Notice of meeting of
Health Overview & Scrutiny Committee

To:	Councillors Funnell (Chair), Riches, Boyce, Hodgson, Doughty (Vice-Chair), Richardson and Cuthbertson
Date:	Monday, 6 August 2012
Time:	5.00 pm
Venue:	The Guildhall, York

A G E N D A

1. **Declarations of Interest** (Pages 3 - 4)
   At this point in the meeting, Members are asked to declare any personal, prejudicial or disclosable pecuniary interests they may have in the business on this agenda.

2. **Public Participation**
   At this point in the meeting, members of the public who have registered their wish to speak regarding an item on the agenda or an issue within the Committee's remit can do so. The deadline for registering is **Friday 3 August 2012** at **5:00 pm**.

3. **Interim Report- End of Life Care Review 'The Use & Effectiveness of DNACPR Forms'** (Pages 5 - 218)
   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.

4. Urgent Business

Any other business which the Chair considers urgent under the Local Government Act 1972.

Democracy Officer:

Name: Judith Betts
Contact Details:

- Telephone – (01904) 551078
- Email – judith.betts@york.gov.uk

For more information about any of the following please contact the Democracy Officer responsible for servicing this meeting

- Registering to speak
- Business of the meeting
- Any special arrangements
- Copies of reports

Contact details are set out above

 Agenda Annex

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Scrutiny Committees

The purpose of all scrutiny and ad-hoc scrutiny committees appointed by the Council is to:

- Monitor the performance and effectiveness of services;
- Review existing policies and assist in the development of new ones, as necessary; and
- Monitor best value continuous service improvement plans

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HEALTH OVERVIEW AND SCRUTINY COMMITTEE

Agenda item 1: Declarations of interest.

Please state any amendments you have to your declarations of interest:

Councillor Doughty	Volunteers for York and District Mind and partner also works for this charity. Member of York NHS Foundation Teaching Trust.
Councillor Funnell	Member of the General Pharmaceutical Council Trustee of York CVS
Councillor Hodgson	Previously worked at York Hospital
Councillor Richardson	Frequent user of Yorkshire Ambulance Service due to ongoing treatment at Leeds Pain Management Unit. Member of Haxby Medical Centre Niece works as a staff district nurse for NHS North Yorkshire and York.
Councillor Riches	Council appointee to the governing body of York Hospital Member of UNITE

Agenda Item 3

Health Overview & Scrutiny Committee **6th August 2012**

Report of the Assistant Director Governance & ICT

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

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 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' 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 Framework[3]
    - 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 id the only form currently in use.

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[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.

Contact Details

Author:	**Chief Officer Responsible for the report:**
Tracy Wallis Scrutiny Office Scrutiny Services TEL: 01904 551714	Andrew Docherty Assistant Director Legal, Civic, Democratic and IT TEL: 01904 551004

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’

Review of compliance

York Teaching Hospital NHS Foundation Trust The York Hospital	
Region:	Yorkshire & Humberside
Location address:	Wigginton Road York North Yorkshire YO31 8HE
Type of service:	Acute services with overnight beds Rehabilitation services Long term conditions services
Date of Publication:	October 2011
Overview of the service:	The York Teaching Hospital NHS Foundation Trust provides most of its health care services from The York Hospital. Acute hospital services are provided for around 350,000 people living in and around the York area. There are also a range of specialist services, which are spread over a wider

	area of North Yorkshire, serving a total of approximately 500,000 people.

Summary of our findings
for the essential standards of quality and safety

Our current overall judgement

The York Hospital was not meeting one or more essential standards. Improvements are needed.

The summary below describes why we carried out this review, what we found and any action required.

Why we carried out this review

We carried out this review as part of our routine schedule of planned reviews.

How we carried out this review

We reviewed all the information we hold about this provider, carried out a visit on 4 July 2011, checked the provider's records, observed how people were being cared for, looked at records of people who use services, talked to staff, reviewed information from stakeholders and talked to people who use services.

What people told us

We visited York Hospital on three separate days. Five inspectors were involved on each visit during the day and two inspectors returned to the hospital during one evening visit to speak to relatives and visitors.

We spoke to over thirty patients across eight wards. Patients told us that the care was good and staff were helpful. Everyone we spoke to about consent to treatment told us they had been consulted, given full explanations about what to expect and that doctors and nurses 'went out of their way' to make sure patients understood what was going to happen. One patient told us, "I have always been provided with a good explanation about the treatment" and said that if they did not understand anything they raised it and 'always received an answer.' Patients also commented positively about the care they received from staff. They told us that where the staff member was of a different gender to them they always made sure that the patient was comfortable with this and they were given opportunities to refuse.

One patient commented that their emergency treatment, prior to moving to a ward, had been carried out "very calmly" and that they had been well looked after. They along with other patients also said that they had been treated with respect.

Two patients did make comments about having to wait too long for staff to answer their buzzers when they needed assistance to use the toilet. One said "sometimes I have to wait a long time when I buzz. I try my best to do what I can but yesterday I wet myself twice because it took them ages to come".

Patients told us that they had no complaints to make but that the staff had told them about the complaints procedure and that they could talk to the ward sister first if they were unhappy about anything relating to their stay in hospital.

Relatives also reported positively about the quality of care provided by the hospital. One relative told us they thought the care was 'excellent and first class.' And another commented that "I feel my relative has been in safe hands".

Patients who commented on the food generally made positive comments about the choice and variety of food available, however a few patients did not think the food was very good.

What we found about the standards we reviewed and how well The York Hospital was meeting them

Outcome 02: Before people are given any examination, care, treatment or support, they should be asked if they agree to it

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 hospitals 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.

We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.

Actions we have asked the service to take

We have asked the provider to send us a report within 28 days of them receiving this report, setting out the action they will take to improve. We will check to make sure that the improvements have been made.

Where we have concerns we have a range of enforcement powers we can use to protect the safety and welfare of people who use this service. Any regulatory decision that CQC takes is open to challenge by a registered person through a variety of internal and external appeal processes. We will publish a further report on any action we have taken.

Other information

Please see previous reports for more information about previous reviews.

What we found for each essential standard of quality and safety we reviewed

The following pages detail our findings and our regulatory judgement for each essential standard and outcome that we reviewed, linked to specific regulated activities where appropriate.

We will have reached one of the following judgements for each essential standard.

Compliant means that people who use services are experiencing the outcomes relating to the essential standard.

A **minor concern** means that people who use services are safe but are not always experiencing the outcomes relating to this essential standard.

A **moderate concern** means that people who use services are safe but are not always experiencing the outcomes relating to this essential standard and there is an impact on their health and wellbeing because of this.

A **major concern** means that people who use services are not experiencing the outcomes relating to this essential standard and are not protected from unsafe or inappropriate care, treatment and support.

Where we identify compliance, no further action is taken. Where we have concerns, the most appropriate action is taken to ensure that the necessary improvements are made. Where there are a number of concerns, we may look at them together to decide the level of action to take.

More information about each of the outcomes can be found in the *Guidance about compliance: Essential standards of quality and safety*

Outcome 02:
Consent to care and treatment

What the outcome says

This is what people who use services should expect.

People who use services:
* Where they are able, give valid consent to the examination, care, treatment and support they receive.
* Understand and know how to change any decisions about examination, care, treatment and support that has been previously agreed.
* Can be confident that their human rights are respected and taken into account.

What we found

Our judgement

There are major concerns with Outcome 02: Consent to care and treatment

Our findings

What people who use the service experienced and told us
Everyone we spoke to about consent to treatment told us they had been consulted, given full explanations about what to expect and that doctors and nurses 'went out of their way' to make sure patients understood what was going to happen. One patient told us, "I have always been provided with a good explanation about the treatment" and said that if they did not understand anything they raised it and 'always received an answer.'

Other evidence
During the site visit we looked closely at twenty two patients care records across the eight wards we visited. Within these we found that patient information details, in relation to consent, were not always fully completed.

In addition to this, we were concerned to find that in some records 'do not attempt resuscitation' forms (DNAR) had been completed by a consultant/doctor but that there was no evidence to say that patients had been consulted about this. Neither was there evidence that relatives, even where they were taking an active role in the patient's progress, had been consulted about this matter. In some examples we saw, there had been no second opinion and no specific date was given for when this serious decision should be reviewed. The date of review section in the form for some records had been noted as "indefinite." We spoke to three doctors during the inspection about this. One

Cleaning schedules on some wards were found to be completed correctly by staff however, on other wards the records were sparse and in some cases blank. However, staff were able to explain the cleaning regime for cleaning patient's rooms and had the required knowledge of how to deal with situations where infections such as, MRSA or clostridium difficile were identified. The trust has a low incidence of hospital acquired infections indicating that there is good practice in this area..

Our judgement
The environment is generally clean and there are procedures and practices in place to protect people from the risk of infection. However there are some areas for improvement on some of the wards visited.

We judged this as a minor concern. An improvement action has been made to ensure compliance with this outcome area is maintained.

Compliance actions

The table below shows the essential standards of quality and safety that **are not being met**. Action must be taken to achieve compliance.

<table>
<tr><th>Regulated activity</th><th>Regulation</th><th>Outcome</th></tr>
<tr><td rowspan="2">Diagnostic and screening procedures</td><td>Regulation 18 HSCA 2008 (Regulated Activities) Regulations 2010</td><td>Outcome 02: Consent to care and treatment</td></tr>
<tr><td colspan="2">How the regulation is not being met:
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 hospitals 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.

