Cabinet **5th March 2013**

Report of the Health Overview and Scrutiny Committee

Final Report - End of Life Care Review – *'The Use & Effectiveness of DNACPR Forms[1]'*

Summary

1. This is the final report arising from the Committee's work on their 'End of Life Care Review – The Use and Effectiveness of DNACPR Forms'.

Background

2. At a scrutiny work planning event held on 25th July 2011 it was agreed that the Health Overview and Scrutiny Committee would do some review work around End of Life Care. This led to a workshop being held on 31st August 2011 between Members of the Committee and a variety of stakeholders to agree a specific focus for the review. Discussions led to this being agreed as the 'use and effectiveness of DNACPR forms'.

3. At a further informal meeting of the Committee held on 13th October 2011 it was agreed that the main ambition for the review was:

   To ensure that patients'[2] wishes and instructions are acted upon by health professionals and carers at the end of life, especially in terms of ensuring that instructions in relation to information on DNACPR forms is up to date and adhered to when required.

4. In October 2011 the Care Quality Commission (CQC) published a 'Review of Compliance'[3] for York Teaching Hospital NHS Foundation

[1] Do Not Attempt Cardiopulmonary Resuscitation
[2] Adults aged 16 and over

[3] The full report is available on the CQC website and can be accessed via the following link:
http://www.cqc.org.uk/directory/rcb00

Trust which highlighted major concerns in relation to 'consent to care and treatment'. During their site visit CQC looked closely at 22 patients' care records across eight wards, within these they found that patient information details, in relation to consent, were not always fully completed. One of the standards reviewed by the CQC was 'Outcome 02: Before people are given any examination, care, treatment or support they should be asked to agree to it' and they said of this:

'People we spoke to about consent to treatment told us they had been consulted and given full explanations about what to expect and this was evident within the records we looked at. However, documentation relating to the serious matter of whether a patient should be resuscitated or not, was not being completed correctly or reviewed as required by the hospital's own guidelines. This could mean that some patients may have an instruction in place, which is out of date, incorrect or is no longer in their best interests.'

5. With this in mind the Committee discussed some potential themes that they wanted to receive information on in the first instance, namely:

   - Clarity on what the DNACPR form is, how the form works and who recognises the form
   - Clarification on the difference between a DNACPR form and a living will
   - An understanding of what variants there are to the DNACPR form, if any
   - To understand how the form came into being
   - To understand what is happening now and why it is happening
   - To understand how clearly the scheme is set up
   - To understand the opinions/guidance and advice of professional organisations in relation to this form
   - To investigate how things can be improved and who can help with any suggested improvements

6. The Committee also discussed who they might like to speak to during the course of the review and began to complete the Scrutiny Topic Assessment Form attached at **Annex A** to this report.

Information Received During the Review

7. This subsequently led to the briefing note on DNACPR forms at **Annex B** to this report being submitted to the Committee by NHS North Yorkshire & York which included a copy of the latest version of the DNACPR form.

8. This annex details key information on what Cardiopulmonary Resuscitation (CPR) is, potential outcomes of CPR, the post CPR period, when to consider making a DNCAPR decision, what a DNACPR form is, variants of DNACPR forms, the Yorkshire and Humber Regional DNACPR form, roll out of the regional DNACPR form, how the regional DNACPR form works, who recognises the regional DNACPR form and the differences between a DNACPR form and a Living Will.

9. The information in **Annex B** was discussed at an informal meeting of the Committee held on 21st December 2011 where three Committee Members and a representative of NHS North Yorkshire & York were in attendance. From this annex Members gained a greater understanding of the background to DNACPR forms, in particular the form currently in place across Yorkshire and the Humber. They also gained a greater understanding around how the form worked and how the form should move with patients between care settings.

10. Discussion of this document led to the representative of NHS North Yorkshire and York indicating that Yorkshire Ambulance Service (YAS) had some time ago reported that the DNACPR form was not working as well as it could within their organisation. However it appeared that most of the problems YAS had experienced with Version 11 of the form had been addressed with the introduction of Version 12.

11. Members also heard and discussed some anecdotal evidence around the fact that DNACPR forms had not been accompanying patients when they were discharged from hospital, with good practice stating that the form should travel with the patient and be reviewed on a regular basis. Whilst the CQC report of October 2011 mentions concerns around the review of DNACPR forms it does not specifically mention the issue of forms not travelling with patients between care settings so the Task Group were unable to substantiate this evidence at this point in the review.

