

**Deciding right
and
Caring for the Dying Patient:
A regional review of use**

August 2018

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Introduction

The Northern England Clinical Network (NECN) through their Supportive, Palliative and End of Life Care group (SP&EOLC) set out to scope the use of the distinct regional guidance:

- Deciding right
- Caring for the Dying Patient document

Variability of use had been identified by the regional Deciding right Education group; the SP&EOLC group endorsing the project to scope the use by locality. To facilitate the project, a Project Lead was appointed for a period of 6 months working 2 days per week.

The two scoping exercises were similar in many aspects with a decision to simultaneously collect the relevant data for each project.

This report includes a dedicated section related to each piece of guidance, with shared sections covering common aspects including feedback from the Learning and Sharing Event hosted by NECN on 17th July 2018.

Project Aims

The Project aims are to:

- Work with regional partners to scope the current use of the regional guidance
- Support the further implementation of the regional guidance
- Coordinate the development of the Network Deliverable [2017-2018]: End of Life Commitment in order to progress the Government's pledge to end of life care which focuses on identification, care planning, documentation, sharing records, involving the family and acting on preferences.
- Identify and share best practice across the region.

Method

Working with support of the NECN programme lead and clinical lead, an action plan was produced identifying the project time scales and priorities.

Data collection templates were formulated and shared through the Supportive, Palliative and End of Life Care Core Group representatives; those representatives were asked to support the project by sharing the templates within their localities and identifying with the project lead key persons in each locality to speak to in order to gather information. Feedback from the completed templates was collated and these form the body of the findings.

Alongside the data collection templates, a variety of focus groups and individuals were contacted and interviewed by the Project Lead. These included a wide range of professionals including CCG leads and service providers.

The Localities within the NECN footprint are:

North Cumbria
Northumberland
North Tyneside

Newcastle upon Tyne
Gateshead
South Tyneside
Sunderland
Durham & Darlington
North Tees & Hartlepool
South Tees including Hambleton, Richmondshire and Whitby

A regional event was planned to be held at the completion of the data collection and analysis where learning and sharing from localities could take place with additional presentations of good practice. Within the event, each locality will be tasked with producing a dedicated action plan from the data collected and sharing good practice with localities being guided to produce next steps and actions to implement in their localities and an opportunity to share progress at future SP&EOLC group meetings.

1. Deciding right

Background

Deciding right was developed by the then North East Strategic Health Authority End-of-life Clinical Innovation team in 2012 as the first framework in the UK to integrate the principles of making care decisions in advance.

Deciding right:

- Emphasises the partnership between the individual, carer or parent and the clinician
- Places the Mental Capacity Act (MCA) at the centre of shared decision-making
- Enables professionals and organisations to comply with the MCA by filling the gap in practice, not just the knowledge gap
- Recognises the individual with capacity as key to making care decisions in advance
- Empowers the individual who lacks capacity to have decisions made in their best interests
- Enables information to be recognisable in all care settings
- Introduces emergency health care plans as an important adjunct in all settings to tailor care to the individual with complex needs

The creation of recognised regional documentation provided a means to standardise practice, using the same Deciding right documentation in any care setting and recognised by all health and social care professionals. A Deciding right **App** is now available following a regional launch in 2016.

The initiative is now managed through the Northern England Clinical Networks Supportive, Palliative and End of Life Care Group. The Northern England Clinical Networks hosted a Summer meeting (July 2017) to debate the option of introducing the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT document, 2017, The Resuscitation Council, UK), to be integrated within the regional approach for future planning. The outcome from the meeting was to continue using the current Deciding right documentation with a proposal to assess the use and impact of Deciding right across the Network.

An opportunity arose to allocate a resource to take this proposal forward.

Outcomes

- Understand how the regional initiative has been adopted across the region.
- Produce individual reports by locality
- Facilitate a regional learning and sharing event to cascade the findings of the project
- Support localities to identify barriers within their areas
- Support localities to produce action plans to further implement regional initiative/documentation within their area

This project focused on the recognised Deciding right documents:

- Advance Decision to Refuse Treatment
- Emergency Health Care Plans
- Do Not Attempt Cardio Pulmonary Resuscitation
- Mental Capacity Assessment 1 & 2

In addition, this project questioned the use of the associated document:

- Advance Statement

Findings

The data findings are presented by locality and are then supplemented by reported individual comments (when provided) and evidence from the professional focus groups. This information gave an insight into how documents were used in practice, how professionals viewed their ease of completion, and how useful they were in the provision of care.

The findings are presented as the direct responses from the individuals representing the localities who returned the information, acknowledging there may be limitations to the findings due to the enormity of the task within the time scale of the project.

The comparable findings from all localities are available in the Executive Summary.

Findings by Locality

North Cumbria

Question	Answer / Comments	RAG Rating: Red - Low uptake Amber- Medium uptake Green - High uptake Pink - Missing data
What training and education is in place to support workforce re Deciding right?	Initially, facilitators in place to implement use of Deciding right across Cumbria. Currently the delivery of this education has not continued with facilitators. We do have a Caring for Dying Patient day where Deciding right would be discussed and staff encouraged to use documents but many don't feel they have the skills	Amber
Where does workforce access information re Deciding right?	The GPs have access via EMIS (so long as they have uploaded the docs). The Cumbria Partnership NHS Foundation Trust (CPFT) staff can access via SPC intranet page (only just in place and not advertised yet). Currently doing an assessment of teams across CPFT to identify training needs and this is one area that was highlighted with the pilot- no access to docs	Amber
Within your organisation who has the responsibility for delivering Deciding right training and education?	Education lead would include in training, but it is not specific to DR. There is no mandatory training.	Amber
Is there an MCA lead person within your organisation?	Yes	Green
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	We could find out how many GPs have completed the docs with pts, but not CPFT as they have not used it, it has mainly been GP lead, but this needs to change. Recent audit regarding DNACPR – identifying communication with patients highlighted 66% yes and 33% no	Red
Do you have a local Advance Statement? Yes/No	No	Red

Do you use it? If not why not?	We would use PPC or advance statement of DR- not sure how widespread it is used	
Would it be helpful to have a Regional Advance Statement Document?	Missing data	
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	I don't think this has been embedded into practice following the facilitators. We are working with Cumberland Infirmary leads to take ownership of all initiatives, DR will be included in this, and we have developed a pathway for HCPs that identify when to use the docs- in draft form.	
EHCP	Missing data	
DNACPR	Missing data	
Advance Statement	Missing data	
Advance Decision to Refuse Treatment	Missing data	
Best Interests	Missing data	
What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained? NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group	There isn't one at present but we are working to have better links with GPs and introducing adapted version of EPaCCS which will assist.	

Comments from those interviewed:

North Cumbria Acute Hospital does not use Deciding right documentation. The DNACPR document in use in the hospital is not the Deciding right document and a patient transferred into hospital who is not for resuscitation requires a North Cumbria DNACPR document to be initiated. On transfer to another care setting the Hospital document does not transfer out with the patient. This trust is intending to implement the ReSPECT document.

Northumberland

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	'On the ground' training for new employees using documents	Amber
Where does workforce access information re Deciding right?	Palliative care pages on intranet From the palliative care teams and direct contact	Amber
Within your organisation who has the responsibility for delivering Deciding right training and education?	It's not isolated as separate training	Red
Is there an MCA lead person within your organisation?	Yes	Green
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	In the past (number of EHCPs completed on discharge from palliative care units) but not currently	Amber
Do you have a local Advance Statement? Yes/No	Yes	Amber
Do you use it? If not why not?	Missing data	Pink
Would it be helpful to have a Regional Advance Statement Document?	Yes	Green
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	Well embedded into practice in the palliative care teams, and interest in developing more systematically in key specialties eg COTE	Amber
EHCP	Regular completion of EHCPs (approx. 40% of those discharged from hospital liaison service have an EHCP but it is patchy across the rest of the service). GPs are the exception and completed EHCPs in selected patients	Amber
DNACPR	DNACPR (which is universally used)	Green
Advance Statement	Used within palliative care service: the most are led by palliative care	Amber

Advance Decision to Refuse Treatment	Used within palliative care service: the most are led by palliative care	
Best Interests Decision	Used within palliative care service: the most are led by palliative care	
<p>What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained?</p> <p>NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group</p>	<p>Direct consultation and contact with palliative care services. No formal structure</p>	

North Tyneside

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	CCG runs at least 1 GP educational event every year but in first 3 years three events took place. Bi-annual education events for new GP/GP registrars to North Tyneside. Training via Palliative Care Team to primary, secondary care and care homes.	Green
Where does workforce access information re Deciding right?	GP team net- interoperable IT service for GP practices. Network website and DR website – all shared at educational meetings. Network site & documents held as hard copies.	Green
Within your organisation who has the responsibility for delivering Deciding right training and education?	Clinical lead for end of life care in the CCG	Green
Is there an MCA lead person within your organisation?	Yes We work closely together delivering training to the GP /registrars	Green
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	On primary care palliative care registers through RAIDR – Reporting Analysis and Intelligence Delivering Results (Healthcare Intelligence Tool)	Green
Do you have a local Advance Statement? Yes/No	Yes	Green
Do you use it? If not why not?	The original Strategic Clinical network document.	Green
Would it be helpful to have a Regional Advance Statement Document?	Missing data	Pink
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	Deciding right embedded well in practice. However data collected on use could be improved – will hopefully be more accurate when EPaCCS introduced	Yellow
EHCP	Missing data	Pink
DNACPR	Missing data	Pink

Advance Statement	Missing data	
Advance Decision to Refuse Treatment	Missing data	
Best Interest Decisions	Missing data	
<p>What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained?</p> <p>NB: link with NECS Deciding right eLearning Resource : data collected</p> <p>Link with Deciding right Regional Education Group</p>	<p>Lead reviewing practice performance and other KPI – system of lead within each practice, ensuring it is on the agenda at meetings in the locality. Our locality is strongly represented at the DR education group, Formal eLearning resource shared with GP practice leads.</p> <p>Data collected re care homes every two weeks</p>	