We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.</td></tr>
<tr><td rowspan="2">Family planning</td><td>Regulation 18 HSCA 2008 (Regulated Activities) Regulations 2010</td><td>Outcome 02: Consent to care and treatment</td></tr>
<tr><td colspan="2">How the regulation is not being met:
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</td></tr>
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We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.</td></tr>
<tr><td rowspan="2">Management of supply of blood and blood derived products</td><td>Regulation 18 HSCA 2008 (Regulated Activities) Regulations 2010</td><td>Outcome 02: Consent to care and treatment</td></tr>
<tr><td colspan="2">How the regulation is not being met:
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We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.</td></tr>
<tr><td rowspan="2">Maternity and midwifery services</td><td>Regulation 18 HSCA 2008 (Regulated Activities) Regulations 2010</td><td>Outcome 02: Consent to care and treatment</td></tr>
<tr><td colspan="2">How the regulation is not being met:
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</td></tr>
</table>

	not, was not being completed correctly or reviewed as required by the hospitals 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. We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.	
Nursing care	Regulation 18 HSCA 2008 (Regulated Activities) Regulations 2010	Outcome 02: Consent to care and treatment
	How the regulation is not being met: 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 hospitals 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. We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.	
Termination of pregnancies	Regulation 18 HSCA 2008 (Regulated Activities) Regulations 2010	Outcome 02: Consent to care and treatment
	How the regulation is not being met: 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 hospitals 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. We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.	
Treatment of disease, disorder or injury	Regulation 18 HSCA 2008 (Regulated Activities) Regulations 2010	Outcome 02: Consent to care and treatment
	How the regulation is not being met: 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 hospitals 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. We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.	
Surgical procedures	Regulation 18 HSCA 2008 (Regulated Activities) Regulations 2010	Outcome 02: Consent to care and treatment
	How the regulation is not being met: 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 hospitals 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. We judged this as a major concern. A compliance action has been made to ensure that compliance with this outcome is achieved.	

What is a review of compliance?

By law, providers of certain adult social care and health care services have a legal responsibility to make sure they are meeting essential standards of quality and safety. These are the standards everyone should be able to expect when they receive care.

The Care Quality Commission (CQC) has written guidance about what people who use services should experience when providers are meeting essential standards, called *Guidance about compliance: Essential standards of quality and safety*.

CQC licenses services if they meet essential standards and will constantly monitor whether they continue to do so. We formally review services when we receive information that is of concern and as a result decide we need to check whether a service is still meeting one or more of the essential standards. We also formally review them at least every two years to check whether a service is meeting all of the essential standards in each of their locations. Our reviews include checking all available information and intelligence we hold about a provider. We may seek further information by contacting people who use services, public representative groups and organisations such as other regulators. We may also ask for further information from the provider and carry out a visit with direct observations of care.

When making our judgements about whether services are meeting essential standards, we decide whether we need to take further regulatory action. This might include discussions with the provider about how they could improve. We only use this approach where issues can be resolved quickly, easily and where there is no immediate risk of serious harm to people.

Where we have concerns that providers are not meeting essential standards, or where we judge that they are not going to keep meeting them, we may also set improvement actions or compliance actions, or take enforcement action:

Improvement actions: These are actions a provider should take so that they **maintain** continuous compliance with essential standards. Where a provider is complying with essential standards, but we are concerned that they will not be able to maintain this, we ask them to send us a report describing the improvements they will make to enable them to do so.

Compliance actions: These are actions a provider must take so that they **achieve** compliance with the essential standards. Where a provider is not meeting the essential standards but people are not at immediate risk of serious harm, we ask them to send us a report that says what they will do to make sure they comply. We monitor the implementation of action plans in these reports and, if necessary, take further action to make sure that essential standards are met.

Enforcement action: These are actions we take using the criminal and/or civil procedures in the Health and Social Care Act 2008 and relevant regulations. These enforcement powers are set out in the law and mean that we can take swift, targeted action where services are failing people.

Information for the reader

Document purpose	Review of compliance report
Author	Care Quality Commission
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Annex B

SCRUTINY TOPIC ASSESSMENT FORM FOR COUNCILLORS
'ONE PAGE STRATEGY'

What is the broad topic area?

End of Life Care

What is the specific topic area?
I.e. what should be included & excluded from the topic? what are the driver behind the topic?

Do Not Resuscitate (DNACPR) Forms – their use and effectiveness

Ambitions for the review:
i.e. what is the review trying to achieve & why e.g. financial / efficiency savings and/or performance improvements? what will be different as a result of the review?

To try and ensure that patients wishes and instructions are acted upon by health professionals and carers at the end of life.

(For completion by the relevant Overview & Scrutiny Committee)

Does it have a potential impact on one or more sections of the population?
Yes [x] **No** [ ]

Is it a corporate priority or concern to the council's partners?
Yes [x] **No** [ ]

Will the review add value? and lead to effective outcomes?
Yes [x] **No** [ ]

Will the review duplicate other work?
Yes [ ] **No** [x]

Is it timely, and do we have the resources?
Yes [x] **No** [ ]

If the answer is 'Yes' to the above questions, then the Committee may decide to proceed with the review. To decide how best to carry out the review, the Committee will need to agree the following:

1) Who and how shall we consult?
i.e. who do we need to consult and why? is there already any feedback from customers and/or other consultation groups that we need to take account of?

Who: Key Health Partners (NHS North Yorkshire & York, Yorkshire Ambulance Service, York Hospital, St Leonard's Hospice, Adult Social Care at CYC, Independent Care Group,)
York Link, the Police, Funeral Directors, public, families

How: Informal meetings, briefing papers, discussions

2) Do we need any experts/specialists? (internal/external)
I.e. is the review dependent on specific teams, departments or external bodies? What impact will the review have on the work of any of these?

Will need technical support from those listed above, what a DNACPR form is, how they work, background information, good practice, examples of when they have worked well and examples of when they haven't worked.

Evidence of how the form is used and whether the forms are recognised by the Police, Hospital & Ambulance Service – for example

3) What other help do we need? E.g. training/development/resources
I.e. does this review relate to any other ongoing projects or depend on them for anything?
What information do we need and who will provide it? What do we need to undertake this review e.g. specific resources, events, meetings etc?

LINks have already undertaken a review on 'End of Life Care' Review however this has no specific recommendations linked with the use of DNACPR form but is focussed around wider issues associated with End of Life Care.

4) How long should it take?
i.e. does the timings of completion of the review need to coincide with any other ongoing or planned work

Briefing Paper

1. Introduction

The purpose of this paper is to provide the Health Overview and Scrutiny Committee with some background information regarding Cardiopulmonary Resuscitation (CPR), the Regional Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Form including its implementation and Living Wills to help them with their review of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms and their use and effectiveness.

2. Cardiopulmonary Resuscitation (CPR) – What it is and what it is not

"When someone suffers sudden cardiac or respiratory arrest, CPR attempts to restart their heart or breathing and restore their circulation. CPR interventions are invasive and include chest compressions, electric shock by an external or implanted defibrillator, injection of drugs and ventilation"[1]. The level and speed of interventions given will depend on the patient's location at the time of cardiac or respiratory arrest.

CPR measures do not include analgesia, antibiotics, drugs for symptom control, feeding or hydration (by any route), investigation and treatment of a reversible condition, seizure control, suction, or treatment for choking.

3. Potential Outcome of CPR

"In reality, the survival rate after cardio respiratory arrest and CPR is relatively low. After CPR for cardio respiratory arrest that occurs in hospital, the chances of surviving to hospital discharge are at best about 15-20%. Where cardiac arrest occurs out of hospital, the survival rate is lower, at best 5-10%. The probability of success depends on factors including the cause of the arrest, how soon after the arrest CPR is started, and the equipment and staff available to deliver it.

[1] Treatment and care towards the end of life, General Medical Council, 2010

Attempting CPR carries a risk of significant adverse effects such as rib or sternal fractures, hepatic or splenic rupture, or prolonged treatment in an intensive care unit (ICU), possibly including prolonged artificial ventilation"[2].

4. Post CPR Period

"In the immediate post-CPR period most patients require at least a brief period of observation and treatment in an ICU or a coronary care unit (CCU) or both. Some patients will require treatments such as artificial ventilation, renal dialysis or haemofiltration, and circulatory support with inotropic drugs and/or an intra-aortic balloon pump. It is not uncommon for difficult decisions about CPR to arise in respect of patients for whom it may be possible to re-start the heart after cardiac arrest but for who admission to an ICU for continued organ support would be clinically inappropriate because they would be unlikely to survive their admission to the ICU.

There is also a risk that the patient will be left with brain damage and resulting disability, especially if there is delay between cardio respiratory arrest and the initiation of the CPR. Some CPR attempts may be traumatic, meaning that death occurs in a manner that the patient and people close to the patient would not have wished"[3].

5. When to consider making a DNACPR decision

The General Medical Council supports the use of a DNACPR decision if:

- The decision is based on the circumstances of the individual patient
- It is the patient wish/choice not to have CPR
- Cardiac or respiratory arrest is an expected part of the dying process and CPR will not be successful
- It will help to ensure that the patient dies in a dignified and peaceful manner

---

[2] Decisions relating to cardiopulmonary resuscitation, A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, 2007

[3] Decisions relating to cardiopulmonary resuscitation, A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, 2007

- The potential outcome of CPR may be successful but the benefits of prolonging life is outweighed by the burdens and risks

In situations whereby the patient requests CPR in spite of a small chance of success or the judgement that it would be clinically inappropriate, the General Medical Council provides advice on how this should be handled and concludes that “when the benefits, burdens and risks are finely balanced, the patients request will usually be the deciding factor.” However, “the medic is not obliged to agree to attempt CPR if it is considered not to be clinically appropriate”[4]

6. What is a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form?

The DNACPR form is a means of communicating a DNACPR decision (an advanced decision specific to CPR) that has been made by a senior doctor (e.g. Consultant, GP) who has responsibility for the patient or a health care professional who has undertaken the necessary training to make the DNACPR decision or by the patient, to those who may encounter the patient in the event of a cardiopulmonary arrest.

The presence or absence of a DNACPR form should not override clinical judgement about what will be of benefit to the patient in an emergency (e.g. choking, anaphylaxis, sepsis etc).

7. Variants of DNACPR forms

Unlike Scotland, England doesn't have a national DNACPR Policy, DNACPR form or Website. In England DNACPR policies are created locally by the care provider and this has led to a number of variants of the DNACPR form. Historically these forms were only valid in the care facility that issued it and did not travel with the patient.

Therefore care providers in Yorkshire and Humber have been working on an approved DNACPR form which will be the agreed form for recording the DNACPR decision, within the Yorkshire and the Humber region.

[4] Treatment and care towards the end of life, General Medical Council, 2010

8. Yorkshire and the Humber Regional DNACPR Form

The aim of the initiative was to establish a common form and protocol to be used across the region to ensure that DNACPR decisions made for a patient, or by the patient, are documented and communicated effectively.

