

Report of the Assistant Director Governance & ICT

Interim Report - End of Life Care Review – ‘The Use & Effectiveness of DNACPR Forms¹’

Summary

1. This report updates the Committee on progress made in relation to their review on End of Life Care. It also asks them to discuss further some of the issues raised to date and to identify the next steps for the review.

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:

Try and ensure that patients² 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’ for York Teaching Hospital NHS Foundation 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

¹ Do Not Attempt Cardiopulmonary Resuscitation

² Adults aged 16 and over

across eight wards, within these they found that patient information details, in relation to consent, were not always fully completed. An extract from the CQC report details their concerns; this is attached at **Annex A** to this report.

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 find out how many DNACPR forms are not adhered to and the reasons why (statistical rather than specific information)
 - 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 B** to this report.

Information Received to Date

7. This subsequently led to the briefing note on DNACPR forms at **Annex C** to this report being submitted to the Committee by NHS North Yorkshire & York. **Annex C** also includes a copy of the latest version of the DNACPR form.
8. The information in **Annex C** 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. A summary of their discussions is at **Annex C1** to this report.
9. On consideration of the discussions set out in **Annex C1** 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

10. In addition to this 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. A copy of the results from the survey is at **Annex D** to this report. 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 you found difficult/unhelpful about the new regional DNACPR forms the following responses were given:
 - Form not accepted in South Tees after North Yorkshire 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 people had received training on how to use the form

11. At the meeting held on 21st December 2011 Members suggested that the above survey 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.

12. Yorkshire Ambulance Service completed a different set of questions and is not, therefore, included in the overall figures above. A copy of a separate survey completed by Yorkshire Ambulance Service staff is attached at **Annex D1** to this report.

13. After consideration of all of the information received at the meeting on 21st December 2011 the Scrutiny Officer wrote to key health organisations with the letter attached at **Annex E** to this report. This letter contained 11 questions that 6 key health partners were asked to respond to. In addition to this the letter was sent to various other partners across the city (listed in the letter) and responses were invited.

14. A table containing all the responses received is attached at **Annex F** to this report. 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
- 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

15. A summary of the discussion is attached at **Annex F1** to this report.
16. To put the discussions in both **Annexes C1** and **F1** into context 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 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.
17. Some of the stories told above, along with several of the points raised, 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.
18. 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 Framework³
 - Working towards consistency in nursing homes
 - Improving practices overall
19. Concerns had also been raised in **Annex F** 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 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 the only form currently in use.

³ 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

20. Various key partners have been consulted during the course of this review. **Annex E** contains a list of persons consulted and invited to the meeting held on 29th February 2012. **Paragraph 14** of this report contains a list of all those who attended on 29th February.

Options

21. There are no specific options for Members arising from the interim Report. However, Members are asked to consider and analyse the information received to date and advise the Scrutiny Officer of the next steps for the review.

Analysis & Next Steps

22. This review has now been going on for sometime; although work is progressing fairly well albeit there has been a slow period. Corporate and Scrutiny Management Committee has agreed that this review can be carried forward into the new municipal year for completion.
23. Members are asked to consider and analyse the information received to date and identify the next steps for the review. Some key themes are beginning to emerge from the evidence gathered such as possible issues around the Out of Hours Service, training provision in care homes in relation to DNACPR forms and training around and handling of expected deaths across all health organisations.

Next Steps and Actions for Today's Meeting

24. The Chair of the Committee has written to the Out of Hours Service (OOH) outlining the issues raised to date as part of this review. The Chair was aware that, to date, the Committee had only heard one side of the story and much of the information that had been received was anecdotal.
25. She felt that It was important that the Committee receive information from the OOH in relation to the comments made to date and to understand what the OOH service are doing in relation to using DNACPR forms and what training they receive as a service .
26. The Clinical Director of Unscheduled Care has confirmed he will be in attendance at the meeting to join the discussions. He has also submitted written evidence for the Committee's consideration and this is at **Annex H, H1, H2, H3 and H4** to this report.

27. In addition to this, at an earlier stage of the review, Members had expressed an interest in discussing the 'End of Life Care Services' report produced by the York Local Involvement Network (LINK) in 2009. This was a much broader review of End of Life Care Services and did not specifically deal with DNACPR forms. A copy of the report is attached at **Annex I** for information. However a representative from the York LINK has been invited to today's meeting in case there are any questions from Members.
28. After considering all the evidence received to date Members are asked to identify the key themes arising from this review to date. They are then asked to analyse these and consider whether they would like to receive more information. If so, Members are asked to identify what further information they would like to receive and from whom.

Council Plan 2011-2015

29. 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 is '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'.

Implications

30. Currently no financial, human resources, equalities, legal or other implications have been identified. However, as the review progresses and recommendations are put together any implications that do arise will be addressed and included within the Committee's final report.

Risk Management

31. In compliance with the Council's risk management strategy there are no known risks associated with the recommendations within this report. Should any risk be identified as the review progresses then these will be clearly identified in the final report of the Committee.

Recommendations

32. Members are asked to consider and analyse the information to date and identify the key emerging themes and the next steps of this review.

Reason: In order to progress the review towards completion.

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Report
Approved

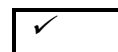


Date 24th July
2012

Specialist Implications Officer(s) None

Wards Affected:

All



For further information please contact the author of the report

Background Papers:

None

Annexes

- Annex A** Extract from Care Quality Commission Report
- Annex B** Topic Assessment Form
- Annex C** NHS North Yorkshire & York Briefing Note on DNACPR Forms
- Annex C1** Summary of Discussion – 21.12.2011
- Annex D** Copy of Survey Undertaken by NHS North Yorkshire & York
- Annex D1** Copy of Survey Results Undertaken by YAS Staff
- Annex E** Letter to Key Health Organisations
- Annex F** Responses from Key Health Organisations
- Annex F1** Summary of Discussion – 29.02.2012
- Annex G** 'What Happens if my Heart Stops' Leaflet
- Annex H** Written Evidence from the Clinical Director of Unscheduled Care
- Annex H1** Supporting Documents Accompanying Annex H
- Annex H2** Supporting Documents Accompanying Annex H
- Annex H3** Supporting Documents Accompanying Annex H
- Annex H4** Supporting Documents Accompanying Annex H
- Annex I** LINK Report 2009 – 'End of Life Care Services'