12. Further discussion highlighted another anecdote around potential problems with the Out of Hours Service (OOH); however at this stage of the review this appeared to be around patients towards the end of life being admitted to hospital from care settings (at times which were felt to be inappropriate by staff and family), rather than specifically being connected to issues related to DNACPR forms. It was not known whether the anecdote concerned patients who had a valid DNACPR in place.

13. And finally, the different levels and provision of training/support around DNACPR and CPR across health organisations was highlighted as a potential issue by NHS North Yorkshire and York. A more in-depth summary of the discussion from the 21st December meeting is at **Annex C** to this report.

14. On consideration of the briefing paper at **Annex B** and the discussions (as set out in **Annex C**) the Committee identified the following as areas that they wanted to receive further information on from key health providers across the city:

    i. What training is provided and to whom
    ii. Are discussions around DNACPR documented in a patient's case notes/how many clinicians are having conversations with patients
    iii. How is the form used within each organisation
    iv. How is the form audited
    v. Have there been any problems with the form
    vi. Is the use of the form written into each organisation's policies
    vii. Evidence that all staff have been trained
    viii. Do YAS, in particular, have any problems with using the form
    ix. What do organisations do if the form doesn't work? How do they address the problems and learn from them

15. In addition to the information provided at **Annex B** the representative from NHS North Yorkshire and York circulated the results of an online staff survey that had been undertaken between January and July 2011 in relation to the use of DNACPR forms. NHS Bradford & Airedale led on this project and the survey was widely disseminated to as many health organisations as possible (including hospitals, GPs, nursing homes and other primary care trusts) across the Yorkshire and Humber Region. Of those that responded 59% were nurses, 26.6% hospital doctors, 4.5% hospice doctors, 4.8% were GPs and 5.1% stated their profession as 'other'. In total there were 441 responses to the survey and 94 of these were provided by the North Yorkshire and York area. Below is a brief summary of the findings from the survey in relation to the responses from staff across North Yorkshire and York:

    - The majority found the overall experience of using the new form 'satisfactory' or 'good', however 9.1 % found it 'fair' and 8.3% found it 'poor'
    - The majority of staff found their experience of completing the new form 'satisfactory' or 'good', similarly a small number did find it 'fair' or 'poor'

- 46% found their experience of understanding completed DNACPR forms in patients' records 'good' and 11% rated this as 'excellent'
- When asked to rate how you found your experience of discussing the new DNACPR forms with patients, 22% stated that this was 'not applicable' and only 6.6% said that this was 'excellent'.
- When asked to explain what they found helpful about the new regional DNACPR forms the following responses were given:
  - Ease of use
  - Patient feels in control
  - transfer of information across services easier
  - improved clarity of decision making

- When asked to explain what they found difficult/unhelpful about the new regional DNACPR forms the following responses were given:
  - Form not accepted in South Tees after North Yorkshire Primary Care Trust (PCT) split
  - Unsure who can sign/counter sign the form
  - Not all staff fully trained in using the new form
  - Non-coloured form

- 61% of respondents had received training on how to use/complete the form

16. At the meeting held on 21st December 2011 Members suggested that the above survey might be repeated in 6 months time after the form had been in place for a little longer and more people were used to using it.

17. Members were informed that Yorkshire Ambulance Service completed a different set of questions and are not, therefore, included in the overall figures above.[4] However, to summarise the outcomes of the survey, 67 members of staff responded and the responses are summarised below:

    - 83.6% indicated that they were not always informed of the existence of the new regional DNACPR form before attending a patient in a community or acute organisation

    - 53.7% did not feel that the new regional DNACPR form was easy to find in a patients' medical records whilst 46.3% felt it was

[4] Copies of both surveys are available as background papers to this review and are also published in the Health Overview and Scrutiny Committee papers of 6th August 2012 available via by clicking here

- 59.7% responded that they were informed of the DNACPR form when attending a patient in their own home. However 68.7% said that the form was not easy to find in patients homes with 70.1% responding that relatives were not always aware of a DNACPR decision being in place for a patient.

- When asked whether the new DNACPR form was easy to understand 87.5% of respondents said yes, however, only 48 out of 67 responded to this particular question with 10.4% (of the 48 respondents) saying that they had attempted CPR despite the existence of a DNACPR form.