Newcastle Upon Tyne

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	Specialist Palliative care team have led education and training on completing specific Deciding right documentation. NUTH Deciding right Implementation Group plan to commence an awareness programme for all staff autumn 2018.	
Where does workforce access information re Deciding right?	NECN website Deciding right NUTH Implementation group members	
Within your organisation who has the responsibility for delivering Deciding right training and education?	Specialist Palliative Care has been actively delivering education and training. MND specialists have provided training regarding ADRT	
Is there an MCA lead person within your organisation?	Yes	
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	Missing data	
Do you have a local Advance Statement? Yes/No	North of Tyne version of Advance statement has been used. Identified the need to personalise to NUTH.	
Do you use it? If not why not?	Missing data	
Would it be helpful to have a Regional Advance Statement Document?	Discussions have been had which would support the move towards having a regional Advance Statement document	
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	Extensive work over years with MND Specialist Services who were early implementers of Deciding right and pre-dating Deciding right had extensive experience with writing Advance Directives with patients. For the last 12-months there has been an active NUTH	

	Deciding right Implementation Group led by Consultant in Anaesthesia and Intensive Care Medicine. This group have met regularly and have a plan to commence an awareness programme of Deciding right for all staff from Autumn 2018. Once staff have received their training NUTH aim to increase the awareness of the programme with patients and the public: Deciding right patient and Public Power Point/video in OPD & primary care, information leaflets and use of media. Work within NUTH parallels some ongoing work at national level by the Faculty of Intensive Care Medicine.	
EHCP		
DNACPR	Yes- well embedded	
Advance Statement	Advance statement conversations. Variable documentary evidence	
Advance Decision to Refuse Treatment	Extensive use	
Best Interests Decisions	Frequently held discussions and decisions made in best interest or an individual lacking capacity	
What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained? NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group	Plan for implementation from Autumn 2018	

Gateshead

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	Deciding right is incorporated in all Palliative Care and End of Life training for all Trust staff.	Green
Where does workforce access information re Deciding right?	From the Specialist Palliative Care team and the Trust intranet site. Intranet and end of life care facilitator and the Specialist Palliative Care Nurses	Amber
Within your organisation who has the responsibility for delivering Deciding right training and education?	Specialist Palliative Care Team, Resuscitation Officer for DNACPR, Macmillan End of Life Care Facilitator and the Specialist Palliative Care Nurses	Amber
Is there an MCA lead person within your organisation?	Yes	Green
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	Specialist Palliative Care Team captures information within their activity data. No CQUIN target.	Amber
Do you have a local Advance Statement? Yes/No	Yes	Green
Do you use it? If not why not?	Example A in Deciding right Clinical Network Site originally a Gateshead South Tyneside and Sunderland document	Green
Would it be helpful to have a Regional Advance Statement Document?	Yes.	Green
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	The SPCT embed Deciding right initiatives into the holistic assessments which are recorded within our workforce activity. DNACPR's and other Deciding right decisions are cascaded to relevant out of hours services and community providers electronically by secure NHS mail. For example using the SPN form for NEAS.	Amber
EHCP	Missing data	Pink

DNACPR	Missing data	
Advance Statement	Missing data	
Advance Decision to Refuse Treatment	Missing data	
Best Interest Decision	Missing data	
<p>What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained?</p> <p>NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group</p>	<p>This is incorporated within the palliative care education strategy and this is evaluated yearly.</p> <p>All Deciding right training is delivered using the regional resources from the Deciding right Group.</p> <p>Local End of Life Training and audit.</p>	

South Tyneside

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	<p>South Tyneside Hospital had CQUIN targeted Deciding right awareness training provided to all staff 2014-2015.</p> <p>Hospital - STFT staff have access to eLearning and face to face sessions. F1 and F2 Education Programme.</p> <p>Link Nurse Meetings.</p> <p>Community - One Study Day held at South Tyneside.</p> <p>Preceptorship</p>	
Where does workforce access information re Deciding right?	<p>NECN Intranet</p> <p>ELearning module accessible to STFT staff through OLM system.</p> <p>South Tyneside Health Pathways</p>	
Within your organisation who has the responsibility for delivering Deciding right training and education?	<p>STFT Specialist Palliative Care Team and St Benedict's Hospice – Educational Department provide and deliver education and training but there are no formal arrangements within policy re: responsibilities and requirements for staff</p>	
Is there an MCA lead person within your organisation?	Yes	
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	<p>Hospital – Nothing formal as yet but encouraging people to upload to NEAS - NEAS could produce evidence of this)</p> <p>Community – documented on EMIS. Some GP's will have this information documented at their Palliative Care Meetings within the Palliative Care Registers. Data is collated by NECS Specialist Palliative Care Team – EMIS MDT Template</p>	

Do you have a local Advance Statement? Yes/No	Use example documentation within Deciding right.	
Do you use it? If not why not?	Yes – we would use the example Advance Statement document within the NECN website	
Would it be helpful to have a Regional Advance Statement Document?	Missing Data	
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	Variable – see below	
EHCP	Improving in Hospital and Community – quality variable	
DNACPR	Well embedded	
Advance Statement	Not well documented – more of a verbal discussion	
Advance Decision to Refuse Treatment	Rarely	
Best Interest Decisions	As necessary	
What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained? NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group	Representative attends DR education Group regularly. We ensure this is highlighted at each teaching forum. Encourage staff to take part in eLearning and /or face to face training as appropriate. Hospital - STFT staff have access to eLearning and face to face sessions. F1 and F2 Education Programme. Link Nurse Meetings Community - One Study Day held at South Tyneside – However continuing education for GPs is identified as a gap Preceptorship Programme	

Comments from those interviewed:

- There is a full and detailed page on the South Tyneside health pathways with links to all printable forms and links to other web pages such as OPG and Deciding right
- There is also a MCA template within the EMIS GP system to record and code. Documents can be saved into the patient record.
- Continuing education for GPs is identified as a gap.
- MCA template into EMIS and all documents can be saved into this and read code recorded.
- GP practices complete an annual E declaration return to NHSE that has a voluntary question on MCA training and support.

Sunderland

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	<p>Sunderland Community services (a part of South Tyneside NHS Foundation Trust) had CQUIN targeted Deciding right awareness training provided to all staff 2014-2015. Once the CQUIN target was lifted the challenge has been to sustain numbers of staff being trained. The option of Deciding right ELearning Training has replaced classroom based awareness sessions, however this is currently recommended training and not mandatory. St Benedict's hospice education team have delivered many forms of education. Developed an e-learning package hosted by NECS and a workbook as well as many other educational approaches for health and social care staff. In 2016-7 Deciding right training was provided on a monthly basis to Sunderland Royal hospital staff by the SPC team and the end of life care facilitator. More recently, due to a review of training resources as part of the regional Deciding right group, training has changed in 2018 to awareness sessions on the wards (to commence April 2018) and quarterly workshops (3 hours) to embed the principles from the awareness training. The Palliative Care consultant has also provided training to medical staff. CCG Commissioned bespoke sessions with SPC from St Benedict's Hospice</p>	

	<p>to deliver Deciding right training and education to all GPs in Sunderland 2016-2017.</p> <p>Sunderland CCG have encouraged all GPs to download the Deciding right App.</p>	
Where does workforce access information re Deciding right?	<p>Trust Website and Intranet and NECN website; hard copies in depts.</p> <p>Information held on the end of life trust Intranet Page.</p> <p>Electronic resources of Deciding right on organisation shared drive.</p> <p>Deciding right eLearning Awareness training module available to access through organisation OLM system.</p> <p>Deciding right Champions have joined with Mental Capacity Champions: meetings are led by the Trust Safeguarding team and Deciding right is a regular feature: this forum is joint community and hospital</p>	
Within your organisation who has the responsibility for delivering Deciding right training and education?	<p>In Hospital: End of Life Care Facilitator who works closely with the Specialist Palliative Care Team: however this is a priority for the End of Life Care facilitator.</p> <p>In Sunderland Community services (including South Tyneside hospital): St Benedict's Hospice Education Team provide workshop training periodically.</p> <p>For Care Homes: The Tyne and Wear Care Alliance have commissioned St Benedict's Hospice Education team to deliver Deciding right Training and education to Care Home staff; Registered Nurses and Health Care Assistants.</p>	
Is there an MCA lead person within your organisation?	<p>Yes</p> <p>Mental capacity act training well accessed</p>	
Is there any formal way of capturing Deciding right activity within your organisation e.g.	<p>No – but EMIS can get some limited information.</p> <p>Hospital Mortality reviews</p>	

CQUIN targets	look at whether any of the Deciding right documents have been used in practice as part of End of life care DNACPR audits are undertaken by Hospital resuscitation team	
Do you have a local Advance Statement? Yes/No	Yes	
Do you use it? If not why not?	A locally produced Advance Statement document is used by SPC teams and Community nursing teams. Care Homes tend to use a company formulated generic Advance Care Planning document which has become apparent when delivering Deciding right education.	
Would it be helpful to have a Regional Advance Statement Document?	Yes	
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	Depends on the service: well embedded and understood in SPC, less so in other services. Concerned re use of language with EHCP taking precedence and often used incorrectly particularly in care homes.	
EHCP	EHCPs are well used in practice, however variable quality. Evidence of some EHCP been utilised sporadically through mortality audits.	
DNACPR	DNACPR well embedded and used within the locality both community and Hospital trust.	
Advance Statement	Some evidence of Advance statements in practice within community nursing services. Could be better as often an EHCP is in place of an Advance Statement	
Advance Decision to Refuse Treatment	Limited use, however beneficial when used well for specific refusals of treatment. SPC experience with using ADRT.	