Work had already commenced at Airedale General Hospital (AGH) in 2009 to review their Do Not Attempt Resuscitation (DNAR) form against the one developed by NHS Lothian. The reason the NHS Lothian template was used as the model form was because its design took into consideration the need to ensure that the form was transferable across care settings.

AGH then engaged with NHS Bradford and Airedale with the aim of agreeing a joint policy to support the transferable form and a local working group was formed to achieve that.

In August of 2009, as a result of feedback given at NHS Bradford and Airedale's Clinical Review Group meeting with Yorkshire Ambulance Service (YAS), it was decided that the issue of the multiplicity of DNAR forms within Yorkshire and the Humber needed to be addressed in order to resolve some of the problems it presented to YAS.

As lead commissioner for YAS, NHS Bradford and Airedale took ownership of the proposal and a bid was submitted to NHS Yorkshire and the Humber to secure financial support from the Regional Innovation Fund.

Once the regional working group was established the DNACPR form now in use across NHS Bradford and Airedale was reviewed against the template recommended by the Resuscitation Council (UK).

The feedback from clinicians regarding the Resuscitation Council template was as follows:

- It didn't request an explanation as to why CPR would be inappropriate
- It was interpreted as a record of a decision being made by the patient
- It didn't include any guidance
- Section 2 did not distinguish between inappropriate, unsuccessful or not in the patients best interests

- The design of the form did not facilitate its transferability of use to patient transfer services or to other care settings

It was agreed that the current NHS Bradford and Airedale model had been tried and tested and therefore was selected as the template from which the regional DNACPR form would evolve.

The regional DNACPR form is:

- Applicable to adults over 16 years old
- Transferable from one care setting to another
- Consistent with the
  - Decisions relating to Cardiopulmonary Resuscitation. A joint statement from the British Medical Association (BMA), the Resuscitation Council (UK) and the Royal College of Nursing (RCN) 2007
  - Treatment and care towards the end of life: good practice in decision making. General Medical Council (GMC) Guidance July 2010
  - Advice statement on resuscitation Nursing and Midwifery Council (NMC) May 2008
- To be in accordance with mental capacity act, safeguarding adults/children

An example of the latest version of the Yorkshire and Humber regional DNACPR form is at appendix A.

9. Roll out of the Regional DNACPR Form

NHS Bradford and Airedale set up a Regional DNACPR Project Board and Regional DNACPR Strategic Working Group which had representation from partner organisations across the Yorkshire and Humber region. Representation on these groups included the Lead Resuscitation Officer from York Teaching Hospitals NHS Foundation Trust and Community and Mental Health Services, NHS North Yorkshire and York, as well as a Commissioning Manager from NHS North Yorkshire and York.

Prior to roll out of the regional DNACPR form, NHS North Yorkshire and York had discussions with and/or wrote to its care provider colleagues. These included:

- Chief Executives of Acute Hospitals
- Managing Director of Community and Mental Health Services, NHS North Yorkshire and York
- Local Medical Council
- Local Authorities
- Hospices
- Independent Care Group
- End of Life Locality Groups
- Cancer Locality Boards

Just prior to the roll out of the regional DNACPR form, care provider colleagues were also invited to a meeting to:

- Understand the current arrangements
- Understand the proposed arrangements
- To finalise the NHSNYY's roll out plan
- To address any outstanding concerns or issues

NHS North Yorkshire and York started rolling out a new single 'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Form v11 in September 2010'. This was quickly adopted within Community and Mental Health Services (including Out of Hours Services) and GPs, Hospices, Local Authorities, and Independent Care Homes but was more problematic in some acute settings.

To overcome concerns in the acute setting staff were invited to a workshop and contributed to discussions on how the form could be amended to make it more user friendly in an acute setting and this lead to version 12 of the form being published in July 2011.

An education package was compiled by members of the Strategic Working Group and consisted of:

- PowerPoint training presentations
- DVD/webcast of doctor to doctor and doctor patient/simulated DNACPR conversations
- CPR Patient information leaflet

These implementation aides and training tools were provided to all organisations to assist with their implementation programme. However, each organisation managed their implementation in accordance with their own project plan and time table.

As roll out progressed staff were given the opportunity to participate in an online survey regarding the roll out of the regional DNACPR form. The results show this opportunity was well received by staff within the NHS North Yorkshire and York patch.

During the introduction of the regional DNACPR form there have been a small number of cases reported across the region where the form was not adhered to. Reported incidents have been investigated and all necessary action taken which includes cascading any lessons learnt from the incident to relevant staff groups to prevent the problem arising again.

10. How does the Regional DNACPR form work?

The regional DNACPR form is adopted by the care provider and incorporated into their DNACPR policy.

The regional DNACPR form is completed using the guidance provided on the reverse of the form, a framework for making a CPR decision from the care provider's local DNACPR policy and/or at the patient's request. Other guidance such as treatment and care towards the end of life (General Medical Council, 2010) and decisions relating to cardiopulmonary resuscitation (A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, 2007) is available to staff when considering a DNACPR decision.

It is the responsibility of the healthcare professional completing the form to ensure that the DNACPR decision is communicated to all who need to know.

Whilst the patient is in hospital, the DNACPR form should remain in front of the case notes or kept in accordance with local hospital policy.

In all other care settings the DNACPR form should be located in the front of the care record/nursing record or kept in accordance with the care providers DNACPR policy.

If no nursing record exists in the home, the patient/family/carer will determine the best place to store it, and communicate this to the health care professionals.

As patients move between care settings, the DNACPR form moves with the patient in a clearly marked envelope. Ambulance control should be informed that a DNACPR form exists at the time of booking a patient transport services (PTS) ambulance or when requesting an emergency ambulance.

11. Who recognises the regional DNACPR form?

The regional DNACPR form is recognised by all health care providers and Yorkshire Ambulance Service in the Yorkshire and Humber region.

12. What is the difference between a DNACPR form and a Living Will?

DNACPR Form

A DNACPR form is an approved document used by care providers to record an advanced decision. The document is limited to the withholding of one treatment only i.e. Cardiopulmonary Resuscitation.

Validating a Regional DNACPR form

Having one regional DNACPR form makes it easier for staff to validate the form quickly. For the form to be validated it must be:

- Completed correctly
- Current i.e. not exceeded any review date set by the person making the DNACPR decision or in accordance with local DNACPR policy if a review date hasn't been set
- Signed by an appropriate person
- An original form with an ink signature

Living Will

A Living Will (also known as Advance Decision in England and Advanced Directive in Scotland) is a document which sets out the future medical wishes of an individual should they become terminally ill or require medical treatment at a time when they do not have the full mental capacity to make those relevant decisions.

The term 'Living Will' can be divided into two categories, Advanced Statement and an Advanced Decision. An Advanced Statement is purely informative and must be fully respected by health care professionals, it outlines the extent of medical intervention that the individual would like whereas an Advanced Decision is legally binding and details the individual's right to refuse any form of treatment from antibiotic medication to intravenous feeding and resuscitation.

In England, Wales and Scotland a Living Will is considered to be a legally binding document which must be respected by all medical professionals. However, this is not the case in Northern Ireland.

A Living Will will only be valid (accepted legally and by health care professionals) if the document has met a number of criteria which include that the individual:

- Was 18 or over and had capacity when they made it
- Has set out exactly which treatments they don't want in future (if they don't want life-saving treatment, their decision must be signed and witnessed)
- Has explained the circumstances under which they would want to refuse this treatment
- Has made the advance decision without any harassment by, or under the influence of, anyone else
- Hasn't said or done something that would contradict the advance decision since it was made

Because of the potential complexity of a Living Will, it is anticipated that individuals may have sought advice and have discussed their Living Will with their GP, or other treating health care professionals while they have the capacity to do so.

To ensure compliance to the Living Will all care providers will need to be aware of the Living Will and would have to have satisfied their selves of its validity.

Validating a Living Will

This can be difficult as there is no set format for a Living Will. If the person providing treatment is aware of a Living Will, they must then consider whether it is valid and applicable to the particular circumstances.

When deciding whether a Living Will is valid, the person providing the treatment should try to find out if the patient has:

- Withdrawn the decision since they made it, at a time when they had the mental capacity to do so
- Done anything which is inconsistent with the decision and suggests that it no longer represents their wishes or
- Made a Lasting Power of Attorney, giving someone else the authority to make the decision consenting to or refusing the particular treatment

When deciding whether a Living Will is applicable to the particular circumstances, the person providing the treatment must also:

- Assess whether the patient actually still haves the mental capacity to make the particular decision about their treatment at the time it has to be made (they must start from the assumption that you have capacity and the advance decision will only be relevant if there is evidence that this is not the case)
- Check that the treatment and circumstances are the same as those referred to in the decision
- Consider whether there are any new developments that the patient didn't anticipate when they made their decision, which could have affected their decision; for example new developments in medical treatment, or changes in their personal circumstances.

Professionals providing medical treatment are protected from liability for not providing treatment if they reasonably believe there is a valid and applicable Living Will.

Health Care Professionals can provide treatment if they are in doubt over the existence, validity or applicability of a Living Will, and they are again protected from liability.

13. Further Reading

This paper only briefly touches on Living Wills and due to the complexity it is recommended that the Health and Overview Scrutiny Committee may wish to seek further advice to ensure clarity over the legal standing of this type of documentation. A number of useful websites/documents are as follows:

National End of Life Care Programme
www.endoflifecareforadults.nhs.uk/publications/pubadrtguide

Directgov UK
www.direct.gov.uk/en/Governmentcitizensandrights/Death/Preparation/DG_10029429

AgeUK
www.ageuk.org.uk/money-matters/legal-issues/living-wills/

Many of the quotes made in this paper have been taken from the following documents:

Decisions relating to Cardiopulmonary Resuscitation. A joint statement from the British Medical Association (BMA), the Resuscitation Council (UK) and the Royal College of Nursing (RCN) 2007.
www.rcn.org.uk/__data/assets/pdf_file/0004/108337/003206.pdf

Treatment and care towards the end of life: good practice in decision making. General Medical Council (GMC) Guidance July 2010
www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

12 December 2011

Annex C

Appendix A

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Yorkshire & Humber Regional Form for Adults and Young People aged 16 and over v12 June 2011

In the event of cardiac or respiratory arrest NO attempts at cardiopulmonary resuscitation (CPR) will be made. All other treatment should be given where appropriate.