18. However, Members did acknowledge that this information was now out of date and improvements had been made within YAS in relation to DNACPR forms since the survey was undertaken.

19. After consideration of all of the information received at the meeting on 21st December 2011 the Scrutiny Officer wrote (on behalf of the Committee) to six key health organisations asking them to respond to 11 specific questions. In addition to this the letter was sent to various other partners across the city and responses were invited.

20. A table containing all the responses received is attached at **Annex D** to this report with the following paragraphs very briefly summarising some of the key points raised in the responses:

    i. <u>Is your organisation using this form? If not why not? Are all the relevant members of staff aware of its existence?</u>

    YAS, Leeds & York Partnership NHS Foundation Trust (LYPFT) and York Teaching Hospital NHS Foundation Trust (YTHFT) all use the form. Whilst the form requires clinical/medical completion staff in care settings, on the whole, are aware of its existence.

    ii. <u>Can you give the Committee some positive examples of the way your organisation has used the DNACPR form?</u>

    Both YTHFT and NHS North Yorkshire and York mentioned the fact that the Out of Hours (OOH) handover forms from GPs to OOH had been redesigned to include information on DNACPR status, ensuring good sharing of information. NHS North Yorkshire and York, whilst not using the forms specifically but being involved with implementation and roll out of the forms, had an identified project lead who is a member of the Regional DNACPR Project Board.

iii. What training has your organisation provided in relation to competing and using the form? What percentage of staff has your organisation trained? When will the remainder be trained? Can you evidence how staff are trained? In addition to this do you offer refresher training and routinely offer training to all new member of staff on how to use the form?

YAS said that all existing staff will receive training on DNACPR and as at February 2012 82.37% staff had been trained. Both LYPFT and YTHFT train their staff on the use and rationale of the form. Training for CYC care staff and care staff working in the independent care sector is not mandatory; whilst some have had training others have not.

iv. How has the use of the form been integrated into your own policies? Is it written into your own policies?

YAS, LYPFT, YTHFT and NHS North Yorkshire & York all have the form integrated into their own policies; however, most care homes do not.

v. Do you audit the use of the form? If so, how?

YTHFT and LYPFT have audit processes in place.

vi. In relation to the DNACPR form – have you received any complaints from families after a relative has passed away? If so, what lessons have you learned from this?

YAS cited two examples of inappropriate resuscitation which appeared to have involved crew members who had not, at that point in time, been trained on the DNACPR process. YTHFT had had 2 or 3 complaints around communications with family members. St. Leonard's Hospice had feedback from a family who had a relative at home with a DNACPR form in place where YAS had attempted CPR.

vii. Are there any barriers to your organisation using the form? If so, what are these and what action have you taken to try and resolve this?

There were no specific barriers to any of the organisations using the form. However it was acknowledged that further training was needed in using the form.

viii. Has your organisation had any experience of the form not working? If so what were these experiences and what course of action was taken to try and resolve the problem?

YAS highlighted three main issues; the first around a document being refused as it did not have a red border, the second around the non-acceptance of a form as it was not thought to be an original document and the third around non-acceptance of the form as it was thought that the review date had expired. This appeared to be a training/educational issue. One care home said that a GP had refused to sign a form.

ix. Has your organisation had any experience of patients being given CPR even though there has been a DNACPR form in place? What were the circumstances that overruled the DNACPR decision?

NHS North Yorkshire and York responded detailing a situation where a patient had been given CPR by YAS. The ambulance crew had not received training around DNACPR and therefore would not accept the form. YTHFT cited two instances where there had been problems; one with an out of date form that YAS would not accept and the other a situation where a patient was given CPR.[5]

x. Is there anything further that you think the Committee should be aware of in relation to the use and effectiveness of DNACPR forms (either generally or within your organisation)?

YTHFT mentioned that there were several issues regarding embedding the form in a community setting. Responses from representatives at independent care homes highlighted a need to provide more publicity around the form, the need for GPs to have more conversations with patients whilst a person has capacity to make a decision and the need to be made aware when a new version of the form was released.

xi. If a DNACPR form was not accepted by Yorkshire Ambulance Service when transporting a patient, why was it not accepted?

YAS have responded to this at question viii but there were four main reasons that forms had not been accepted, these being; the form should have red borders, the form was a copy, the crew felt the form was several months old and there were no instructions for ambulance crews.