Best Interest Decisions	Best interest decisions are made frequently. Limited evidence of using MCA 1&2 forms.	
<p>What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained?</p> <p>NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group</p>	Tends to be led by SPC MDTS in primary care (vanguard) End of life steering group monitors progress in this area	

Durham & Darlington

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	All clinical staff attended training as part of initial roll out. Elements remain on the staff training matrix i.e. DNACPR,ACP, communication skills Induction for all clinical staff and annual clinical training. Mandatory palliative care training for all staff includes key elements of DR.	
Where does workforce access information re Deciding right?	Website	
Within your organisation who has the responsibility for delivering Deciding right training and education?	Clinical Services Manager. Workforce development officer and Nurse Consultant internal to staff and also to visiting medical students(yr3) on placement	
Is there an MCA lead person within your organisation?	MCA lead with Trust	
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	Captured in SystemOne but it is not currently a CQUIN target. In the electronic patient record and this activity can be collated from this.	
Do you have a local Advance Statement? Yes/No	Yes	
Do you use it? If not why not?	Missing data	
Would it be helpful to have a Regional Advance Statement Document?	Yes	
How well are Deciding right outcomes embedded into practice?	Fairly well embedded – Assessed on admission and reviewed at weekly MDT. ACP provision for patients in all nursing services. There are a number of incidents reported	

Methods of capturing information linked to key outcomes:	that involve inadequate best interest assessment. A recent audit of admissions from care homes to ED showed low (but improving) levels of recording of EHCPs, DNACPR forms and personalised care plans. Discussions at clinical team meeting, Specialist MDT all logged in electronic patient records.	
EHCP	Nurse Consultant document in EHCP Critical event analysis with staff involved when required.	
DNACPR	Although there has been an audit of DNACPR forms since 2011 there remain gaps in DNACPR recording especially capacity assessment, and discussion with family. All resuscitation attempts are analysed; the most common reason for a resuscitation attempt that might have been avoided is lack of DNACPR discussion.	
Advance Statement	Missing data	
Advance Decision to Refuse Treatment	Missing data	
Best Interests	Our recent CQC report identified room for improvement in best interest and MCA processes.	
What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained? NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group	Embedded in practice forms part of the process of delivering care on a daily basis. Is part of our training matrix. Audit tool been developed. DR is not specifically identified as requiring embedment into practice, many elements however (DNACPR, personalised care plans, capacity assessment, compliance with MCA particularly best interest process) are integral to the delivery of high quality health care and are of great importance to the Trust. The palliative and end of life strategy is based on the 'foundations' set out in the national ambitions document; this provides a basis for embedding and sustaining many aspects of Deciding right.	

North Tees & Hartlepool

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	Last year there were regular teaching sessions run by the SPC team for hospital consultants and GPs. However at present none have been planned for this year. Again, ad hoc teaching has been given to district nurses, specialist nurses, and on the preceptorship course. Deciding right is included in 3 rd year and 5 th year teaching provided by the SPC team. Deciding right e-learning is available on the intranet Holistic admission and assessment documentation. All admissions go through this process	
Where does workforce access information re Deciding right?	Every clinical area in the hospital has a set of blue drawers which contains all of the palliative and end of life paperwork including DR. EHCP document available as PDF on Trust intranet under Palliative Care. A pack is held in the trust library. Access to the website.	
Within your organisation who has the responsibility for delivering Deciding right training and education?	Education Lead SPC Team	
Is there an MCA lead person within your organisation?	Yes Adult Safeguarding lead	
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	The CCG does ask for regular data on how many patients under the care of the SPC team have undertaken advance care planning. CQUIN target – not known However there is a role within the Trust with responsibility to gather data.	
Do you have a local Advance Statement? Yes/No	Yes	
If Yes Do you use it? If not why not?	Yes - Preferred Priorities of Care Document (Originated by Lancashire & South Cumbria Cancer Network.	

Would it be helpful to have a Regional Advance Statement Document?	Yes - a Regional Advance Statement Document to use alongside the other regional DR documents.	
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	Hospital discharge letters include palliative section where the palliative status of the patient is captured and any Deciding right documents that are in place recorded. The SPC team are on System One in the hospital and community and the templates include a section on advance care planning.	
EHCP	Missing data	
DNACPR	Missing data	
Advance Statement	Missing data	
Advance Decision to Refuse Treatment	Missing data	
Best Interests	Missing data	
What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained? NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group	A member of the SPC team attends the regional education group. A member of the team has attended the DR meetings since they began. E-learning resource on Intranet. Holistic admission and assessment documentation. All admissions go through this process	

South Tees including Hambleton, Richmondshire and Whitby

Question	Answer / Comments	Red –Low uptake Amber -Medium uptake Green – High uptake Pink – missing data
What training and education is in place to support workforce re Deciding right?	Elements of Deciding right are central to almost all palliative and end of life care education delivered within the organisation. This includes sessions delivered through the preceptorship programme to all new starters (nurses and AHP’s). All foundation doctors are made familiar with the Deciding right tools as part of the foundation teaching programme. We are in the process of adding the Deciding right e-learning link to our mandatory training platform. Elements/principals of Deciding right are brought into a variety of teaching/education sessions delivered in both Hospital and community settings.	
Where does workforce access information re Deciding right?	They are encouraged to access the regional network web site.	
Within your organisation who has the responsibility for delivering Deciding right training and education?	Not one person.....but the palliative care team and lead nurse for end of life care have taken this on.....no central ownership of Deciding right.....taught as part of advance care planning. It is also mentioned within mental capacity training but not in any depth.	
Is there an MCA lead person within your organisation?	Yes	
Is there any formal way of capturing Deciding right activity within your organisation eg CQUIN targets	No	
Do you have a local Advance Statement? Yes/No	No	
Do you use it? If not why not?	We do have a policy and tend to use national templates	

Would it be helpful to have a Regional Advance Statement Document?	Not sure if a regional one would add anything.	
How well are Deciding right outcomes embedded into practice? Methods of capturing information linked to key outcomes:	DNACPR is measured by audit regularly and reported to the trust board. All others are not captured formally and are not linked to any KPI's or other formal assessment processes. Best interest decisions are monitored through the MCA compliance audit which we submit to the CCG on quarterly basis (this started last quarter; 5 case notes per month)	
EHCP	Missing data	
DNACPR	Regional DNACPR is well established throughout the organisation. NB. Our North Yorkshire colleagues in the community use the Yorkshire & Humber DNACPR form as that is recognised by the Yorkshire Ambulance Service.	
Advance Statement	Missing data	
Advance Decision to Refuse Treatment	ADRT (has this been asked during admission process; on admission proforma)	
Best Interests	Best interest decisions made are reported through compliance audit	
What system/structure do you have within your organisation to ensure Deciding right is embedded into practice and sustained? NB: link with NECS Deciding right eLearning Resource : data collected Link with Deciding right Regional Education Group	Missing data	

Additional Comments from respondents relating to individual documents

Advance Statement

“A verbal or written statement by an individual with capacity describing their wishes and feelings, beliefs and values about their future care. There is no requirement to involve anyone else, but individuals can find professionals, and relatives or carers helpful. An advance statement cannot be made on behalf of an individual who lacks capacity to make these decisions. It only becomes active when the individual loses capacity for these decisions. It is not legally binding, but carers are bound to take it into account when deciding the best interests of a person who has lost capacity.”
(Deciding right; Your Life, Your Choice, 2015. NECN)

They are used but are very variable how or when used. Some teams find them useful; some have not heard of them or confuse them with other documents.

There is no regional Advance Statement, but there are examples of the national Preferred Priorities of Care document and this is the most widely used. Often care homes and Learning Disability units use a preference form, or “passport”. Sometimes information is written on a blank sheet of paper.

The Mental Capacity Act allows for an Advance Statement to be verbal; however in practice this has severe limitations for professionals, a written and signed document has greater benefit for the individual and for the professionals.

Because it is not “legally binding” patients are often more comfortable with this than a formal documentation.

Preferences have been incorporated within other forms i.e. Emergency Health Care Plan. This can result in some uncertainty regarding what is a request and which a demand. Therefore, it is recommended that there is clear definition of what is being documented.

Advance Statements can be very useful and more widespread use would not only allow preferences to be adhered to, but the conversations required for these often prove to be beneficial for all concerned, even if no paperwork is completed.

The use of advance statements should be encouraged and training should be provided for all agencies giving care. Recognition should be made that they can be used for all aspects of care, not only “medical”.

Advance Decision to Refuse Treatment (ADRT)

An ADRT must be made by a person with capacity for these decisions, and only becomes active when the individual loses capacity for these decisions. To be legally binding it must be valid (made by an individual with capacity and following specific requirements if refusing life-sustaining treatment) and applicable to the circumstances. ADRTs that refuse life-sustaining treatment must follow specific requirements including being written, signed, witnessed, state clearly the treatment being refused and the circumstances under which the refusal must take place, and contain a phrase such as, “I refuse this treatment even if my life is at risk.” If valid and applicable, an ADRT has the same effect as if the individual still had capacity.
(Deciding right; Your Life, Your Choice, 2015. NECN)

Because of the complexities of this document and the serious nature of its implementation (legally binding) few patients will go for this.

The document has been used with patients with neurological conditions such as Motor Neurone Disease (MND) or Huntingdon's Disease. They know what is ahead of them, it is unavoidable, and they often want to prepare for this. Each patient will set the bar at the level they are comfortable with and this can be very varied.

An average GP will be approached about these very rarely, perhaps less than one every few years. They are unlikely to build up any level of competency in completing them; therefore they will need support and guidance.

The M.N.D. teams and some of the S.P.C.T.s are beginning to gain experience with supporting people to complete an ADRT.

Emergency Health Care Plans

Care plan covering the management of an anticipated emergency. Can be written in discussion with the individual who has capacity for those decisions, with the parents of a child, or made in an adult who lacks capacity following the best interests' requirements of the Mental Capacity Act." (Deciding right; Your Life, Your Choice, 2015. NECN)

These are widely used and are generally well received by professionals. When correctly completed they provide a framework/guidance on what to do for an anticipated emergency.

They give step by step instructions with time scales which family, care workers and professionals can find helpful.

It also offers reassurance to the patient that the correct procedures will be followed when a crisis occurs.

Inpatient units such as Care Homes and Learning Disability units find these invaluable.

Some Care Homes have many changes of staff including the frequent use of agency staff therefore the EHCP provides quick and clear instructions when they are most needed.

Unfortunately, they are not always written in this way. Often, they are purely communication tools between professionals. "Do not admit to hospital" for example, may be the only item on the form. EHCP have been misused in place of an Advance Statement or DNACPR form.

Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)

A DNACPR decision to withhold cardio-pulmonary resuscitation (CPR) in the event of a future arrest. Communication is a key to making this decision. If a patient has capacity and an arrest is anticipated and CPR could be successful, but the patient is refusing CPR, this must be respected. In such a situation the individual may wish to

complete an ADRT refusing CPR which, if valid and applicable, is legally binding on carers. A DNACPR decision made for an individual who does not have capacity must follow the best interest's requirements of the Mental Capacity Act. (Deciding right; Your Life, Your Choice, 2015. NECN)

The standardised form has been extremely beneficial to the ambulance and emergency out of hour's services.