NHS No	Hospital No	Next of Kin / Emergency Contact
Name		
Address		Relationship
Postcode	Date of Birth	Tel Number

Section 1 Reason for DNACPR: Select as appropriate from A - D (see reverse)

Details of all discussions, mental capacity assessments and MDT decisions must be recorded in the patient's notes.

A. ☐ **CPR has been discussed with this patient. It is against their wishes and they have the mental capacity to make this decision.**

B. ☐ **CPR is against the wishes of the patient as recorded in a valid advance decision**
The right to refuse CPR in an Advance Decision only applies from the age of 18.

C. ☐ **The outcome of CPR would not be of overall benefit to the patient and:**
i) They lack the capacity to make the decision ☐ **or**
ii) They have declined to discuss the decision ☐
This must be discussed with relevant others wherever possible (details overleaf)
This **has** been discussed with .... (name) Relationship to patient:...............................

D. ☐ **CPR would be of no clinical benefit because of the following medical conditions:**
....

Even in situations in which CPR is not expected to be successful, it is still good practice to explain to the patient and/or relevant others why CPR will not be attempted.

This **has** been discussed with the patient ☐
This **has not** been discussed with the patient because it would cause them unnecessary distress ☐
This **has** been discussed with .... (name) Relationship to patient:...............................

Section 2 Healthcare professionals completing DNACPR form (see reverse)

Name & Designation	Name & Designation (Counter Signature if required)
Organisation	Organisation
Signature Date	Signature Date

Section 3 Review of DNACPR decision (if appropriate)

This order is to be reviewed by: Date: ....

Review Date	Full Name and Designation	Signature	Still applies	Next Review Date
			☐ (tick)	
			☐ (tick)	

AMBULANCE CREW INSTRUCTIONS

If Cardiopulmonary Arrest occurs, please do not attempt CPR. All other appropriate treatment should be given.
Any other specific instructions: ....

Annex C

These guidelines are based on an agreement within the Yorkshire and Humber region.
For more details refer to your local policy relating to DNACPR.
This is not a legally binding document; the decision may change according to clinical circumstances

Section 1 Guidance (*Please write legibly and with black ink)*

Option A

Record details in the patient's notes, including the assessment of the patient's mental capacity to make this decision.

Option B

The Mental Capacity Act (2005) confirms that an advance decision refusing CPR will be valid and therefore legally binding on the healthcare team, if:

1. The decision is in writing, signed, witnessed and the patient is aged 18 or over;
2. It includes a statement that the advance decision is to apply even if the patient's life is at risk;
3. The advance decision has not been withdrawn;
4. The patient has not, since the advance decision was made, appointed a welfare attorney to make decisions about CPR on their behalf;
5. The patient has not done anything clearly inconsistent with its terms; and
6. The circumstances that have arisen match those envisaged in the advance decision.

16 and 17-year-olds: *Whilst 16 and 17-year-olds with capacity are treated as adults for the purposes of consent, parental responsibility will continue until they reach age 18. Legal advice should be sought in the event of disagreements on this issue between a young person of 16 or 17 and those holding parental responsibility*

Option C

1. The term "*overall benefit*" is used in the context defined by GMC Guidance 2010 (Treatment & Care towards the End of Life; pg. 40-46; paragraphs 6, 13) and takes into account "*best interests*" as defined by the Mental Capacity Act, 2005.
2. This situation **must** be discussed with relevant others where possible. Record details of your discussion in the patient's notes.
3. The term "*relevant others*" is used to describe a patient's relatives, carers, representatives, people with lasting power of attorney, independent mental capacity advocates (IMCAs), advocates, and court appointed deputies (refer to Mental Capacity Act) http://www.dh.gov.uk

Option D

Record underlying condition/s eg poor Left Ventricular function, end stage obstructive airway disease, disseminated malignancy with poor performance status.

Section 2 Authorisation

Responsibility for making the DNACPR decision lies with a senior doctor (e.g. Consultant, GP) who has responsibility for the patient. In some localities, other healthcare professionals who have undertaken the necessary training may make the DNACPR decision.

If junior medical staff or other authorised professionals have been instructed to sign the form by a senior clinician, the form should be countersigned by the senior doctor, as soon as possible or as per local policy.

Section 3 Review – In accordance with your local Policy.

It is considered good practice to review DNACPR status in the following circumstances:

- At the consultant ward round, MDT or Gold Standards Framework meeting;
- On transfer of medical responsibility (eg hospital to community or vice versa); or
- Whenever there are significant changes in a patient's condition.

When the form is no longer valid, either because the patient is for CPR or because a new form has been completed, it must be marked as cancelled by making two thick, dark, diagonal lines across the form, writing **CANCELLED** in large capitals and adding your signature and date. It should then be filed in the patient's notes.

COMMUNICATING DNACPR DECISIONS

It is the responsibility of the healthcare professional completing the form to ensure that the DNACPR status is communicated to all who need to know.

For patients being transferred between different care settings, it is essential that all professionals including Out of Hours (OOH) and Ambulance (e.g. Yorkshire Ambulance Service) are made aware of this DNACPR order

1. Send the **original form** with the patient.
2. A photocopy should only be retained in the patient's notes for audit, marked with the words '**COPY**' in large capitals, signed and dated.
3. In circumstances where patients are being transferred to community: the DNACPR status should be communicated to patient (if appropriate) and '*relevant others*'. They may prefer the form to be placed in a clearly marked envelope.
4. For discharges to community settings: communicate to the GP, Out of Hours service, and any other relevant services as appropriate e.g. Hospice.

v12 June 2011
Regional Review Date: June 2013
Regional Lead Contact: Palliative Medicine Consultant
Airedale NHS Foundation Trust, West Yorkshire

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Summary of discussions from the meeting held on 21st December 2011

1. The present version of the form is Version 12; this currently meets the needs of all the health providers across the Yorkshire and Humber region [including Yorkshire Ambulance Service (YAS) and has been approved for use. It is hoped that all health providers, in all locations across Yorkshire and Humber will have adopted the form by the end of 2012. The form is already live across York and North Yorkshire. Members commended NHS North Yorkshire and York for getting agreement for the use of the form from all parties.

2. In York the hospital started using the form in June 2011 and other health commissioners in the city throughout 2011.

3. YAS had, sometime ago, reported to NHS North Yorkshire and York that the form had not been working as well as it could have done within the organisation, this was due to several reasons, one of which was having to implement a huge staff training programme based around the use of the form. Also with the introduction of Version 12 the form had been standardised (with clinical input) and made transferable across health organisations and sites which had made it much more practical for YAS to use.

4. In the first instance it is usually the lead clinician and/or the patient that broaches the subject of DNACPR. The involvement of family is dependent on the patient’s wishes (where the patient has the capacity to make their own decision). Sometimes the patient asks that the matter is not discussed with the family. It was noted that conversations around this subject matter were of a very sensitive nature but despite this, they still needed to happen.

5. The public were becoming more aware of the existence of the form. This was a positive note as it meant that patients could, if they wished to, start conversations with their GPs about their ‘End of Life Care’ wishes.

6. NHS North Yorkshire and York have given a copy of the form to all health providers across the region along with a best practice guide. However, this is only a guide and each individual organisation has its own policy on resuscitation which is where things can become complicated.

7. The representative of NHS North Yorkshire and York had anecdotal evidence that DNACPR forms had not been accompanying patients and were being cancelled on discharge from hospital. Good practice says that the form should travel with the patient but be reviewed on a regular basis. It was noted at this point that it was hard to act upon anecdotal evidence.

8. It was noted that there was still work to be done to improve the use of the form and to encourage all organisations to use the form in a consistent way.

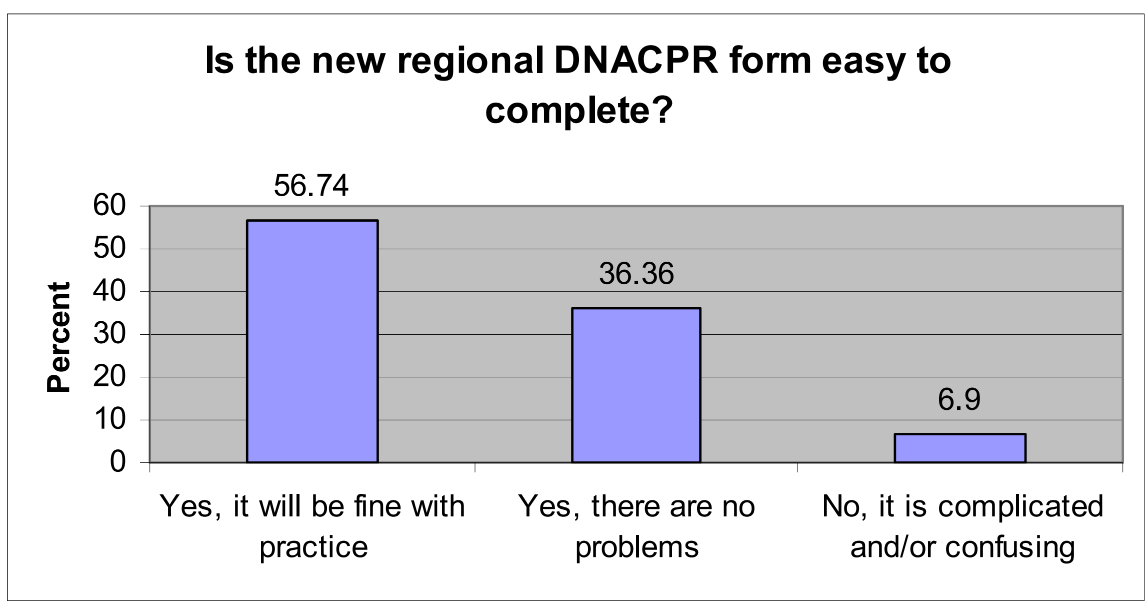
9. There was a training issue within certain organisations around the use and completion of the form. Some organisations provided better training than others. Some organisations provided regular resuscitation training but there was a lot to cover within these sessions and they were not solely dedicated to the use, completion and validity of the DNACPR form.

