who do not have Deciding right;
- Introducing another document will confuse everyone just as we are starting to make inroads into Deciding right;
- Summary document will replace the full document resulting in less detail;
- A network wide decision should be made so that we are not back to different approaches per locality;

- How will education be rolled out. Need to have a good education plan in place prior to implementation and organisations take the education requirement seriously and don't just talk about 'awareness'.

**For patients:**

- Transferring to a different document would necessitate further discussion with the patient and for those who found the previous conversations difficult this could potentially cause distress;
- Understanding the point of the form over and above what is already out there. They could misinterpret the sale in box 3 and look at it as an 'either/or'.

**For professionals:**

- Risk of professionals feeling frustrated that they have to become familiar with a different document and could lead to disengagement with principles of advance care planning;
- Implementation would require many stages as indicated in the road map. Would need agreement from all stakeholders and potential that this would be a challenge to negotiate;
- Persuading clinicians that this is a good idea. Overall clinicians need education in communication and on what the current forms can and cannot do. Adding a new form will not solve this fundamental problem. In fact it will confuse matters for patients and doctors.

**Table 3**

**Benefits:**

- Standardisation of forms across region (step plans – clinical and not holistic);
- Patient focused;
- Ensures more patient engagement;
- ReSPECT Leads (forces) HCP to have discussion;
- About DNACPR and other ACP;
- Enabling earlier discussions;
- Prevents opportunities being missed;
- Opportunity for further public engagement;
- Avoidance of people not for resus automatically not having treatment

**Risks:**

- Expensive – money and time;
- Clinical disengagement;
- Forced on to patients;
- Risk of financial target;
- Negative media response;
- Areas on form to fill in very small – DNACPR not obvious;
- Form in notes may be incorrectly interpreted as not for resus;
- Updating forms/version control;
- Updating form – whole form to be filled in;
- May only fill in resus status;
- Early conflict if patient does not wish to have discussions;
- May use less EHCs and ADRTs

**Challenges:**

- Who will lead this work?
- We already have Deciding right;
- Implementation – we only implemented deciding right over last five years;
- Finance;
- Time;
- Audit;
- ?Mandatory training;
- Who provides the forms!
- Colour purple – difficult!
- Guidance complicated / form busy;
- Identifiable signature on opposite side to resus status

**Table 4**

**Benefits:**

- National form;
- Good found boundaries etc... (geographical);
- Compassionate Communities (fits with Public Health EoLC approach)

**Risks:**

- Potential to 'undo' cause confusion 'DR' use;
- We may 'fall behind' nationally – used to being leaders;
- Potential to erode clinical judgement/decision making (lessons from LCP to be learned);
- Lots of energy and resource required – re-educate;
- Credibility of palliative care possibly in jeopardy;

**Challenges:**

- Engagement/time factor;
- Too much, too soon after Deciding right which is not yet evaluated. Who will review? Change in sliding scale;
- “Emperor’s New Clothes”;
- “Ain’t broke, don’t fix it” or just tweak existing;

**Table 5**

**Benefits:**

- Can include all specialities – acute, community, chronic;
- Empowering patients;
- Patient wishes;
- ‘Right thing’;
- One document nationally;
- Potential for education – patients and professionals;
- Representative for national CQC inspection;
- Good life and good death

**Risks:**

- Goes way of LCP in public perception;
- Ongoing research – too early;
- Pootle out without momentum;
- DNACPR = written off

**Challenges:**

- Already got Deciding right;
- Ownership and responsibility for resources;
- Energy and time to implement;
- Phases in and out;
- Perception;
- Education and training;
- Not just one organisation – communication;
- Colour of form;
- Buy-in of all specialities;
- Funding;
- Facilitators