Generally the form is used and completed well.

Highlighted challenges in practice:

- *The logistics of DNACPR forms being completed.*
- *Getting a DNACPR form to the patient if completed in the surgery and then returning to the patient's home.*
- *Ensuring the DNACPR form stays with the patient if transferred etc.*
- *Hospital DNR form different from the regional Deciding right document, not transferable, presents challenges when patient are admitted from community with a Deciding right DNACPR and discharged from hospital where a hospital DNR isn't viable for the community.*

Issues are not easily overcome except by professionals being diligent in ensuring the principle of "forms stay with the patient" is adhered to.

"Does it have to be a doctor completing the form?" Some localities have senior nurses and advanced nurse practitioners initiating DNACPR forms where local policy and protocol supports nurses to do so.

Mental Capacity Assessment (MCA1 & 2)

The ability of an individual to understand the information relevant to a specific decision retains that information, weigh up the facts and communicate their decision. Capacity must be assumed in all individuals unless there is an indication of an impairment or disturbance of mind or brain. In this situation, capacity for that decision must be tested (see MCA1&2 forms in the regional forms section of the Deciding right website). A person with capacity can make any decision they wish, even if others view that decision as illogical or unwise. Capacity is specific to the decision being made- therefore an individual can have capacity for one decision, but not another. If an individual lacks capacity for specific decision carers must make the decision following the best interest's requirements of the Mental Capacity Act (see MCA1&2 form).(Deciding right; Your Life Your Choice, 2015. NECN)

Where MCA 1&2 forms are used professionals commented on their value for being short but comprehensive. (Not often said about other documentation).

It guides professionals through the process of a mental capacity assessment and ensures all aspects of the Mental Capacity Act are included in the assessment.

Conclusion

Deciding right is a regional wide approach to implement the directives outlined in the Mental Capacity Act. It standardises the documentation used across the region for many aspects of advance care planning. Some are required to be completed by the

patient whilst they have capacity and are effective after capacity is lost and some can be completed for patients both with and without mental capacity.

The usage of the regional documents varies widely between localities. There is almost total adoption of the DNACPR form, with the ADRT form being rarely used. Where Deciding right documents are used they are universally valued and recognised as empowering for patients.

This project has demonstrated that having someone who is recognised as having the experience and expertise to provide guidance and training in the use of these forms is seen to be advantageous to an organisation. Almost all localities in the region could identify with someone within organisations having a lead role for Mental Capacity Act, however this is not so for Deciding right. There is widespread awareness of Deciding right documents, but many professionals are unsure when to use what or the implications of each document, especially an uncertainty of documents being “legally binding” and association to the Mental Capacity Act. This lack of awareness and understanding has had impact on the uptake of Deciding right documents except for the DNACPR. There are variances across the localities regarding who completes DNACPR documents with quite a number of examples where nurses are now initiating the DNACPR document; it is beyond the remit of this exercise to advise on the appropriateness of this but nurses should be supported by local policy and guidance to support them. This is not the responsibility of the Northern England Clinical Networks to set precedence.

There would appear to be an appetite to use Emergency Health Care Plans (EHCP) across the region with CCGs particularly emphasising and encouraging use of this to satisfy a specific deliverable. This, in turn, has resulted in EHCPs being overused or misused where general care planning would suffice or an advance statement would be more appropriate.

Advance statements are used in a range of semblances where localities are engaged with their use, therefore there lacks a consistent standard approach across the region; however there is an interest to have a standard regional Advance Statement. The challenge with this is that the MCA clearly states an Advance Statement can be presented in any way that suits a patient. Findings suggest that patients’ preferences often concern issues other than medical ones; therefore any regional form should reflect this.

The least used document from Deciding right would appear to be the Advance Decision to Refuse Treatment (ADRT); lack of experience or understanding how the document can support individuals was a common theme. Where extensive experience has been achieved with patients with ADRTs this, in the main, has been possible with Specialist input and examples of patients achieving their specific refusals of treatment.

Best interest decisions were acknowledged to be done in regularity; however the MCA 1 and 2 documents, despite being valued and useful, were not always seen to be used.

This project has revealed that for the majority of localities Specialist Palliative Care and End of Life Care Facilitators are still taking responsibility for education and promotion of use of Deciding right.

Over time, there has been widespread investment from individual CCGs to educate and upskill the care home workforce; however it is acknowledged that the ability to retain staff in the care homes is a constant challenge and therefore difficult to appraise where education and training has had an impact. Where NHS staff/ services support the care home setting there is a definite uptake in the use and completion of Deciding right documents, and subsequently achieving greater patient choice fulfilment. However, overall, there appears to be a lack of engagement from the Care Home workforce and the NHS input can be at the risk of disempowering the care home staff. It also has to be acknowledged that care home providers often have their own Advance Care Plan documentation and therefore there is conflict in what should be completed.

Where specialist services are involved, there is evidence that patients with progressive life limiting conditions frequently are being offered advance care planning discussions and Deciding right documents are being implemented to record the individual patient's wishes or refusals related to specific treatments. However project findings have revealed that for many patients "the doctor knows best" is still a widely held belief and, combined with apathy and a general reluctance for generalists to engage with or complete Deciding right documents; there is a lack of experience in assisting patients to complete specific documents. Ownership of Deciding right has largely sat with Specialist Palliative Care, however there are good examples where Intensivists are now taking a lead and driving forward the implementation for Deciding right; where this is happening, shifting the ownership has positive impact.

Standardised education resources for Deciding right and the recent work from the regional Deciding right Education group has provided an opportunity for some organisations to take stock and re-think where Deciding right needs to be progressed. Good examples have been shared by localities identifying Deciding right training being re-launched or re-focused. Examples of where CQUIN targets were set against Deciding right training provided evidence of organisations achieving on mass workforce awareness training; however, without a continued "top down" approach, sustainment is lost and training becomes a constant challenge. Good practice has to be acknowledged where Deciding right training has been incorporated into mandatory training within organisations with a supportive approach.

In conclusion, there would appear to be more to be done with embedding Deciding right especially in conjunction with the Mental Capacity Act. As it is widely expected, the Mental Capacity Act is due to be reviewed by the Government and any changes in the law will need to be implemented, to ensure professionals/organisations are compliant.

Section 2: Caring for the Dying Patient

Background

The Caring for the Dying Patient documentation was developed within the region in response to the national decision to withdraw the Liverpool Care Pathway.

The withdrawal followed intense media coverage and criticisms; the Liverpool Care Pathway (LCP) was reviewed by a parliamentary committee led by Julia Neuberger in July 2013, who published a report/response entitled *More Care, Less Pathway*. Whilst the report acknowledged that when used correctly the LCP was effective, there was evidence of widespread misuse and even patient harm. It was recommended that the LCP was withdrawn from use and alternative system be developed.

The Leadership Alliance for the Caring for Dying People published *One Chance to get it Right* document in June 2014. This addressed the failings identified in the LCP and introduced national recommendations; the Five Priorities of Care for The Dying Person. This proposed a more person-centred care approach with guidelines and aims but did not specify how they were to be delivered.

In response to these recommendations and guidelines the Northern England Strategic Clinical Network, through its regional Supportive, Palliative & End of Life Care group, formed a task & finish group with representation from localities within the region and clinical representatives. The group firstly produced a guidance document for interim use to support staff in caring for a dying person. The group then produced a document entitled 'Caring for the Dying Patient'. The aim was to produce a 'toolkit' to support staff with difficult conversations. It is made up of a number of sections:

- Medical assessment
- Nursing assessment
- Daily reassessment
- Community prescription chart
- Optional care plans

The regional document was piloted initially and the findings from the pilot brought about some changes with the final regional Document available to use from July 2015.

Outcomes

To understand how the Caring for the Dying Patient document is used within the region.

To benchmark the training available to the workforce within localities.

To understand the barriers to the use of the Caring for the Dying Patient document.

The Findings

The data findings are presented by locality and are then supplemented by reported individual comments and evidence from the professional focus groups. This information gives an insight into how the document is used in practice, how professionals view the ease of completion, and how useful this document is in the provision of care.

The findings are presented as the direct responses from the individuals representing the localities who returned the information.

The comparable findings from all localities are available in the Executive Summary.

Findings by Locality

North Cumbria

NHS North Cumbria CCG

North Cumbria University NHS
Hospital Trust

Cumberland Infirmary, Carlisle
West Cumberland Hospital

Community Services

Cumbria Partnership NHS Foundation Trust

Hospices

Eden Valley Hospice, Carlisle
The Copeland Unit, Whitehaven Hospital
Hospice at Home services x 2

Specialist Palliative Care

Community and Hospital

Mental Health

Cumbria Partnership NHS Foundation Trust

Service	Usage	Comments
Hospital	Occasionally	Paper document kept at Nurses station. A reluctance to accept the dying stage appears to be an issue.
Community	Rarely	Electronic copy populated/completed it is then printed and taken to patient's house and updated as required. Only a few practices are using it regularly.
Hospice	Frequently	Electronic template and care plans
Care Home	Occasionally	Some Nursing homes use paper copies with support of Nurse Practitioners

Question	Answer / Comments
What training and education is in place to support the workforce?	Originally had two facilitators for an 18 month period for East and West Cumbria to implement the tool. This required education for CPFT, Nursing homes, hospices, Hospital trust, GPs etc. face to face
Where does the workforce access the document to use?	The document is accessible by CPFT staff via EMIS, Shared drive. The GPs can access it via EMIS but only as a document. Work is being undertaken to develop it into a template for easy use
Within your organisation who has the responsibility for training and education for Caring for the Dying Patient documentation?	Currently there is no facilitators, the education is now done through Caring for the Dying Patient days which are available for any organisation, the CNSs with GPs, the bereavement team in Hospital trust- although the education work stream are looking at developing a robust EOLC champion group so they can take the lead with these things.
Is there a formal way to capture activity of using Caring for the Dying Patient document in your organisation?	There is a code on EMIS but not sure how well this is used. GPs are not using /initiating the document as allegedly they think it is too long and should not be paper document in house; there are huge challenges. A cross county audit is being undertaken to identify what information is being documented in order to meet the NICE guidance and five priorities of care; results should be available in March
What have been the successes within your organisation using the Caring for the Dying Patient : audit	As above

<p>What have been the challenges when using the Caring for the Dying Patient document?</p>	<p>If the GP doesn't initiate it then the DNs are not able to continue it. We are considering ways around, such as senior nurses to initiate following MDT discussion. This will depend on results of audit.</p>
<p>NHS Benchmark will be leading The Caring for Dying Adult Audit" July – Oct 2018 Will your organisation be participating?</p>	<p>Yes</p>

Comments from those interviewed:

The Caring for the Dying Patient document is available across the locality, but the uptake is patchy, only some GPs & District Nurses will use it.