10. Anecdotal comments highlighted that there may be potential problems with the GP Out of Hours Service (OOH). For instance, where a nursing home contacted the OOH, usually for clinical support (such as pain control/breathing changes) towards the end of a patient's life there had been times when an ambulance had been called and the patient taken to hospital unnecessarily.

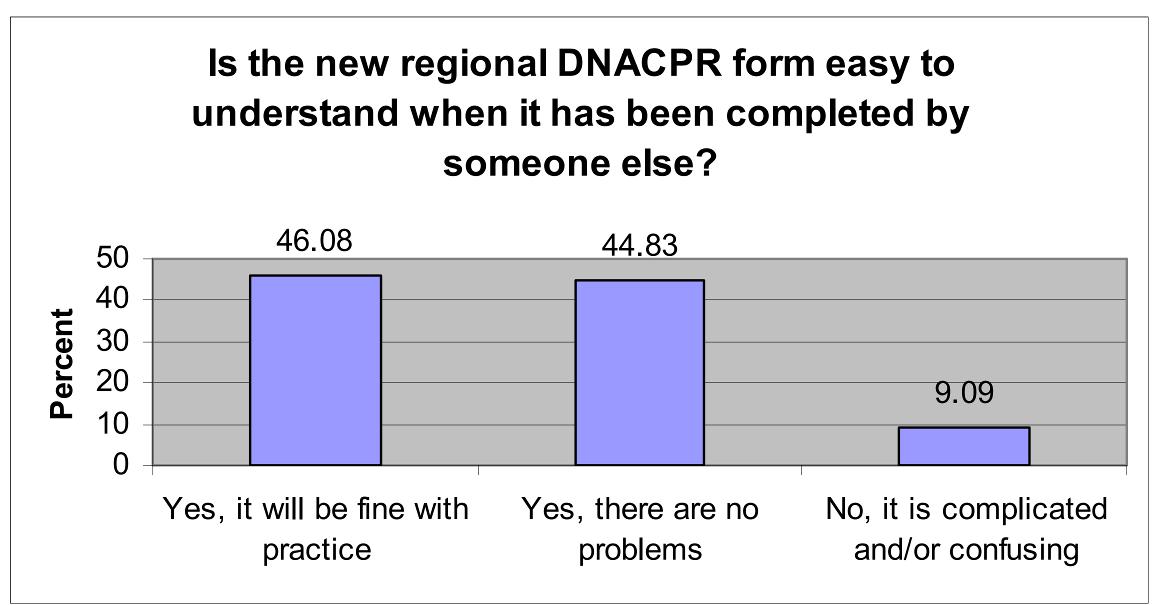
Annex D

Survey Monkey – All Areas

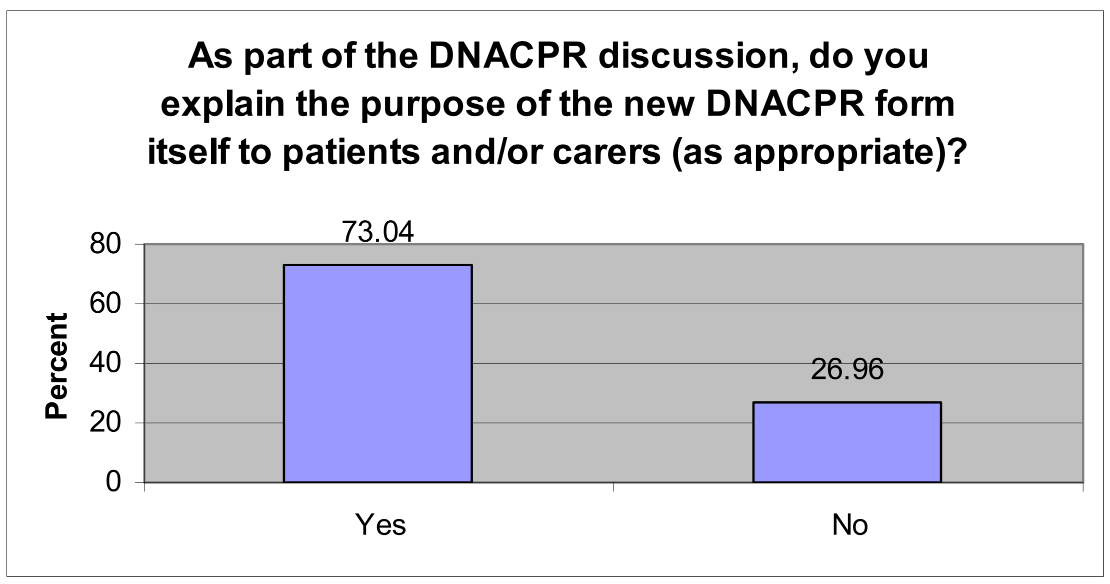
1. **Is the new regional DNACPR form easy to complete?**



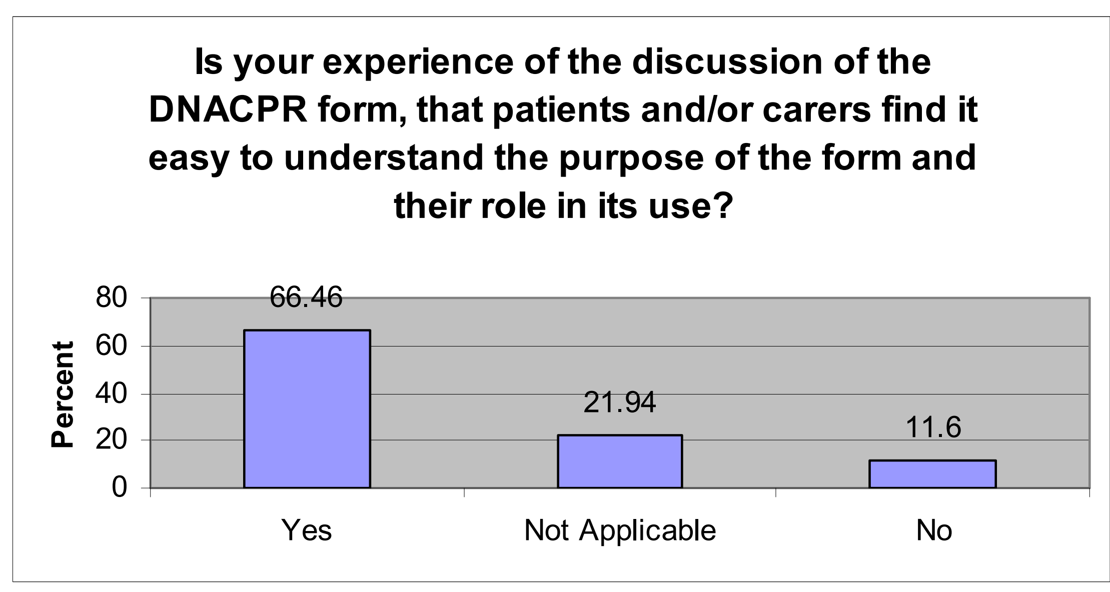
2. **Is the new regional DNACPR form easy to understand when it has been completed by someone else?**



3. **As part of the DNACPR discussion, do you explain the purpose of the new DNACPR form itself to patients and/or carers (as appropriate)?**

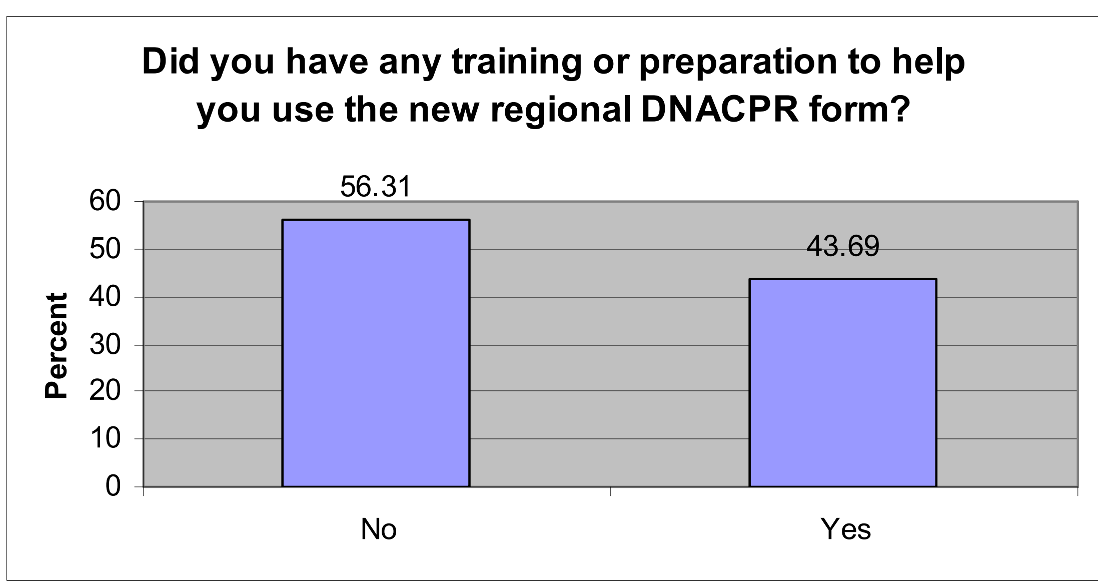


4. **Is your experience of the discussion of the DNACPR form, that patients and/or carers find it easy to understand the purpose of the form and their role in its use?**