21. This information was discussed at a further informal meeting held on 29th February 2012 with the following in attendance to join the debate:

- 4 Members of the Health Overview & Scrutiny Committee
- Representative of Yorkshire Ambulance Service

[5] These appear to be a repetition of incidents previously highlighted

- Representatives from York Teaching Hospital NHS Foundation Trust (Medical Director and Palliative medicine Consultant)
- Representatives from NHS North Yorkshire & York
- A GP from Strensall Medical Group
- Representative from North Yorkshire Police
- Representative from York Council for Voluntary Service (CVS)
- Representative from York Local Involvement Network (LINk)
- 1 renal social worker and 1 hospital social worker
- Representatives from City of York Council
- Representative from St Leonard's Hospice
- Representative from Macmillan Cancer Support

22. A detailed summary of the discussion is attached at **Annex D1** to this report but briefly this includes the implementation of training courses at the hospital to increase awareness of the form, other practices at the hospital leading to improvements and an increased awareness of what a patient's wishes were around DNACPR, a training programme being run by Yorkshire Cancer Network and the Out of Hours Service.

23. To put the information received to date and the discussions had in relation to this into context the Committee felt at this stage, that it was necessary to identify some areas where either improvements needed to be made or further information was needed, not forgetting to acknowledge there were areas of good practice. In the first instance it was important to understand and reiterate that DNACPR was just one element of the end of life care process and advanced decisions/plans about life saving should be in the context of a patient's deteriorating condition. However, this review was around the use and effectiveness of DNACPR forms and any recommendations arising would be in the context of this.

24. Some of the anecdotes heard, along with several of the points raised in discussions, illustrated that some of the information given to families had been poor and some of the experiences traumatic. Information, in the future, needed to be joined up and about the whole end of life care pathway. Good experiences should not be disease specific (at the moment cancer patients nearing the end of their life appeared to be offered a better 'service' than others) and good practice should be rolled out to all services to allow all patients nearing the end of their life to be treated with dignity.

25. At this stage in the review Members sought further clarity on the following:

26. The form itself - On several occasions throughout the review concerns had been raised, including in **Annex D** to this report, about whether photocopies and/or black and white copies of the form could be accepted. The representative from NHS North Yorkshire & York confirmed that the form with the red borders was the preferable one but as long as the form was 'original' with appropriate and original signatures then black and white was acceptable. He also confirmed that at the moment Version 11 of the form was acceptable however, older forms should be reviewed and the current Version, Version 12 should really be used. In the Acute Trust Version 12 is now the only form in use. The Committee felt that this was an issue that could be addressed by further training on how to use the form.

27. The Out of Hours Service (OOH) – The Chair wrote to the OOH Service outlining the issues that had been raised in the papers received and the associated discussions. The Chair was also aware that to date, the Committee had only heard one side of the story and much of the information that had been received about the OOH Service was anecdotal. It was therefore felt that clarity on much of what had been said needed to be sought from OOH.

28. Training and Support on the DNACPR form – This had been a recurring theme running through the evidence received as part of this review and training now appeared to be in place for all hospital and YAS staff. However, whilst DNACPR forms were, in the main, completed by clinicians it was felt that it was still important for staff in all care homes across the city to have a good understanding of how and why DNACPR forms were put in place. Members felt that there should be adequate support mechanisms in place to allow for this, specifically to reduce the amount of avoidable hospital admissions for those at the end of life.

29. At a further meeting held on 6th August 2012 the Clinical Director of Unscheduled Care and the Director of Partnerships and Innovation from Harrogate and District Foundation Trust (who had the contract to run the York and Selby Out of Hours Service) attended a meeting of the Committee, alongside key partners[6]. They submitted written evidence to the meeting and this is at **Annex E**, to this report [7]

[6] Representatives of Yorkshire Ambulance Service, York Mental Health Forum, York Local Involvement Network, St. Leonard's Hospice, NHS North Yorkshire & York, York Teaching Hospital NHS Foundation Trust, Harrogate and District Foundation Trust, Leeds and York Partnership NHS Foundation Trust, Vale of York Clinical Commissioning Group, York Branch Royal College of Nursing, Independent Care Group, York Carer's Forum, York

30. This set out information on the pathway by which DNACPR forms are received into the OOH service, an overview of the difficult issues relating to the use of the forms, the verification of death process, evidence supporting the use of DNACPR forms in the OOH period and current action.

