NHS
Northern England
Clinical Networks

Deciding right
and
Caring for the Dying Patient:

A regional review of use

Executive Summary

August 2018

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.

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.

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

Data collection and analysis was undertaken by the project lead over a six month period then a regional Learning and Sharing Event, hosted by NECN on 17th July 2018, was held where learning and sharing cross the localities could take place with additional presentations of good practice. Within the event, each locality were 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.

A full report of the project including dedicated guidance is available with shared sections covering the common themes from the project. The full report includes individual locality findings with additional comments from respondents when these were provided. Conclusions have been reached for each of the guidance and summarised below. The comparable findings from all localities are tabulated at the end of this executive summary.

Deciding right

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.

Caring for the Dying Patient document

The Caring for the Dying Patient (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, e.g. drug and treatment review etc.

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.

DECIDING RIGHT – Summary: regional use of Deciding right by locality.

KEY:	Low uptake	Medium uptake	High uptake	No response

Q1: WHAT TRAINING AND EDUCATION IS IN PLACE TO SUPPORT THE WORKFORCE RE DECIDING RIGHT?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q2: WHERE DOES THE WORKFORCE ACCESS INFORMATION RE DECIDING RIGHT?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q3: WITHIN YOUR ORGANISATION DO YOU HAVE SOMEONE WHO HAS THE RESPONSIBILITY FOR DELIVERING DECIDING RIGHT EDUCATION AND TRAINING?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q4: DO YOU HAVE AN MCA LEAD PERSON WITHIN YOUR ORGANISATION?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q5: DO YOU HAVE A FORMAL WAY OF CAPTURING DECIDING RIGHT ACTIVITY WITHIN YOUR ORGANISATION EG CQUIN TARGETS?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q6: DO YOU HAVE A LOCAL ADVANCE STATEMENT?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q7: IF YOU HAVE AN ADVANCE STATEMENT IN PLACE, DO YOU USE IT?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q8: WOULD IT BE USEFUL TO HAVE A REGIONAL ADVANCE STATEMENT DOCUMENT?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby

Q9: HOW WELL ARE DECIDING RIGHT OUTCOMES EMBEDED INTO PRACTICE?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q10: HOW WELL ARE EHCPs EMBEDED INTO PRACTICE?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q11: HOW WELL ARE DNACPRs EMBEDED INTO PRACTICE?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q12: HOW WELL ARE ADVANCE STATEMENTS EMBEDED INTO PRACTICE?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q13: HOW WELL ARE ADVANCE DECISIONS TO REFUSE TREATMENT EMBEDED INTO PRACTICE?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q14: HOW WELL ARE BEST INTEREST DECISIONS EMBEDED INTO PRACTICE?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby
Q15: DO YOU HAVE SYSTEMS/STRUCTURES IN PLACE IN YOUR ORGANISATION TO ENSURE DECIDING RIGHT IS EMBEDDED INTO PRACTICE AND SUSTAINED?									
North Cumbria	Northumberland	North Tyneside	Newcastle	Gateshead	South Tyneside	Sunderland	Durham & Darlington	North Tees & Hartlepool	South Tees (including Hambleton, Richmondshire & Whitby

Summary: regional use of Caring for the Dying Patient Document by locality

LOCALITY	SERVICE	USAGE	COMMENTS
North Cumbria	Acute	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 using it regularly.
	Hospice	Frequently	Electronic template and care plans
	Care Home	Occasionally	Some nursing homes use paper copies with the support of Nurse Practitioners
Northumberland	Acute	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
North Tyneside	Acute	Frequently	Paper copy
	Community	Occasionally	Paper copy
	Hospice	Frequently	Paper copy
	Care Home	Frequently	Paper copy
Newcastle upon Tyne	Acute	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
Gateshead	Acute	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
South Tyneside	Acute	Occasionally	Despite education and presence of palliative care team, not used as often as could be
	Community	Occasionally	Reluctance from GPs. Not considered often in time.
	Hospice	Frequently	
	Care Home	Occasionally	
Sunderland	Acute	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	
Durham & Darlington	Acute	Rarely	Paper records, then scanned electronically. An adapted version of the regional document is used.
	Community	Rarely	SystmOne template - no paper record. An adapted version of the regional document is used.
	Hospice	Rarely	Electronic using EMIS - does not collate with SystmOne. An adapted version of the regional document is used.

	Care Home	Rarely	An adapted version of the regional document is used.
North Tees & Hartlepool	Acute	Frequently	Paper copy. Not always completed correctly.
	Community	Frequently	
	Hospice	Frequently	
	Care Home	Occasionally	
South Tees (including Hambleton, Richmondshire & Whitby)	Acute	Occasionally	Paper copy
	Community	Rarely	An adapted version of the regional document is used.
	Hospice	Rarely	
	Care Home	Rarely	