It is often perceived as time consuming and a "tick box" exercise. The delay from instigating document to it being in patient's house may be delayed at weekends etc.

The recognition of being in the dying phase seems to be an issue particularly in the Hospital setting.

Also, in the Care of the Elderly wards it is felt that the document could be applied to most patients when ill in hospital, but many will respond to treatment.

Within the hospital, printers are not available on every ward station creating issues of confidentiality and physically collecting the document.

Eden Valley Hospice has a template within EMIS which is used, but numbers suggest it could be used more. The system populates demographic data which can be printed to be taken with the patient if they are discharged/transferred.

Nursing Homes will use it if supported by other professionals such as Care Home Support Nurses.

Training and support was originally provided by the two facilitators (East & West Cumbria) covering Hospital, Community, Nursing Homes etc. These facilitators were in post for 18 months. Since their posts ceased to exist education is provided ad-hoc via the Palliative Care Team & Bereavement Services.

READ codes have been set up to capture data and an audit is currently underway.

Northumberland

NHS Northumberland CCG

Northumbria Health Care
NHS Foundation Trust

Northumbria Specialist Emergency Care Hospital
Hexham General Hospital
Haltwhistle War Memorial Hospital

Community Hospital

Alnwick Infirmary

Palliative Care Unit

Wansbeck Palliative Care Unit

Community Palliative Care Teams

SE/Central Northumberland
North Northumberland
West Northumberland

Hospital Liaison teams

Cramlington
Wansbeck

Learning Disability Specialist Palliative Care Nurse working with Community Disability Teams
Care Home Teams

Mental Health

Northumberland Tyne and Wear NHS FT

Service	Usage	Comments
Hospital	Frequently	Paper copy
Community	Frequently	Paper copy often generated by District or palliative Care Nurse, held in patient's house then incorporated into SystemOne
Hospice	Frequently	Paper Copy
Care Home	Occasionally	Paper copy

Question	Answer / Comments
What training and education is in place to support the workforce?	Widespread training on introduction but little since 2014. GP event afternoons Face to face training in GP practices and with DNs Face to face training in hospital by hospital palliative care team
Where does the workforce access the document to use?	Paper documents kept in the patient's house. Available on SystemOne Internet
Within your organisation who has the responsibility for training and education re Caring for the Dying Patient documentation?	Specialist Palliative Care Teams Learning Disability Specialist Palliative Care Nurse Education lead
Is there a formal way to capture activity of using Care for the Dying Person document in your organisation?	SystemOne
What have been the successes within your organisation using the Caring for the Dying Patient : audit	Good uptake within the community setting and care Homes. Inpatient units less so. Use of the document in patients anticipated to be dying is high and there is good engagement in community services. Recognition of dying in Hospital remains a challenge but when a patient is recognised, completion of the document is high.

<p>What have been the challenges when using the Caring for the Dying Patient document?</p>	<p>Anticipatory drugs being prescribed but CDP not being used. Variation in quality of documentation Waiting too long before commencement of CDP Identifying dying Good and systematic completion of the document – across all sites completion is patchy (excluding palliative care units)</p>
<p>NHS Benchmark will be leading The Caring for Dying Adult Audit” July – Oct 2018 Will your organisation be participating?</p>	<p>Yes</p>

Comments from those interviewed

Training was provided in the beginning but little, apart from ad-hoc training has been carried out since 2014.

Care Homes have an ongoing education schedule usually using the Six Steps programme.

Community use is variable depending on the level of support available from the palliative care teams. Most GPs & D/Nurses will use it. The preferred method is when a joint assessment visit is done.

Care Plan based care is used and the CDP is fitted into the routine care planning documentation. These are all paper documents kept in the patient’s house in a purple folder. Information is later written into SystemOne template.

Inpatient units do use the CDP, but this can vary between units depending on support available.

North Tyneside

NHS North Tyneside CCG

Northumbria Health Care
NHS Foundation Trust

North Tyneside General Hospital

Community Services

Northumbria Health Care NHS Foundation Trust

Palliative Care Unit;

Redesdale Court, North Shields

Specialist palliative care

North Tyneside General Hospital
Care Home Team

Mental Health

Northumberland Tyne and Wear NHS Foundation Trust

Service	Usage	Comments
Hospital	Frequently	Paper copy
Community	Occasionally	Paper copy
Hospice	Frequently	Paper copy
Care Home	Frequently	Paper copy

Question	Answer / Comments
What training and education is in place to support the workforce?	Clinical lead for CCG has at least 1 education session /yr. and does bi- annual educational session for new GP /registrars to NT
Where does the workforce access the document to use?	Their Macmillan nurse takes it to the surgery or their DN brings them
Within your organisation who has the responsibility for training and education re Care for the Dying Person documentation?	The Specialist Palliative Care Team and the CCG GP End of Life Lead
Is there a formal way to capture activity of using Care for the Dying Person document in your organisation?	Through Northumbria trust The EPaCCs project hope to capture this activity
What have been the successes within your organisation using the Caring for the Dying Patient : audit	It is used well across our area
What have been the challenges when using the Caring for the Dying Patient document?	There is a perception that it can take a long time for a GP to complete the document, so some GPs only prescribe anticipatory meds without completing documentation. Need to audit whether GPs are documenting 5 priorities of care if not using document.
NHS Benchmark will be leading "The Caring for Dying Adult Audit" July – Oct 2018: [Will your organisation be participating?	Initial focus will be with Hospital Services The Regional SP&EoLC Group recommend that all Organisations across the Region take part

Comments from those interviewed

Paper records are transferred with patients across sectors in particular, between Hospital and Redesdale Unit. In North Tyneside a recent CDP audit shows that there is variation in how well the CDP is completed. In particular there are concerns that the document is started late and not enough time is available to have the conversations before the patient's condition deteriorates or dies.

Newcastle upon Tyne

NHS Newcastle Gateshead CCG

The Newcastle Upon Tyne Hospitals NHS Foundation Trust
Freeman Hospital
Royal Victoria Infirmary (RVI) Hospital
Campus for Ageing and Vitality

Community Services The Newcastle Upon Tyne Hospitals NHS Foundation Trust

Hospices Marie Curie Hospice, Newcastle
St. Oswald's Hospice, Gosforth

Specialist Palliative Care Freeman Hospital
RVI Hospital
Newcastle Community
Palliative care nurse within the Care Home Team

Mental Health Services Northumberland Tyne & Wear NHS Foundation Trust

Service	Usage	Comments
Hospital	Frequently	Paper document
Community	Frequently	Paper documents from a central store, copied to electronic later
Hospice	Frequently	Electronic version on SystemOne
Care Home	Frequently	Paper documents replenished as required

Question	Answer / Comments
What training and education is in place to support the workforce?	Clinical Staff receive training during their induction and we have RGNs/HCAs within the EOL Team who act as Clinical Educators as part of their working remit. The Palliative Care and End of Life Team also provide ad-hoc training sessions for staff as well as the Internal Intranet Page for advice. All wards with 12 deaths or more a year are fully trained to use the document and are using it Also Fully embedded in the community in Newcastle
Where does the workforce access the document to use?	The document is stored within each clinical ward area and each area has order codes to gain more should they need to. The community has access to printed documents via the admin team
Within your organisation who has the responsibility for training and education re Caring for the Dying Patient documentation?	Palliative Care and End of Life Team
Is there a formal way to capture activity of using Caring for the Dying Patient document in your organisation?	Biannual Care for the Dying Person Real Time Audit both in the Hospital and community setting Databases held by the End of Life Team Medication Alert System
What have been the successes within your organisation using the Caring for the Dying Patient : audit	Physical Patient Care has improved Conversations are Taking place PPOD achievements improving End of Life Team visible – visiting clinical areas daily Different/unusual clinical areas requesting support – Theatres/Recovery, Dermatology, Burns Unit etc.

	Staff feel supported – Reference Point A greater team of HCP supporting patients & families Reduced amounts of verbal and written complaints Incident Reporting
What have been the challenges when using the Caring for the Dying Patient document?	Finding the Document on the Wards Medical/nursing Staff not recognising that the patient is dying No designated person taking responsibility for the Document Changeover of staffing – Medical staff rotation Staffing Levels – Busy Clinical Environments
NHS Benchmark will be leading The Caring for Dying Adult Audit” July – Oct 2018: Will your organisation be participating?	Yes

Comments from those interviewed

The Liverpool Care Pathway was embedded within the Newcastle Hospitals and therefore the hospitals welcomed the introduction of the CDP document.

Clinical Staff receive training during their induction and mandatory training. We have RGNs/HCAs within the EOL Team who act as Clinical Educators as part of their working remit. The Palliative Care and End of Life Team also provide ad-hoc training sessions for staff as well as the Internal Intranet Page for advice.

All wards with 12 deaths or more a year are fully trained to use the document and are using it. The document is stored within each clinical ward area and each area has order codes to gain more should they need to.

Also the CDP is fully embedded in the community in Newcastle; approximately at least 90% of expected deaths have a CDP document.