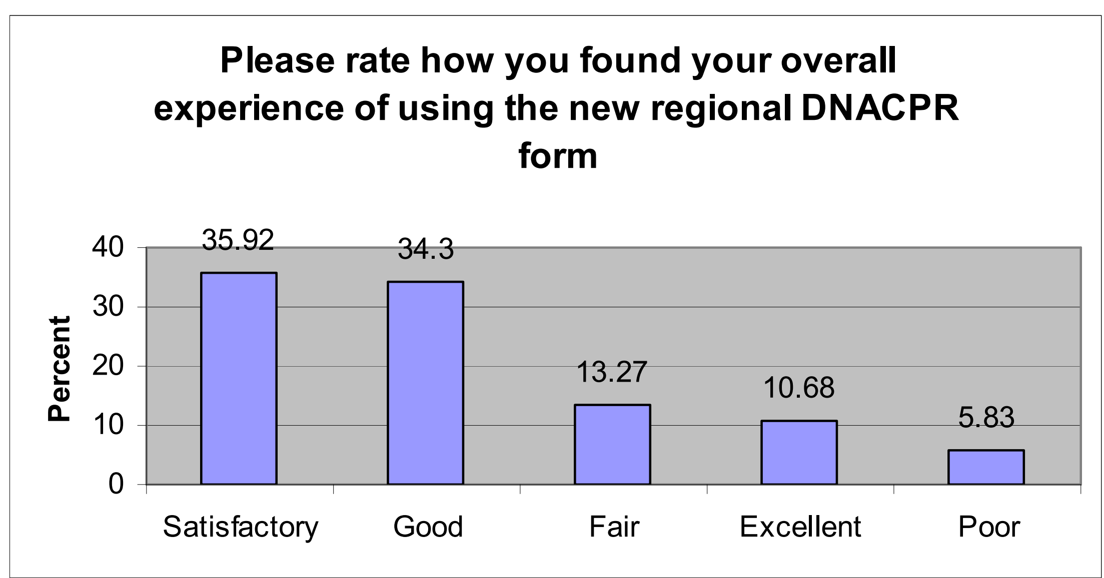


Annex D

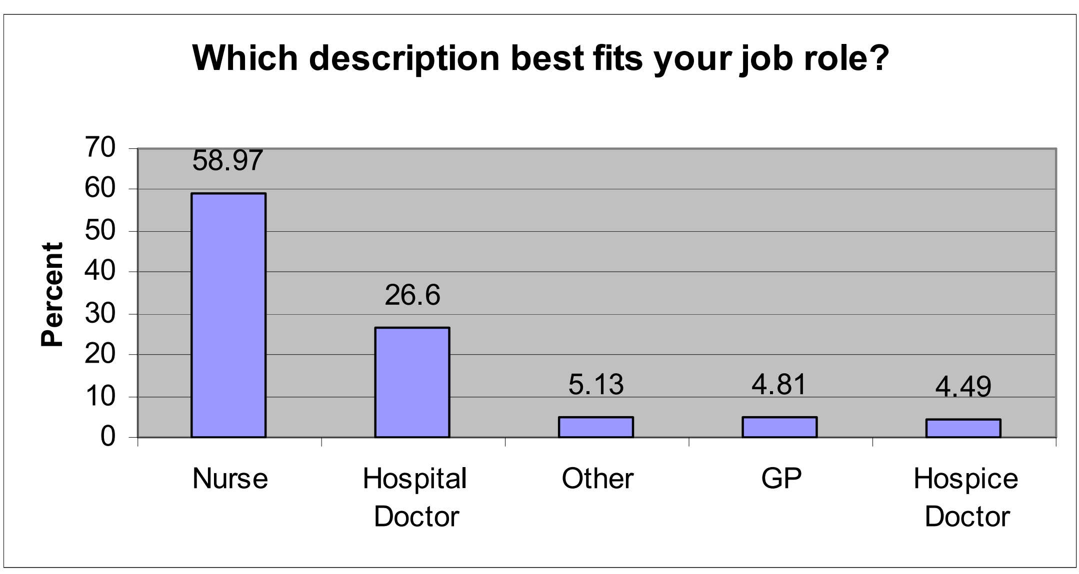
5. **Did you have any training or preparation to help you use the new regional DNACPR form?**



6. **Please rate how you found your overall experience of using the new regional DNACPR form**



7. Which description best fits your job role?



YAS - On-line staff survey for staff with patient facing responsibilities only

1. Are you always informed of the existence of the new regional DNACPR form before attending a patient in a community or acute organisation?

	Response Percent	Response Count
Yes	16.4%	11
No	**83.6%**	**56**
	Comments	21
	answered question	**67**
	skipped question	**0**

2. Is the new regional DNACPR form easy to find in the patients' medical records?

	Response Percent	Response Count
Yes	46.3%	31
No	**53.7%**	**36**
	Comments	21
	answered question	**67**
	skipped question	**0**

3. Are you informed of the existence of the new regional DNACPR form by relatives, when attending a patient at home?

	Response Percent	Response Count
Yes	40.3%	27
No	**59.7%**	**40**
	Comments	21
	answered question	**67**
	skipped question	**0**

4. Is the new regional DNACPR form easy to find in patients homes?

	Response Percent	Response Count
Yes	31.3%	21
No	**68.7%**	**46**
	Comments	21
	answered question	**67**
	skipped question	**0**

5. Are relatives always aware of the DNACPR decision and form when you attend patients at home?

	Response Percent	Response Count
Yes	29.9%	20
No	**70.1%**	**47**
	Comments	18
	answered question	**67**
	skipped question	**0**

6. Is the new regional DNACPR form easy to understand?

	Response Percent	Response Count
Yes	**87.5%**	**42**
No	12.5%	6
	Comments	7
	answered question	**48**
	skipped question	**19**

7. Have you attempted CPR despite the existence of a new regional DNACPR form being available, for any reason?

	Response Percent	Response Count
Yes	10.4%	5
No	**89.6%**	**43**
	Comments	8
	answered question	**48**
	skipped question	**19**

8. Please explain what you have found to be helpful about the new DNACPR forms.

	Response Count
	48
answered question	**48**
skipped question	**19**

9. Please explain what you have found to be difficult about the new DNACPR forms.

	Response Count
	48
answered question	**48**
skipped question	**19**

10. Please rate your overall experience of using the new regional DNACPR forms.

	Response Percent	Response Count
Poor	8.3%	4
Fair	18.8%	9
Satisfactory	27.1%	13
Good	**39.6%**	**19**
Excellent	6.3%	3
answered question		**48**
skipped question		**19**

Annex E

Customer & Business
Support Services

Scrutiny Services
Guildhall
York
YO1 9QN

Tel; 01904 551714
(Tracy Wallis)
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tracy.wallis@york.gov.uk
cllr.cfunnell@york.gov.uk

Name
Address

Monday 30th January 2012

Dear ... ...

York Health Overview & Scrutiny Committee - End of Life Care Review (use & effectiveness of DNACPR forms)

As you will hopefully be aware the Health Overview & Scrutiny Committee in York are currently undertaking a review entitled 'End of Life Care – The Use and Effectiveness of DNACPR[1] Forms'. As part of this review the Committee would like to receive evidence from key partners who provide services across the city.

The Committee will be meeting on Wednesday 29th February 2012 at 3pm in the Guildhall, York and hope that you will be able to attend to give evidence and join the discussion. The meeting will be informal, but will be open to the public and all material submitted will, potentially, form part of the final report arising from the scrutiny review. Please can you let me know as soon as you can who will be attending from your organisation?

[1] Do Not Attempt Cardiopulmonary Resuscitation

Annex E

In the meantime, in order that the Committee, can collate some background information (on which the content of the meeting will be based) you are kindly requested to answer, in writing/via e-mail, the following questions in order that the Committee can give consideration to your responses prior to the meeting. It would be appreciated if you could respond directly to the Scrutiny Officer by no later than Friday 17th February 2012.

Questions

In the Yorkshire and Humber region there is a collectively recognised and agreed DNACPR form. This form has been adopted by all health care providers in the Yorkshire and Humber region and the Yorkshire Ambulance Service.

1. Is your organisation using this form? If not, why not? Are all the relevant members of staff aware of its existence?
2. Can you give the Committee some positive examples of the way your organisation has used the DNACPR form?
3. What training has your organisation provided in relation to completing 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 members of staff on how to use the form?
4. How has the use of the form been integrated into your own policies? Is it written into your own policies?
5. Do you audit the use of the form? If so, how?
6. 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?
7. 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?
8. 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?
9. 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 which overruled the DNACPR decision?
10. 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)?

Annex E

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

I look forward to receiving your written response and seeing you at the meeting on 29th February 2012.

Yours sincerely

Tracy Wallis
Scrutiny Officer (on behalf of the Chair of the Health Overview & Scrutiny Committee)

This letter has been sent to the following key partners for response:
Yorkshire Ambulance Service
St Leonard's Hospice
York Teaching Hospital NHS Foundation Trust
Independent Care Group
Adult Social Services – City of York Council
NHS North Yorkshire & York

A copy of this letter has been sent to the following who will also be invited to the meeting:
Vale of York GP Commissioning Consortium
Dr Faller from Haxby Group Practice
Dr Ian Lyall, Strensall Medical Group
Julie Dale, MacMillan Palliative Care Nurse, York Hospital
Jenny Carter Directorate Manager for Community Services, York Hospital
Co-operative Funeral Directors
Macmillan Cancer Support (York Branch)
Leeds Partnership Foundation Trust
Alzheimer's Society (Local Branch)
The Stroke Association (York Branch)
Age UK (York Branch)
Older People's Assembly
The Police
British Heart Foundation
York CVS
York Link
York Carer's Centre

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Health Overview & Scrutiny Committee End of Life care Review (Use & Effectiveness of DNACPR[1] Forms)
Responses to questions asked

1. **Is your organisation using this form? If not, why not? Are all the relevant members of staff aware of its existence?**

Organisation	Response
Yorkshire Ambulance Service (YAS)	Yes YAS is a sitting member of the DNACPR Strategic Working Group and has worked closely with all 12 PCTs across the Yorkshire & Humber Strategic Health Authority (SHA) region since the inception of the project. All operational staff are aware of the existence of the new form and associated processes, although it needs to be noted that not all staff in the North Yorkshire area of YAS are yet formally trained (please see YAS answer to question 3)
Leeds & York Partnership Foundation Trust	Yes, the form is included in the Trust's *Do not attempt cardiopulmonary resuscitation (CPR) policy* All staff were briefed on the updated policy and it is available to access from the NHS North Yorkshire & York intranet
NHS North Yorkshire & York (NHSNYY)	NHSNYY does not use the form but does require the use of the form in secondary care provision and