31. A summary of the discussions had at the meeting held on 6th August 2012 is at **Annex F** to this report. However some of the issues raised at the 6th August 2012 meeting went beyond the scope of this review but included issues around Living Wills and Advanced Decisions along with their role in ensuring good end of life care and giving patients control over key decisions in their life.

32. These discussions further identified areas of concern and where improvements could be made. The York Hospital Medical Director identified four possible areas where he felt tangible outcomes could be made namely:

- Working better in partnership
- Working towards the Gold Standards Framework[8]
- Working towards consistency in nursing homes
- Improving practices overall

33. In addition to this Members also felt that the following could be improved:

- Training/support on DNACPR forms
- Publicity of the DNACPR form and end of life care issues in general
- Partnership working
- Ensuring that reviews of existing DNACPR forms already in place are done in a systematic way

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Council for Voluntary Service, York Older People's Assembly, North Yorkshire Police and City of York Council.

[7] Further supporting papers were submitted by the OOH and these were published in the health Overview and Scrutiny Committee agenda of 6th August 2012 and can be accessed here

[8] The Gold Standards Framework (GSF) is a systematic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting.

Consultation

34. Various key partners have been consulted during the course of this review and are referenced in the annexes and background papers associated with this report, as well as in the report itself

Options

35. There are no specific options for Members arising from the draft final report. However, Members are asked to identify any amendments they might wish to make to the body of the report or the recommendations contained within it prior to it being presented to Cabinet for consideration.

Analysis

36. It would be appropriate to mention again at this stage that the remit of this review was specifically:

    To ensure that patients' wishes and instructions are acted upon by health professionals and carers at the end of life, especially in terms of ensuring that instructions in relation to information on DNACPR forms is up to date and adhered to when required.

37. It has been very difficult for the Committee not to, on occasion, stray from this very specific focus in light of the enormous amount of information they have received which has spanned across much wider issues around end of life care. in spite of this, the recommendations arising from the review are, however, focussed around the agreed remit.

38. The Committee had originally started this review after a CQC report had identified issues around the completion and review of DNACPR forms at York Teaching Hospital NHS Foundation Trust in October 2011. Since this report the Committee are pleased to acknowledge that significant improvements have been made and that the CQC had re-inspected the hospital in February 2012 and now considered them compliant. The short paragraph below is an extract from the CQC's report:

    'In July 2011 we carried out a review and found that improvements were needed to documentation relating to the serious matter of whether a patient should be resuscitated or not. This was not being completed correctly or being reviewed as required. Over the course of this most recent visit we found that the trust and their staff had worked hard to make sure improvements had been made. New practices had been introduced and staff, including doctors and consultants, had received appropriate training and information relating to the trust's policy on this matter.

We reviewed, in total, 12 'do not attempt resuscitation' (DNAR) forms across the wards we visited. All of these had been completed on the correct forms and all the information required was present.'

39. However, despite this positive move forward and the relatively low numbers of complaints and incidents that can be evidenced in relation to DNACPR forms, the Committee still felt there were further improvements that could be made to improve their use and effectiveness. Whilst there was no evidence that a large number of people within the city were having a poor death, in the few instances where things had gone wrong it had obviously, from the evidence received, caused distress to all parts of the system and this needed to be avoided if at all possible.

Conclusions

40. Having considered all the information received over the course of the review the Committee identified several areas where they thought improvements needed to be made namely:

- Raising awareness with the general public about the DNACPR form and end of life care choices more generally
- Ensuring that once DNACPR forms have been completed the right people know they are in place
- Ensuring that everyone knows what to do with the form once it has been completed and co-ordinates and shares it appropriately
- Ensuring that staff in care homes are supported to respond to and respect the clear wishes of residents as set out in a DNACPR agreement
- Ensuring that any DNACPR forms in place are reviewed in a timely and systematic way

these themes are expanded upon in the paragraphs below:

41. Public information and public awareness – The general underlying context of the review as set out in the first part of the remit set was *'to ensure that patients' wishes and instructions were acted upon by health professionals and carers at the end of life ...*'. Whilst the main focus of the review was around the use and effectiveness of DNACPR forms ensuring that end of life care was good in much wider terms was also implicit throughout the whole review.