Biannual Care for the Dying Person Real Time Audit is completed both in the Hospital and community setting

Databases held by the End of Life Team

Medication Alert System

It is generally seen as a positive, useful document, improving care and ensuring the essential conversations are being attempted. It is gradually spreading to more areas within the hospital

Gateshead

NHS Newcastle Gateshead CCG

Gateshead Health
NHS Foundation Trust

Queen Elizabeth Hospital
Bensham Hospital

Community Services

Gateshead Health NHS Foundation Trust

Hospice

Marie Curie Hospice, Newcastle
St. Oswald's Hospice, Gosforth

Specialist Palliative Care Teams;

Hospital based and community: Blaydon Health Centre

Mental Health Services

Northumberland Tyne & Wear NHS Foundation Trust

Service	Usage	Comments
Hospital	Frequently	Paper documents, but plans are to change to an electronic version
Community	Occasionally	Being re-launched
Hospice	Frequently	Electronic version on SystemOne
Care Home	Occasionally	Being encouraged

Question	Answer / Comments
What training and education is in place to support the workforce?	Caring for the dying patient Document is integrated in our Palliative and End of life Care education strategy. There is an action plan in place to support both hospital and community in rolling out the Caring for the Dying patient Document on to all wards and departments within the Trust and homes and care homes in Gateshead. Individual bespoke training is provided to all ward based staff regarding the Document.
Where does the workforce access the document to use?	Copies of the document are provided currently by the Specialist Palliative Care Team and there are plans for this to be computerised in the future, with continual audit attached to it.
Within your organisation who has the responsibility for training and education re Caring for the Dying Patient documentation?	Specialist Palliative Care Team
Is there a formal way to capture activity of using Caring for the Dying Patient document in your organisation?	Yes. A recently introduced palliative care register captures this activity; there are plans to continually audit this.
What have been the successes within your organisation using the Caring for the Dying Patient : audit	Following the role out programme, There are plans to consolidate, evaluate and audit use of the Care for the Dying Document.
What have been the challenges when using the Caring for the Dying Patient document?	In the wards and departments that are using the document , there have been no challenges identified as the SPCT nursing establishment within the hospital has increased therefore the team are able to support the roll out and the ward teams in a timely manner..
NHS Benchmark will be leading "The Caring for Dying Adult Audit" July – Oct 2018: Will your organisation be participating?	Yes

Comments from those interviewed

Caring for the dying patient Document is integrated in our Palliative and End of life Care education strategy. There is an action plan to support both hospital and community in rolling out the Caring for the Dying patient Document on to all wards and departments within the Trust and homes and care homes in Gateshead. Individual bespoke training is provided to training to all ward based staff regarding the Document.

At present we are in a pre-print stage. Copies of the document are provided currently by the Specialist Palliative Care Team and there are plans for this to be computerised in the future, with continual audit attached to it.

End of Life Care facilitator responsible for and are promoting use of document.

Some GPs do not complete it.

South Tyneside

NHS South Tyneside CCG

South Tyneside
NHS Foundation Trust

South Tyneside Hospital

Community Hospital

Palmers Hospital

Community Services

South Tyneside NHS Foundation Trust

Hospice

St. Clare's Hospice Jarrow

Specialist Palliative Care

Hospital based and Community SPC Team, Hebburn

Mental Health Services

Northumberland Tyne & Wear NHS Foundation Trust

Hospital	Occasionally	Despite education and presence of pall care team, not used as often as could be. Used more often in Hospital than community. From our figures the document is used 32% of the time
Community	Occasionally	Reluctance from GP's. Not considered often in time.
Hospice	Frequently	St Clare's Hospice
Care Home	Occasionally	

Question	Answer / Comments
What training and education is in place to support the workforce?	<p>Hospital –</p> <ol style="list-style-type: none"> 1. Ward based education during the roll out 2015/16. 2. New F1s – included in Palliative Care teaching sessions. 3. Link Nurse Meetings 4. Preceptorship Programme – discussed within this programme <p>Community –</p> <ol style="list-style-type: none"> 1. Rolled out with all GP Practices 2015/16 and Community Nursing Teams (Planned) 2. Community Nursing Study Day – Five times a year for newly qualified/new to community staff nurses and 2nd year student nurses 3. Link Nurse meetings
Where does the workforce access the document to use?	<p>Hospital – pre-printed, restocked by supplies and available on all wards. Also available within the intranet</p> <p>Community - pre-printed, restocked by supplies and available at Clarendon via Planned Community Nursing Teams. Also available within the intranet. NECN website.</p> <p>GP – South Tyneside Health Pathways website</p>
Within your organisation who has the responsibility for training and education re Caring for the Dying Patient documentation?	<p>STFT Specialist Palliative Care Team and St Benedict's Hospice – Educational Department provide and deliver education and training but there are no formal arrangements within policy re: responsibilities and requirements for staff.</p>

Is there a formal way to capture activity of using Caring for the Dying Patient document in your organisation?	Hospital – patients case notes are ‘coded’ using Z518 Community – no
What have been the successes within your organisation using the Caring for the Dying Patient : audit	Conclusions from mini audit last year: Overall we are good at recognising and communicating with dying patients and relatives and involving them in decisions about care. The Care for the Dying document prompts conversations re hydration and nutrition and symptom management (i.e. when compared with care / documentation without use of CDP doc)
What have been the challenges when using the Caring for the Dying Patient document?	Hospital – to use the document as a single point of documentation and not to use case notes and nursing notes. Community – GPs reluctant to use paper document whilst they use electronic systems (EMIS etc.). Difficulty accessing the documents. Perception from some GPs- duplication of documentation Both – perceived as a lengthy document and time doesn’t allow this to be completed
NHS Benchmark will be leading “The Caring for Dying Adult Audit” July – Oct 2018: Will your organisation be participating?	Yes

Comments from those interviewed

The document is used more often in the hospital than the community. Completion of the initial medical assessment is satisfactory (but could be a lot better) and the nursing assessment / care plans are not always used. There is a need for more education. Capacity within the specialist palliative care team to deliver education and for ward staff to attend training is the main limiting factor.

Conclusions from mini audit last year: Overall Clinicians are good at recognising and communicating with dying patients and relatives and involving them in decisions about care. The Care for the Dying document prompts conversations re hydration and nutrition and symptom management (i.e. when compared with care / documentation without use of CDP doc)

GPs who do not use the document may consider it duplication of work and time consuming.

Sunderland

NHS Sunderland CCG

City Hospitals Sunderland NHS Foundation Trust	Sunderland Royal Hospital Sunderland Eye Infirmary
Community Services	South Tyneside NHS Foundation Trust
Hospice Care	St. Benedict's Hospice and Centre for Specialist Palliative Care
Specialist Palliative Care	Specialist Palliative Care Teams Hospital and Community
Mental Health Services	Northumberland Tyne & Wear NHS Foundation Trust

Service	Usage	Comments
Hospital	Frequently	Paper copies. Plans to convert to electronic version.
Community	Rarely	Available through EMIS, but rarely used
Hospice	Frequently	Electronic version, printing an issue. Not always used
Care Home	Rarely	

Question	Answer / Comments
What training and education is in place to support the workforce?	Through education department at the hospice several forms of study available re 5 priorities, communication skills, Care for the Dying. In the hospital the End of Life Facilitator has delivered training on all ward areas on the document and the principles behind this. Attendance has taken place at clinical governance meetings, ward/ department meetings, and allied health professionals have also received training on the document. Training is embedded through care certificate and preceptorship programmes
Where does the workforce access the document to use?	Available in hard copies in community nurse bases – used fully at the hospice. In the hospital, the document is part of supplies materials management 'top up' although there are plans to add the document to our patient electronic record system (Meditech)
Within your organisation who has the responsibility for training and education re Caring for the Dying Patient documentation?	St Benedict's Hospice education team/specialist nurses End of Life Care Facilitator
Is there a formal way to capture activity of using Caring for the Dying Patient document in your organisation?	EMIS but rarely used – GP resistance In the hospital training records are held via electronic staff record and end of life facilitator holds training records on each ward within the hospital indicating who has been trained and who is outstanding
What have been the successes within your organisation using the Caring for the Dying Patient : audit	In the hospital it has been very successful – a tremendous amount of time and effort has been put into using the document across the trust and there is evidence that this is now embedded

What have been the challenges when using the Caring for the Dying Patient document?	GPs reluctance to engage Getting hospital medical staff engagement Transferring from electronic patient recording to 'paper'
NHS Benchmark will be leading The Caring for Dying Adult Audit" July – Oct 2018: Will your organisation be participating?	Hospital - yes

Comments from those interviewed

The Hospice staff state that using the document doesn't change their care in any way but "tidies it up".

It provides good guidelines and means nothing is missed.

The problem of public perception was highlighted and occasionally relatives have questioned whether this was the "death pathway". Relatives' dislike of the document was quoted as being a reason it was sometimes not used.

The document is not printed due to formatting issues. This results in the document not being transferred out of the hospice on discharge or transfer.

The Community Nursing staff would like to use the document and have had training, though this was several years ago, and they feel they would require a refresher.

They already complete numerous care plans and feel the Caring for the Dying Patient document may reduce paper related workload.

GPs will not use it though it is unclear why, but perhaps historical reasons hinder its use. It is certainly seen as a "time-consuming tick box exercise" by the GPs spoken to.

Nurses, especially those who are Nurse Practitioners and can prescribe, question why the document could not be used by nurses if the GPs have given verbal agreement that the patient is in the terminal phase of illness.

The document is occasionally sent home with a patient on discharge, but this has been problematic, again because the GPs will not engage with it. This has led to issues of patients being referred to the Coroner, which relatives have questioned.

Durham & Darlington

NHS North Durham CCG

Darlington CCG

County Durham and Darlington
NHS Foundation Trust

Darlington Memorial Hospital
University Hospital Of North Durham
Bishop Auckland Hospital

Community Hospitals

Chester-le-Street Community Hospital
Shotley Bridge Community Hospital
Sedgefield Community Hospital
Richardson Hospital
Weardale Community Hospital

Community Services

County Durham and Darlington NHS Foundation Trust

Hospice

St. Cuthbert's Hospice, Durham
Willowburn Hospice, Lanchester
St. Teresa's Hospice, Darlington

Specialist Palliative Care Teams

North Durham
Easington
Durham Dales & Sedgefield

Mental Health Services
Durham

Tees Esk & Wear Valleys NHS Foundation Trust

Service	Usage	Comments	
Hospital	Rarely	Paper records, then scanned electronically	An adapted version of the Regional document is used.
Community	Rarely	SystemOne Template, no paper record.	
Hospice	Rarely	Electronic using EMIS - does not collate with SystemOne	
Care Home	Rarely		

Question	Answer / Comments
What training and education is in place to support the workforce?	Initial roll out to all staff in IPU ongoing training in matrix annually. Clinical training for all clinical staff.
Where does the workforce access the document to use?	In the community there is a designed SystemOne template based on the documentation. Only paper documents are the drug charts etc.
Within your organisation who has the responsibility for training and education re Caring for the Dying Patient documentation?	Workforce development officer and Nurse Consultant Senior clinical staff
Is there a formal way to capture activity of using Caring for the Dying Patient document in your organisation?	Audit of patient records on SystemOne The community have recently completed a trust wide audit of care in the last days of life with an audit tool based on the NICE Quality Standard Caring for Dying Person.
What have been the successes within your organisation using the Caring for the Dying Patient : audit	Acts as a prompt to address contentious issues arising from LCP Focusing on the patients' and relatives' individual needs. This is reported as one of our KPI's to CCG

What have been the challenges when using the Caring for the Dying Patient document?	Working well now, initially however staff kept referring to <i>pathway</i>
NHS Benchmark will be leading The Caring for Dying Adult Audit” July – Oct 2018: Will your organisation be participating?	We have not had the information

Comments from those interviewed

In the Community a modified version of the Regional Guidance Document (NECN 2015) to provide advice to clinical staff is used.