[1] Do Not Attempt Cardio Pulmonary Resuscitation

Organisation	Response
	promotes the use of this form by all care providers
York Teaching Hospital NHS Foundation Trust (YTHFT)	Yes Everyone in the organisation is using Version 12 of the Strategic Health Authority (SHA) form. This has been rigorously implemented across Acute and Community Hospitals, along with the roll out of the new DNACPR policy from December 2011. Discussions are underway with GPs about encouraging the use of the forms and also with Nursing Home Forum in Selby and York locality to encourage the use of the forms.
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	This form requires clinical medical completion. Our social work/care managers are aware of its existence. The staff in CYC residential homes work with their GPs to ensure this form is completed when appropriate.
Independent Care Group[2] – Home 1	Yes, we are all using the form
Independent Care Group – Home 2	Yes all trained staff are aware of the form
Independent Care Group – Home 3	Yes, we are using the form
Independent Care Group – Home 4	Yes
Independent Care Group – Home 5	Yes, our organisation is using the DNACPR form, senior staff do know of their existence, however most of our new clients have had the form

[2] The Independent Care Group received responses from several residential homes and nursing homes across the city – each response has been included in this document individually

Organisation	Response
	completed before admission, which makes the process easier for us
Independent Care Group – Home 6	Yes
Independent Care Group – Home 7	Yes
Independent Care Group – Home 8	Yes, we are using the form and all the RNs are aware of it
St Leonard's Hospice	Yes, we are utilising the DNACPR form
Macmillan Cancer Support (MCS)	MCS does not employ the Macmillan professionals directly however we do advocate the use of the DNACPR form and are aware that palliative care teams are actively working together on the development and utilisation of the form. The aim being to improve quality of care, informing patients and families and involving timely, active discussions with patients/carers and the wider health care teams about proactive plans and advocating patient choice about treatment plans for End of Life Care. The DNACPR form is part of the discussions about patient choice, active involvement in discussions about preferred place of care and what support practically, emotionally, socially and psychologically is required by the patient and family. The essential component within this is not only the discussions taking place but more importantly that the specialist and wider generalist teams have the skills, competence and confidence to discuss end of life

Organisation	Response
	care issues in a timely and supportive way.

2. **Can you give the Committee some positive examples of the way your organisation has used the DNACPR form?**

Organisation	Response
Yorkshire Ambulance Service (YAS)	The pre-dominant object of the regional DNACPR process is to offer a robust method of communicating the resuscitation status of a patient in cardiac arrest to all health professionals who may come into contact with the patient along their care pathway. Ultimately this objective is to support a dignified death and to negate inappropriate and futile resuscitation efforts that would be contradictory to the views of the medical team of the patient. Across YAS and certainly one example within the North Yorkshire area, trained crews have been presented with a valid regional DNACPR form on arrival at the scene of a patient in cardiac arrest. This then has rightly led to no further clinical intervention but equally importantly the instigation of an element of pastoral care for the relatives who were present at the time of death.
Leeds & York Partnership Foundation Trust	The Older People's service ensures that discharged patients to nursing homes have their form retained in the records that are kept by the nursing home. This prevents nursing homes from raising the issue

Organisation	Response
	again with patients and/or their families
NHS North Yorkshire & York (NHSNYY)	NHSNYY has an identified project lead who is a member of the Regional DNACPR Project Board and Strategic Working Group. The project lead has been involved in the roll out and implementation of the form across North Yorkshire Information on the project has been cascaded to providers and NHSNYY has a web page on their intranet The Out of Hours handover forms from GPs to Out of Hours (OOH) doctors has been re-designed to include information on DNACPR status, ensuring good sharing of information
York Teaching Hospital NHS Foundation Trust (YTHFT)	Julie Dale (Specialist Palliative Care Nurse, YTHFT), is able to present an example of a gentleman from Ward 32 who went home for end of life care. It was clear to all involved - ward staff, ambulance crew, community district nursing, hospice, at home and out of hours GP that the patient had a DNACPR order and had expressed a wish for a natural peaceful death that was achieved. Out of Hours handover forms from GPs to OOH doctors have been re-designed to include information on DNACPR status, ensuring good sharing of information.
CYC – Adults Children's Education (ACE)	N/A as we do not lead in using the form

Organisation	Response
Directorate – Assessment & Safeguarding	
Independent Care Group – Home 1	It prevents admission into hospital when not appropriate
Independent Care Group – Home 2	We are speaking to all our residents/or their families to ensure they understand why we want these forms in place and it is part of the discussions we have about end of life care so we understand our residents/families wishes
Independent Care Group – Home 3	No
Independent Care Group – Home 4	When the service user moves to Hospital or Nursing home, clear information for staff
Independent Care Group – Home 5	We always send our completed DNACPR form with our resident if admitted to hospital, none have been put into action yet
Independent Care Group – Home 6	All new admissions are assessed and the family are involved with this process and it is care planned if DNACPR is in place. The family sign to say they are agreeing to the plan, also a red sticker is on the resident's file to say DNACPR
Independent Care Group – Home 7	If we know the person does not want to be resuscitated we have managed to talk to them and their family. Sometimes doctor slow in signing the form
Independent Care Group – Home 8	Our GPs are using the forms and are happy to complete them. Our Company (Mimosa Healthcare) like the forms as they are in line with the MCA

Organisation	Response
St Leonard's Hospice	We ensure that patients are discharged from the Hospice with either a DNACPR, if appropriate, or a documented conversation that it had been discussed.
Macmillan Cancer Support (MCS)	As per question 1 – there is discussion with the teams about the use of DNACPR forms and the part that this has in quality of care and management of patients. No operational examples available at this time, however MCS is aware of the core part that this form has in active patient management and involving patients and families in choices related to actively taking part in decision making.

3. **What training has your organisation provided in relation to completing 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 members of staff on how to use the form?**

Organisation	**Response**
Yorkshire Ambulance Service (YAS)	All existing staff receive a module session on DNACPR which is incorporated with their mandatory Resuscitation Guidance Update training programmes – as at 13th February North Yorkshire A/E staff training compliance is 82.37% (327). It may be noted that the reason for DNACPR training to be added to other mandatory training is that there is no specific funding available to support DNACPR education to any area of the health economy within the Yorkshire & the Humber region. It naturally applies therefore that this lack of financial support slows the process of training and education to all professionals. It can be further confirmed that all new staff are provided with DNACPR training within their formal education programme and refresher training is also accounted for within the future mandatory Resuscitation Guidance updates. Seventy A/E frontline staff are yet to receive formal DNACPR training and based on the on-month training progression it would not be unrealistic to

Organisation	Response
	suggest that completion of this programme in North Yorkshire may be completed by around May/June of this year.
Leeds & York Partnership Foundation Trust	The use and rationale of the form is covered in the Basic Life Support (BLS) presentation. The Intermediate Life Support (ILS)Training is being modified to cover the use of the form 29%of staff have received BLS training for the first 7 months of this financial year 95% of staff identified as requiring ILS training have been trained in the same timeframe Additional training is in place to the end of this financial year
NHS North Yorkshire & York (NHSNYY)	Staff do not require formal training but there is information regarding the form and training materials on the intranet if required. The project lead is also available to provide training/briefings in-house
York Teaching Hospital NHS Foundation Trust (YTHFT)	Basic Life Support training is delivered annually to all staff who have patient contact and this training includes information about DNACPR and the form. 1,789 acute and community staff have had this annual mandatory basic life support training. This training from 2011 has included information about the DNACPR form, and an awareness about its use. This will be repeated annually for all staff who are in

Organisation	Response
	patient contact. Training DVD and information also given to GP & dental practices who access our training (recently Copmanthorpe, South Milford, dentist at Orthokind, York, Pickering, Sherburn) DVD on form completion & difficult conversations shown to new doctors on Induction Programme in PGME (Post Graduate Medical Education) (first week in February & August) DVD & Question & Answer sessions with Band 6 and higher nurses and therapists facilitated by Resuscitation Officers. Planned to repeat for Community staff new to the Trust across Scarborough, Whitby and Ryedale. Additional Training by Hempsons, solicitors for medical staff and senior nurses in January 2012 on form completion and difficult scenarios. (this information supplied by Resuscitation Officer and Corporate Learning & Development Team)
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	No specific training to care management staff

Organisation	Response
Independent Care Group – Home 1	Only nurses complete the form, would only train everyone else if this is a requirement
Independent Care Group – Home 2	We are a small Nursing Home so at present it has been the manager or her deputy who have dealt with the forms
Independent Care Group – Home 3	The form is of constant discussion at our nurses meetings for the difficulty in getting GPs to sign the form and the families and resident not wanting to enter into conversation about it. All the nurses have been trained on them. Staff were trained by the General Manager who attended a meeting with a representative from the PCT who came along and explained the need and how to use the form effectively. The form is constantly on care file audits we complete as General Managers. New staff are shown the form as part of their documentation training on induction.
Independent Care Group – Home 4	None, the organisation speaks to the GP in relation to completing and using the form and at the moment the GP does all the form filling We are residential care
Independent Care Group – Home 5	We have attended meetings about the form but no official training has been given yet
Independent Care Group – Home 6	I have been advised that all staff are aware in the use of the DNACPR paperwork
Independent Care Group – Home 7	All our trained staff have been trained to use the

Organisation	Response
	form. We have included the topic in staff meetings. If the form changes in any way staff are updated
Independent Care Group – Home 8	Staff have not been trained on the form itself
St Leonard's Hospice	The training has been informal and via a cascade approach in team meetings. I have not been able to gain evidence of who has been trained at this point.
Macmillan Cancer Support (MCS)	MCS provides education and learning grants for Macmillan professionals which they can access on an individual basis or as part of the team. The grants could potentially be used in this area for improving the knowledge, competence and skills of teams if this was requested.