42. As can be seen from the various annexes and background papers associated with this report, several times during the review, including in the initial workshop held in August 2011, mention was made of there not being enough understanding of end of life care choices. It was accepted that it was a difficult subject to raise with discussions around it needing to be treated sensitively. There was also little public profile of such matters

43. The Committee believed that better press and publicity around the existence of DNACPR orders and also end of life care issues in general would lead to an increased public awareness and willingness to have conversations around this subject. It could also lead to more people asking to have a DNACPR order put in place towards the end of their life.

44. Representatives from York Carer's Forum spoke at the meeting held on 6th August 2012 and said that community meetings could provide a chance for discussion and input into the successful use of the DNACPR form. This was felt to be a positive move, especially if it gave residents confidence to start discussions with their GPs.

45. these considerations led to the Committee making the following recommendation:

    Recommendation 1 – that key health partners, namely York Teaching Hospital NHS Foundation Trust, Yorkshire Ambulance Service, Independent Care Group and York GPs, led and co-ordinated by the Vale of York Clinical Commissioning Group look at ways of better publicising the existence of DNACPR forms and in doing this they make use of the wealth of experience and knowledge that already exists within voluntary organisations such as the Carer's Forum' and LINks[9] (soon to be HealthWatch) to assist them with holding public events

46. Information Sharing - Evidence received throughout the review also highlighted room for improvement in relation to information sharing between key health partners and that further work needed to be done to allow the Out of Hours Service to better access a patient's GP/hospital record to see whether a DNACPR order was in place.

47. Information given by both York Hospital and NHS North Yorkshire and York in response to question 2 at **Annex D** to this report stated that the Out of Hours handover forms from GPs to doctors at the Out of Hours Service had been re-designed to include information on DNACPR status and to ensure good sharing of information. However the Committee felt that more still needed to be done around this in light of the information

[9] Local Involvement Networks

submitted by the OOH Service and the discussions around this that took place at the meeting on 6th August 2012 (**Annex E** refers).

Recommendation 2 - That key health partners namely York Teaching Hospital NHS Foundation Trust, Yorkshire Ambulance Service, Independent Care Group, York GPs and the Out of Hours Service led and co-ordinated by the Vale of York Clinical Commissioning Group review whether the redesigned handover forms for the OOH Service GPs have improved the sharing of information around end of life care wishes (including DNACPR forms) and explore whether there are further improvements that can be made in relation to information sharing.

48. Partnership Working – This was highlighted on several occasions throughout the review where it was acknowledged that there needed to be improvements to partnership working between all health agencies in relation to the health needs of the city's residents. New Neighbourhood Care Teams were being developed within the Vale of York Clinical Commissioning Group's area and it was hoped that these teams would offer a more holistic view and be able to plan more proactively for the health and support needs of individuals, including having discussion around end of life care choices. It was hoped that the new Neighbourhood Care Teams could also take the lead role in co-ordinating plans in response to people's individual end of life care choices.

    Recommendation 3 – That key health partners ensure that there are appropriate co-ordination arrangements in place to ensure that patients can discuss their end of life care wishes and those wishes are enacted. The Neighbourhood Care Teams should play a pivotal role in responding to this recommendation, in particular in terms of identifying patients most at risk of health problems and looking at ways of talking to patients about their End of Life Care needs, including DNACPR orders.

49. Support for Care Home Staff – As can be seen from the evidence given in the annexes attached to this report mention has been made on several occasions that a significant proportion of avoidable admissions to hospital at end of life were coming from care homes (both Council run and independently run). Members felt that it was important that care homes had a greater understanding around their role at end of life and felt supported and part of any end of life care plan in place for their residents.

    Recommendation 4 – That the Multi-Agency Workforce Development Group within the city be asked to consider how they can support all care homes within the city to achieve this.

50. Review of Existing DNACPR Forms - At various stages throughout the review concerns were raised about how existing DNACPR orders were reviewed and whether they were always up to date. The Committee felt that any reviews should be done in a systematic way. It was noted that when NHS North Yorkshire and York had given a copy of the current DNACPR form to all health providers across the region this was accompanied by a best practice guide. However, this was only a guide and each individual organisation had its own policy around resuscitation which could complicate matters.

    Recommendation 5 – That once a DNACPR form is in place:

    i. there is a known protocol setting out who will undertake the review of the form and when

    ii. the review date should be clearly stated on the front of the form

    iii. there are processes in place within key health partners' internal policies to identify which forms are due for review and how these will be undertaken

    iv.it is ensured that the completion of planned reviews is monitored.