There is a mandatory palliative care education program which supports staff to understand these priorities and how to ensure they are delivered. We have used the available palliative care resource to teach these principles and to make sure that people understand the care that is required.

North Tees & Hartlepool

NHS Hartlepool & Stockton-on-Tees CCG

North Tees and Hartlepool

NHS Foundation Trust

The University Hospital of North Tees

The University Hospital of Hartlepool

Community Hospitals

Community Services

Peterlee Community Hospitals

North Tees and Hartlepool NHS Foundation Trust

Hospice

Butterwick Hospice, Stockton

Alice House Hospice, Hartlepool

Specialist Palliative Care Team

SPC Team, Farndale House

Mental Health Services

Tees Esk & Wear Valleys NHS Foundation Trust
(Durham)

Service	Usage	Comments
Hospital	Frequently	Paper copy not always completed correctly
Community	Frequently	
Hospice	Frequently	
Care Home	Occasionally	

Question	Answer / Comments
What training and education is in place to support the workforce?	Rolling Programme run by SPC team, Reflective practice, eLearning
Where does the workforce access the document to use?	Within the hospice documentation In hospital there is a "blue" drawer system where all documents are kept
Within your organisation who has the responsibility for training and education re Care for the Dying Person documentation?	Education lead, Palliative care Consultant, SPC team
Is there a formal way to capture activity of using Caring for the Dying Patient document in your organisation?	An activity sheet is completed daily. OACC, Audit Regular audits
What have been the successes within your organisation using the Caring for the Dying Patient : audit	More proactive in its use with its commencement having to be started by a medical member of the team. Continuous use from one organisation to another when a person is admitted. The Trust has embraced the use of the document and teaching has reassured consultants as to the appropriate use. Sometimes difficulty getting GPs to use the document. They often want to fill in on line and are concerned about duplication of their documentation. With the LCP GPs would fill in in anticipation but difficult to do with new document. Balance between practicalities and ideal.
What have been the challenges when using the Caring for the Dying Patient document?	Ensuring new staff understands its use. The challenge leads to its success in being proactive. Audits have shown that ward nurses do not fill in the document.
NHS Benchmark will be leading "The Caring for Dying Adult Audit" July – Oct 2018: Will your organisation be participating?	Yes

South Tees including Hambleton, Richmondshire and Whitby

NHS South Tees CCG

NHS Hambleton Richmondshire & Whitby CCG

South Tees Hospitals NHS Foundation Trust	James Cook University Hospital Friarage Hospital
Community Hospitals	East Cleveland Primary Care Hospital Guisborough Primary Care Hospital Redcar Primary Care Hospital The Friary Community Hospital
Community Services	South Tees Hospitals NHS Foundation Trust
Hospice	Teesside Hospice, Middlesbrough Harriot's - Day Care only St. Catherine's Scarborough
Specialist Palliative care Team	Hospital and Community
Mental Health Services	Tees Esk & Wear Valleys NHS Foundation Trust (Durham)

Service	Usage	Comments
Hospital	Occasionally	Paper copy
Community	Rarely	An adopted version of the regional document is used.
Hospice	Rarely	
Care Home	Rarely	

Question	Answer / Comments
What training and education is in place to support the workforce?	Regular end of life care update sessions for all staff. Training provided to HR&W via South tees and Specialist Palliative Care Team
Where does the workforce access the document to use?	The document is available on the inter and intranet systems and provided by SPC teams
Within your organisation who has the responsibility for training and education re Caring for the Dying Patient documentation?	Specialist palliative care teams- led by Lead nurse for end of life care/ consultant in Palliative Medicine. For HR&W: EOL Care lead SPCT
Is there a formal way to capture activity of using Caring for the Dying Patient document in your organisation?	Yes- regular end of life care audit. No – HR&W
What have been the successes within your organisation using the Caring for the Dying Patient : audit	Our end of life care pro-active service ensures that end of life care documentation is completed (as much as is possible in a 9-5 Mon-Fri service) so our audit results are very positive for both nursing and medical documentation.
What have been the challenges when using the Caring for the Dying Patient document?	Engaging medical staff firstly to identify patients nearing end of life so that all documentation and conversations can be had with the patient and their family and also encouraging medical staff to

	recognise their responsibility regarding the plan of care and decision making. In terms of the community setting this is even more difficult as community nurses struggle to get GP's to engage with the documentation at all!
NHS Benchmark will be leading "The Caring for Dying Adult Audit" July – Oct 2018 Will your organisation be participating?	Yes

Comments from those interviewed

We have split the documentation/responsibilities into a very distinct nursing and medical documentation.

For nursing care plans we use an adapted version of the regional documentation which amalgamates the individual care plans into one document. It therefore has all the elements of the five priorities for care but within one care plan.

For the medical plan of care we give two options; the regional 'recognition' template or our own adapted local version which essentially has the same information- just in a slightly different format.

Ambulance services for some of the region are provided by Yorkshire & Humberside, therefore, documents relevant for these areas will only be accepted, this creates some variances.

Additional Comments from respondents

When the Caring for the Dying Patient (CDP) document was introduced, a comparison with the Liverpool Care Pathway (LCP) was inevitable. Professionals, who used and found the LCP beneficial, were far more likely to welcome the CDP. Those professionals who disliked the LCP were unlikely to embrace the CDP. There was also some understandable anxiety of using another “tick box” form. The apprehension regarding the attitude of the media was also evident in some of the interviews; “the press will have a field day” and “does the Daily Mail know about this?” were some of the comments made.

The CDP is a tool to guide staff in the priorities of care in the last days of life. It is also a record of this care and the conversations between patient/relatives and professionals. It was noticeable that junior staff were much more enthusiastic than professionals who had been qualified for longer. One junior Doctor said, “I like it because it clarifies where we are (the patient is terminal) and guides me on what to do, it actually saves me time”. A Nurse said, “These conversations are hard to get right but this points me in the right direction”, “it is a good aide memoir”.

An area of concern that was often raised was “it takes too long to fill it in”. For the majority of Doctors this ranged from 10 - 30 minutes. For nurses the time element was less of an issue, they often expressed feeling overburdened with paperwork generally, but most felt the CDP was not excessively time consuming and some felt it decreased their paperwork.

A health care professional commented that this process is not easy and may take some time to become embedded in a team “The CDP is only a tool”; “the conversations and planning of the care is what’s important”

Conclusion

The CDP document has been available now for several years and is compliant to the national recommendations: The five Priorities for Care for the Dying Person. However, despite the lengthy development process and pilot phase of this document and the subsequent changes to reflect regional comments, the uptake of the regional CDP document is variable and also dependent upon setting.

The use of the regional CDP documentation is evidenced throughout the region but very few areas have adopted it wholeheartedly or comprehensively. This would suggest, for some localities, that it is still work in progress.

This project has revealed that recognition of the patient who is dying as well as stopping interventions appropriately in the last days of life is often a challenge, especially in the Hospital setting. Several nurses felt they came to a decision that the patient was dying before their medical colleagues, and in the view of the nurses who commented, this resulted in the CDP being instigated late and, in some cases, only hours before the patient died.

Success with implementation of the CDP within localities has been attributed to having a sustained role/ professional who is responsible for training and implementing the document. Other areas have had temporary facilitators for varying lengths of time. The acceptance and embracing of the CDP document is a long-term challenge and never-ending, as new personnel come into post and issues arise

outside the norm. Where there lacks a direct person to take responsibility for roll out, contact and query, providers of care frequently give up on using the document. Key professionals with responsibility for implementation of the CDP include Specialist Palliative Care Doctors and Specialist Nurses as well as End of Life Care Facilitators, the implementation of the CDP document being intrinsic to their role, along with other priorities.

This project has identified two ways of approaching an introduction of change: a “big bang” or “phased in” approach. Whilst the second takes much longer and seems slow, the first does have its challenges. When the CDP document was introduced, on a pre-set date, across the locality, the professionals who are responsible for its implementation are often overwhelmed as problems occur across the patch/hospital. With a more gradual approach, problems can be identified and quickly corrected. Once established within a practice/ward, the facilitator can then move on gaining confidence and expertise as they go.

Success within localities has been apparent following invested time and effort into looking carefully at how the document will practically work in practice. An example from primary care demonstrated engagement with Local Medical Committees as a first line and, once agreement was sought, then an implementation plan with clinicians and also including Practice Managers and administrators. Similarly for secondary care, successful implementation included engagement with Ward Clerks at the planning stage of the roll out of CDP and these strategies paid dividends; those areas now have the document well embedded into practice.

In an age where good care must not only be delivered but also seen to be delivered, the CDP is extremely useful. If audited, all versions of the CDP can give quality information not only to Commissioners, CCGs, the CQC, but also to the professional teams involved. It can highlight where care is good and where areas need to be addressed and therefore training issues can be identified. Without a version of the CDP, no service could identify a way of carrying out an effective audit of care in the last days of life.

The pending National Audit of Care at End of Life (NACEL) has provided a lever for change in some localities. Particularly for Hospitals and Community Hospitals participating in the audit, use of the CDP has been adopted latterly within the time frame to comply with NACEL with organisations working to implement the CDP within a focused time scale.