Council Plan 2011-2015

51. This review is linked with the 'protecting vulnerable people' element of the Council Plan 2011-2015; specifically the theme of 'safeguarding adults and promoting independence'. Two of the key outcomes of this theme are 'more people will live for longer in their own homes' and 'there will be a focus on independence and greater choice and control over their lives for vulnerable people'.

Comments from Key Health Partners

52. All organisations involved in this review were asked if there were any further comments they wished to make on the recommendations arising from this review. All responses received are set out below:

53. NHS North Yorkshire and York is reviewing the Yorkshire and Humber wide DNACPR form, and this review is due to be completed by June 2013, with a new version of the form being released shortly after. As a result of this the Yorkshire Cancer Network have taken the opportunity to review the current position across the Yorkshire and Humber by way of a 'DNACPR Education Questionnaire'; this asks questions around what changes should be made to any new version produced, what education in

relation to DNACPR has been implemented in individual localities, any issues that should be raised with a DNACPR Working Group, any complaints about the DNACPR form or any areas of good practice that should be shared.

54. NHS North Yorkshire and York also confirmed that they would cease to exist as of 1st April 2013. However most of the recommendations arising from this review refer to health partners working together, improving communication, sharing information, training and protocols to be in pace which are fair and necessary. The review of the document will be managed by Yorkshire and Humber Strategic Working Group who met on 12th November and will be meeting again in January, York Teaching Hospital NHS Foundation Trust have representation on this group.

55. The Directorate Manager for Specialist Medicine at York Hospital said that we agree with the recommendations that have been made and they fit well with our own strategy. I do not foresee any major obstacles to progression and there are no implications that I feel need to be raised at this stage. There will be challenges in areas such as patient information, consent and getting systems to talk to each other; however we will work through these issues with other key health partners.

56. Coincidently York Hospital have already started looking at a number of work streams which fit well with the recommendations that have been made, as follows:

- A new York Hospital internal End of Life Care Forum has been formed with internal hospital and community representation.
- From the Forum, a new End of Life Care Strategy and Workplan are being developed to ensure progress against a number of initiatives in end of life care (this includes a specific item on DNACPR)
- The York and Scarborough End of Life Care Board has also recently formed and met. This is a multi-agency provider collaborative to aid working across care settings.
- A Lead Nurse for End of Life Care starts on 2nd January 2013 appointed jointly by the Acute Trust and St. Leonards Hospice to give greater emphasis to End of Life Care issues and give a dedicated voice and ears to these issues. The Lead Nurse will also lead our education programme and work closely with volunteer and partner organisations.

57. The Vice-Chair of York Local Medical Committee (YORLMC) indicated that YORLMC welcomed this report and its findings. However, it did feel that all local GPs needed to have a clearer understanding of what was expected of them, in relation to implementing the recommendations.

58. YORLMC also advised that NHS North Yorkshire and York had given notice on the current specification for the Gold Standards for Palliative Care Local Enhanced Service, with the termination date for this being 31st January 2013. This effectively means that funding will be withdrawn to support this service and this will impact on capacity within general practice from February 2013. To explain this further part of the Gold Standard around palliative care was for all those involved in palliative care to have regular meetings together, this would include (for example) GPs, palliative care nurses and district nurses to discuss all patients on the palliative care register. The Primary Care Trust introduced a service (with funding) to allow this to happen. This service and the regular monthly meetings with all involved flagged up areas of good practice, new services on offer, and overall better communication between all those involved. A report writing template was introduced and this was completed for every patient on the palliative care register, making it easier to spot what help might be needed at an early stage for individual patients as well as increasing awareness around palliative care in general.

59. When the funding for the formalised meetings is withdrawn in 2013 good practice is still likely to be followed by GPs, however the requirement to follow the Gold Standard is removed. The regular and more formalised meetings may well cease (although this will be dependent on the capacity of each individual GP surgery) and information will be shared in a more informal and ad hoc way; especially as the formalised meetings can take up quite a lot of clinical time. This could mean that those involved with palliative care do not get to look at issues with colleagues in such a holistic way as they did when the meetings were more formalised and everyone was present in the same room.

60. A representative of Yorkshire Ambulance Service responded that they were happy to support, where possible, such initiatives as those raised in the recommendations in association with other key health partners.

61. The Chief Executive from the Independent Care Group (ICG) has confirmed that she has put an item in the weekly ICG update reminding people about the DNACPR form and where to find it on the NHS website. She also confirmed that on the occasions when a new version of the form is issued she lets people know that this has happened.

62. In relation to the recommendation around supporting care homes; if training could be sourced, even potentially through City of York Council's Workforce Development Unit then the ICG would be happy to promote this.

Implications

63. **Financial** – It is recognised that improvements to the processes and protocols will need to be delivered within the existing resources of all partners. Providing better information so that people can die in the settings they choose, and other than a hospital, will help reduce unnecessary hospital admissions.

64. In relation to recommendation 4 the Multi-Agency Workforce Development would be happy to receive this recommendation and consider the evidence of need for training alongside identifying how solutions may be implemented to meet this need. Development and implementation of solutions is likely to include consideration of : how much of the care sector workforce need the training, the costs of providing the training and how this will be funded, methods for assessing and evaluating impact and outcomes. If agreed the Strategy Group is likely to require partnership contributions to implement this.

65. **Human Resources** - There are no specific implications for staffing. Support and training for staff, including those in care homes will require multi agency collaboration. This could be progressed through the multi agency workforce development strategy group.

66. **Other** – There are no other implications associated with the recommendations within this report.

67. **Implications for health partners** – The implications set out above are directly for City of York Council and not for any of our key health partners that have been involved in this review. It will be for those health partners to identify any support or contributions, in kind or otherwise, to assist in the delivery of the recommendations.

Risk Management

68. In compliance with the Council's risk management strategy there are no high risks associated with the recommendations within this report. However if no action is taken then end of life care may not be as effectively planned as it could be, and this will increase risks in respect of finances within the health care system.

Recommendations

69. Members are asked to consider the draft final report and the associated recommendations arising from this scrutiny review which are listed below:

70. Recommendation 1 – that key health partners, namely York Teaching Hospital NHS Foundation Trust, Yorkshire Ambulance Service, Independent Care Group and York GPs, led and co-ordinated by the Vale of York Clinical Commissioning Group look at ways of better publicising the existence of DNACPR forms and in doing this they make use of the wealth of experience and knowledge that already exists within voluntary organisations such as the Carer's Forum' and LINks (soon to be HealthWatch) to assist them with holding public events.

71. Recommendation 2 - That key health partners namely York Teaching Hospital NHS Foundation Trust, Yorkshire Ambulance Service, Independent Care Group, York GPs and the Out of Hours Service led and co-ordinated by the Vale of York Clinical Commissioning Group review whether the redesigned handover forms for the OOH Service GPs have improved the sharing of information around end of life care wishes (including DNACPR forms) and explore whether there are further improvements that can be made in relation to information sharing.

72. Recommendation 3 – That key health partners ensure that there are appropriate co-ordination arrangements in place to ensure that patients can discuss their end of life care wishes and those wishes are enacted. The Neighbourhood Care Teams should play a pivotal role in responding to this recommendation, in particular in terms of identifying patients most at risk of health problems and looking at ways of talking to patients about their End of Life Care needs, including DNACPR orders.

73. Recommendation 4 – That the Multi-Agency Workforce Development Group within the city be asked to consider how they can support all care homes within the city to achieve this.

74. Recommendation 5 – That once a DNACPR form is in place:

    i. there is a known protocol setting out who will undertake the review of the form and when
    ii. the review date should be clearly stated on the front of the form
    iii. there are processes in place within key health partners' internal policies to identify which forms are due for review and how these will be undertaken
    iv. it is ensured that the completion of planned reviews is monitored.

    Reason: In order to complete this scrutiny review.

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Wards Affected: **All** ✓

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Background Papers:
(available from the Scrutiny Officer on request)
1. Care Quality Commission Review of Compliance (October 2011)
2. Results of online staff survey undertaken by NHS Bradford and Airedale
3. Survey Results Undertaken by YAS Staff
4. Letter to Key Health Organisations
5. 'What Happens if my Heart Stops' Leaflet
6. Supporting Documents submitted by OOH
7. Care Quality Commission Review of Compliance (March 2012)

Annexes (online only)
Annex A Topic Assessment Form
Annex B NHS North Yorkshire & York Briefing Note on DNACPR Forms
Annex C Summary of Discussion – 21.12.2011
Annex D Responses from Key Health Organisations
Annex D1 Summary of Discussion – 29.02.2012
Annex E Written Evidence from the Clinical Director of Unscheduled Care
Annex F Summary of Discussion – 06.08.2012