Some localities are using an alternative document and examples of CDP alternatives have also been found in places such as Critical Care. Acknowledging there are variances in practice, the project has benchmarked the findings against the Regional CDP document.

Whilst there may be differences in the alternative documents and the way they are used, there are also fundamental similarities that they all share;

- Recognition of the patient being in the terminal phase.
- Communication between professionals, patients and relatives.
- The reviewing of medical and nursing interventions.
- The rationalisation of routine medication.
- Prescribing of anticipatory medication (“just in case”).

The CDP is not without its challenges and one major area of consideration is the logistics of the implementation and planning process. Ideally the team needs to decide how the document will be generated, stored and used and by whom. The document then should be held at the patient's bedside; whether in the person's house or easily accessible within an inpatient unit, it must be available to demonstrate transparency in multidisciplinary care. Teams have been successful in using both paper or electronic records or a mixture of both. The key to success is the process being well thought out and agreed. This will be different for each team, influenced by factors such as: how other documents are used, whether teams are based together, whether the patch is rural or urban, and the location of the printer. These and other aspects will affect what is most suitable for each individual team. There is no ideal process and compromises and delays may be inevitable, but these should be identified, considered and reflected on.

Primary care has presented several consistent challenges or resistance to adopt the CDP with several comments raised to the preference to have an electronic version of the document; IT advice and involvement have been highlighted as a requirement to facilitate this. Both EMIS & SystmOne present their own individual challenges for where the document could be stored and utilised and the formatting once printed from electronic version. Without a logical approach, professionals find it difficult to retrieve the document or take several stages to access the forms, print etc. If this process is intuitive and quick, then it is more likely to be used. The intrinsic problem of requiring professionals to keep electronic contemporaneous records and the desire to keep documents in the patient's home or ward bedside has inherent complications; therefore any electronic processing requires a printable document as the end product to ensure that the individual care plan remains with the patient, ensuring transparency in practice is achieved. Professionals are working through what is appropriate for their specific practice but compromises are often made and the CDP is therefore not used.

Several participants suggested a review of the document to streamline the information required and what subsequent additional information is needed depending on situation/locality. The core nursing care plans are sometimes used without the Medical Assessment, reassessment and review document sections; however the medical assessment, reassessment and review information is not extractable from other documentation which carries concern for documentary evidence, as recognition of dying and review by a senior clinician is nationally recommended.

The recognition that the patient is dying and the associated communication have been identified by participants as challenging. However, when recognition and communication are addressed, then the remaining assessment follows systematically, eg drug and treatment review etc.

Project Findings and Good Practice Event

The event took place on the 17th July 2018 with 45 delegates attending. All localities within the region were represented with the exception of Hambleton, Richmondshire and Whitby.

The aim of the event was to share the findings of the Scoping Project of the two regional initiatives: Deciding right and the Caring of the Dying Patient document, facilitated by The Northern England Clinical Networks.

Delegates were the Supportive, Palliative and End of Life Care Core Group representatives and colleagues from across the region. The outcomes of the event were:

- The sharing of the findings from the project
- Learn from the sharing of examples of good practice and group discussion
- Participate in locality led next steps planning, using the findings of the project.

The Programme

The programme provided opportunity to share the findings of the project and showcase examples of practice through a dedicated workshop for both initiatives. The project lead presented the findings of both initiatives from the project with individual locality reports being made available on the day.

The programme delivery lead shared the learning from the Regional Education Group, it was this work that highlighted variation of use of Deciding right and contributed to the decision to embark on this project.

Workshop 1, Caring for the Dying Patient document, was facilitated by the Palliative and End of Life Lead for Newcastle CCG and by the Macmillan Lead Nurse – End of Life Care; Operational Lead for Specialist Palliative Care North Tees and Hartlepool NHS Foundation Trust. (Power Point presentations are available on NECN website)

Workshop 2, Deciding right, facilitated by Nurse Specialist Motor Neurone Disease Care MND Centre and Palliative Care Modernisation Facilitator from St Benedict's Hospice representing the Regional Deciding right Education Group. (Power Point presentations are available on NECN website)

All delegates were given a scheduled time to attend both the Deciding right and Caring for the Dying Patient document workshops.

The event included opportunity for delegates to work within their locality to:

- Benchmark localities on the use of the regional initiatives (prior to hearing the project findings)
- Post workshops: reflect on the days presentations and work from their individual locality reports to identify:
 - The strengths they want to build on
 - Identify barriers in the locality
 - Connections to be made
 - Improvements they want to make

- Action Plan their Next Steps and Goals

The action plans from each locality were retained by each locality and photographed prior to the end of the event and retained by the Northern England Clinical Networks. Each locality will be expected to update their actions at the next Supportive and Palliative care and End of Life Core Group meeting 16th October 2018.

The programme from the event, benchmarking tool and Next Steps/Action Planning document are available as Appendix 1.

Reflections

On reflection, this project has revealed the enormity of the task undertaken to scope both of the regional initiatives within the time frame. However it is evident from the findings there are many examples of good practice across the region which demonstrated how the initiatives are being implemented into practice. However this project has also exposed widespread variation intrinsically within localities and comparatively across the region.

The project findings are inclusive from all localities, largely dependent on the personnel the project lead was able to engage with, and therefore it has to be acknowledged that the project uses a small sample and the information received may not be entirely comprehensive; however it provides an excellent place for discussion and re-focus.

This project has identified gaps where there were challenges in retrieval of information, particularly from social and domiciliary care and therefore this project lacks the engagement with this workforce.

The locality findings have highlighted areas of missing data from specific key documents; on reflection what the project asked was beyond the accessible information available.

The action planning within the event provided the opportunity to re-focus priorities and this was evident by the content within the next steps and the post event conversations.

Acknowledgements

This project has been possible with the support from NHS England End of Life Care; The Northern England Clinical Networks and Members of the Supportive, Palliative and End of Life Care Core Group: who often provided the feedback and other contacts to facilitate the sharing of information. Thanks to the individuals who participated in the locality focus groups.

On behalf of the Northern England Clinical Networks, thanks to all participants.

Melvyn Laycock – Project Lead

Louise Watson - Network Delivery Team Lead Palliative and End of Life Care:

Project Programme Lead

Adrienne Moffett – Cancer Alliance Delivery Manager

Alexa Clark – Clinical Lead Palliative and End of Life Care

Alison Featherstone –Cancer Alliance Network Manager

**Northern Clinical Networks Supportive, Palliative and End of Life Care
 Sharing Deciding Right and Regional Caring for the Dying Patient Document Project
 Findings
 and Good Practice Event**

Tuesday 17th July 2018
 The Durham Centre, Belmont Industrial Estate, DH1 1TN
 12.30-5pm

The aim of the event is to share the findings of a Scoping Project of two regional initiatives: Deciding Right and the Care of the Dying Person Document, facilitated by The Northern England Clinical Networks.

Delegates will be of Supportive, Palliative and End of Life Care Core Group representatives and colleagues from across the region. The outcomes of the event are:

- The sharing of the findings from the project
- Learn from the sharing of examples of good practice and group discussion
- Participate in locality led next steps planning, using the findings of the project.

The Programme of the afternoon is below:

1230-1300 : Buffet lunch and registration		
1300	Welcome and introduction to the event	Dr Alexa Clark, Clinical Lead for Palliative and End of Life Care Louise Watson, Network Delivery Team Lead for Palliative and End of Life Care
1310	Localities – benchmarking exercise	Delegates
1320	Summary of project findings	Melvyn Laycock, Project Lead
Interactive Workshops:		
1345	Group A: Sharing good practice for Deciding Right – Auditorium Group B: Sharing good practice for Care of the Dying Person Document – Conference Room	
Round 2: Refreshments available		
1450	Group A: Sharing good practice for Care of the Dying Person Document – Conference Room Group B: Sharing good practice for Deciding Right - Auditorium	
1550	Main auditorium: Locality table top discussions and <i>Next Steps</i> planning	
1630	Summary	Dr Alexa Clark and Louise Watson
1645	CLOSE OF EVENT	

Appendix 1b

Northern Clinical Networks Supportive, Palliative and End of Life Care
Sharing Deciding Right and Regional Caring for the Dying patient Document Project
Findings and Good Practice Event
Benchmarking Exercise

Please identify where you consider the uptake for the two regional initiatives currently is within your localities:

Indicate *with a cross "x"* the frequency of use of the **Care of the Dying Person Document** which is representative to the individual care setting matched using the following options: **Rarely; Occasionally; Frequently**

	Rarely	Occasionally	Frequently
Hospital			
Hospice			
Community/ Primary Care			
Care Homes			
Social Care			
Other (Please indicate i.e Prisons)			

Deciding Right

Indicate *with a cross "x"* the frequency of use of the **Deciding Right** outcomes which is representative to the individual care setting matched using the following options: **Rarely; Occasionally; Frequently**

	Rarely	Occasionally	Frequently
Hospital Advance Statement ADRT EHCP DNACPR MCA 1&2			
Hospice Advance Statement ADRT EHCP DNACPR MCA 1&2			
Community/Primary Care Advance Statement ADRT EHCP DNACPR MCA 1&2			
Care Homes Advance Statement ADRT EHCP DNACPR MCA 1&2			

Social Care Advance Statement ADRT EHCP DNACPR MCA 1&2			
Other (Please indicate: i.e Prisons) Advance Statement ADRT EHCP DNACPR MCA 1&2			

Appendix 1c

Caring for the Dying Patient Document

Locality:

Strengths we will build on.....

Identified Barriers in your locality.....

Connections we will make.....

Improvements we want to make.....

Identify the *Next Steps* and Goals for your locality:

- **By September 2018**

- **By November 2018**

- **By January 2019**

Deciding Right

Locality:

Strengths we will build on.....

Identified Barriers in your locality.....

Connections we will make.....

Improvements we want to make.....

Identify the Next Steps and Goals for your locality:

- **By September 2018**

- **By November 2018**

- **By January**

References

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Sharing Good Practice Event : Power Point presentations

The presentations from the event can be accessing the links below or at

www.necn.nhs.uk



Care for the Dying
Patient 2018 (2) Dr P



Regional CDP JS
Workshop.pptx



Deciding Right MND
Frances Kelly 2018.ppt



20170717 Deciding
Right Regional Educal