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

Organisation	**Response**
Yorkshire Ambulance Service (YAS)	Yes. YAS not only has integrated the DNACPR regional form and processes into its Resuscitation Policy but also now has a specific Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) Policy and Procedure that outlines the processes for both the A/E and PTS elements of the trust when treating and/or transporting patients with a DNACPR decision in place. This policy at the time of writing was circulated to all PCTs via the DNACPR Strategic Working Group to inform and assist with the newly adopted processes within both the community and acute setting to ensure alignment of services.
Leeds & York Partnership Foundation Trust	Yes, the form is included in the Trust's *Do not attempt cardiopulmonary resuscitation (CPR) policy*
NHS North Yorkshire & York (NHSNYY)	The form has been fully integrated into our policy
York Teaching Hospital NHS Foundation Trust (YTHFT)	Yes. It is integral to our DNACPR policy and has been rolled out across the organisation and is available for all staff on the Intranet. It has been the focus of much work post CQC inspection and is high profile within the organisation.
CYC – Adults Children's Education (ACE)	N/A

Organisation	Response
Directorate – Assessment & Safeguarding	
Independent Care Group – Home 1	Yes, and now kept in residents' files
Independent Care Group – Home 2	We are trying to ensure that we ask all our residents their wishes but find we have to pick the appropriate moment. We are currently deciding what our time scale for doing this will be and then we will include it in our policies
Independent Care Group – Home 3	The form has not been written into our policies being a national company all PCT areas are not working with these
Independent Care Group – Home 4	Work in progress
Independent Care Group – Home 5	No, this has not been incorporate into our policies and procedures
Independent Care Group – Home 6	No comment provided
Independent Care Group – Home 7	We already had end of life wishes integrated into our documentation/policies
Independent Care Group – Home 8	The forms are used in conjunction with the end of life section of our care plans and policy
St Leonard's Hospice	It is not integral to any of our policy currently but we have our end of life pathway review ongoing
Macmillan Cancer Support (MCS)	The education and learning grants offer opportunities for the Macmillan teams to identify education and learning needs and devise their own bespoke education programme, which the grant could support. MCS also has 'Learn Zone' which is a resource available to anyone whether they are a Macmillan

Organisation	Response
	professional, health or social care professional or member of the public. This is free and only requires registration. There are already many resources available including specific resources e.g. Out of Hours toolkit, palliative care education modules which are highly relevant to the delivery of specialist and generalist palliative care and have been devised with the involvement of MacMillan GPs and Macmillan Clinical Nurse Specialists. www.macmillan.org.uk/learnzone

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

Organisation	Response
Yorkshire Ambulance Service (YAS)	At this juncture there is no formal audit in place for DNACPR within the trust annual audit cycle. However within the YAS Patient Report Form (PRF) all DNACPR patients are recorded irrespective of clinical intervention or otherwise as it needs to be remembered that YAS may attend DNACPR patients with an acute episode of illness or injury. This facility will therefore allow for future planning to include any audit relating to the new process.
Leeds & York Partnership Foundation Trust	Yes, after completion of a DNACPR form, staff must complete and submit a DNACPR completion form to the Governance Manager
NHS North Yorkshire & York (NHSNYY)	Audits have been completed as part of the Regional Project. The audit has focussed on questions relating to the implementation of the form, training received and quality checks on completeness of forms
York Teaching Hospital NHS Foundation Trust (YTHFT)	Yes. The Trust's Compliance Unit regularly audit the completion of DNR/CPR forms and feeding this back to Ward Sisters, Consultants and the Corporate Directors. Any errors identified are addressed. (Information supplied by Compliance Unit)
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	N/A

Organisation	Response
Independent Care Group – Home 1	No
Independent Care Group – Home 2	Not yet
Independent Care Group – Home 3	The form is audited in the care file audit process in the home
Independent Care Group – Home 4	Work in progress- we have just started to look at the audit
Independent Care Group – Home 5	We include the form in discussion with the family and GP when need arises i.e. review or change in a persons health needs
Independent Care Group – Home 6	It is audited when the care file is audited which is done in a planned way
Independent Care Group – Home 7	No we haven't up to now
Independent Care Group – Home 8	No
St Leonard's Hospice	There is currently no audit, but our audit process is currently under review
Macmillan Cancer Support (MCS)	Macmillan services undergo service reviews which involve the Macmillan Development Manager, the Macmillan team and their managers. The review will include looking at the evidence which demonstrates quality issues around impact and added value which the specialist teams provide. Involvement with DNACPR forms will be an operational issue which may be discussed at the review together with appropriate tools e.g. Gold Standards Framework, Liverpool Care Pathway. The service review provides opportunity to acknowledge best practice

Organisation	Response
	and to share good practice from other areas as appropriate.

5. **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?**

Organisation	Response
Yorkshire Ambulance Service (YAS)	YAS is aware of two examples of inappropriate resuscitation each of which appears to have involved crews who were not trained on the new DNACPR process.
Leeds & York Partnership Foundation Trust	There have been no complaints
NHS North Yorkshire & York (NHSNYY)	No complaints from families/carers
York Teaching Hospital NHS Foundation Trust (YTHFT)	In the last year there have been 2 or 3 complaints. These have focussed on the issue of communication with family members. In light of these complaints the policy has been reviewed regarding communication and a training programme put in place for all medical staff and appropriate senior nursing staff. See other comments from YTHFT (Information supplied by Complaints team)
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	No
Independent Care Group – Home 1	No complaints received
Independent Care Group – Home 2	No
Independent Care Group – Home 3	No complaints
Independent Care Group – Home 4	No
Independent Care Group – Home 5	We have not used one yet
Independent Care Group – Home 6	No
Independent Care Group – Home 7	We have not received any complaints

Organisation	Response
Independent Care Group – Home 8	No complaints about the form, but have brought up the subject at the recent relatives meeting so all are aware of it
St Leonard's Hospice	We have had feedback from a family who had a relative at home that had a DNACPR form and was at the end of life. At the point where the patient stopped breathing the family called 999 and an ambulance crew attended the house and attempted to resuscitate the patient despite being aware of a DNACPR. The issues for us were relating to our communication to families on what to do and who to call when a patient dies to prevent 999 calls in the future. This information was fed back to YAS at the time by the previous Director of Clinical Services for the Hospice
Macmillan Cancer Support (MCS)	I have no information related to this area. If MCS receives a complaint about patient care or experience we have a complaints procedure to follow and would discuss with the appropriate employer/organisation.

6. **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?**

Organisation	**Response**
Yorkshire Ambulance Service (YAS)	There does not appear to be any specific barriers other than the educational issues as described in our answer to question 6
Leeds & York Partnership Foundation Trust	We have found no barriers in using the form
NHS North Yorkshire & York (NHSNYY)	No
York Teaching Hospital NHS Foundation Trust (YTHFT)	All staff to be using the most current version of the form and to be aware of its use and developing the skills in having difficult conversations around end of life care. Feedback regarding the form itself has been given to the SHA project group to say that the design of the form and the flow of information within the form is not intuitive and the information could flow better DNACPR task group started at end of 2011 to prioritise issue, new policy, training and education.
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	N/A
Independent Care Group – Home 1	No
Independent Care Group – Home 2	Not really – some GPs are sometimes reluctant to have them in place unless the resident is terminally ill
Independent Care Group – Home 3	No
Independent Care Group – Home 4	Too early to say

Organisation	Response
Independent Care Group – Home 5	We do feel that these could be used inappropriately if everyone was not in agreement as to the person's capacity and general health status
Independent Care Group – Home 6	No barriers
Independent Care Group – Home 7	No, not once all were on board
Independent Care Group – Home 8	Only that most staff leave this subject to deal with at a later date and then forget about it
St Leonard's Hospice	No barriers to using the form, our difficulty is around the timing of the conversations with patients and their expectation when they are admitted. The area has often not been discussed prior to a patient coming into the Hospice
Macmillan Cancer Support (MCS)	MCS has a role in negotiating with teams, their managers and employers and using opportunities to influence from a local, regional or national level. MCS advocates working to develop and improve DNACPR and End of Life Care.

7. **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?**

Organisation	**Response**
Yorkshire Ambulance Service (YAS)	A number of issues have been raised via the DNACPR Lead for the PCT to YAS all of which in the main have related to three specific areas of concern: 1. YAS crews not accepting a document which does not have a red border. This remains very much an educational issue within YAS and relates to the agreement by the DNACPR Strategic Working Group that a document can either have a red or black border as long as it is the original document. It may be noted that this decision was agreed to accommodate the desires of GP practices across all PCT areas who argued that they did not have colour printers in their surgeries not the budget to replace or upgrade. YAS is continuing to work hard both inside the trust and with colleagues from the PCTs to address this issue 2. YAS crews not accepting forms as they were concerned that the form was not an original as agreed within the original process. At the most recent meeting of the Strategic

Organisation	Response
	Working Group - is now agreed that crews no longer are required to obtain assurance that the document is the original but may act upon the document provided and as long as they are satisfied that the DNACPR decision relates to the patient in their care and that it is both in date and fully signed by an appropriate clinician. 3. YAS crews not accepting the form as they are under the belief that the review date of the form has expired. This appears to be a further educational issue probably based on staff's previous understanding of the time limitations of the old DNAR style forms Once again YAS is working hard to ensure that staff are fully aware that the form is valid if the review date is in date (and this period can be anything up to six months) or alternatively if there is no review date included (but is signed) that the form can be deemed as valid for an indefinite period.
Leeds & York Partnership Foundation Trust	We have had no experience of the form not working
NHS North Yorkshire & York (NHSNYY)	• Yes: • Ambulance Crew call to transport patient from home to hospice. Crew stated DNACPR

Organisation	Response
	form was out of date and refused to transfer the patient with the DNACPR form at the house. The crew wanted the form updating and also the section regarding ambulance crew guidance completed. • GP was contacted to complete another DNACPR form. • Ambulance crews have stated it was not a valid document because: • The form should have red borders • The form is a copy • The crew felt the form needed reviewing as the form was several months old (i.e. more than 3 but less than 6 months) • There are no instructions for ambulance crews • Not always resolved at the time but reported to Yorkshire Ambulance Service (YAS) as the forms were valid at the time of the incident
York Teaching Hospital NHS Foundation Trust (YTHFT)	The form itself works well. See other answers for issues that are raised
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	No
Independent Care Group – Home 1	No
Independent Care Group – Home 2	No
Independent Care Group – Home 3	Where residents and relatives have agreed their decisions then the GP has refused to sign them, the

Organisation	**Response**
	resident was then part of an unexpected death procedure in the home and the resident had been dead a matter of minutes before they were found. The ambulance came blue light after being told it is not an emergency as the person was dead (confirmed by a registered nurse) and they carried out CPR
Independent Care Group – Home 4	Received forms from York Hospital not filled in correctly – family not signing the form and do not know anything about it
Independent Care Group – Home 5	No
Independent Care Group – Home 6	No
Independent Care Group – Home 7	No
Independent Care Group – Home 8	No, Ii think it is a good form and has saved us having to create another ;best interest’ decision form of our own
St Leonard’s Hospice	See Hospice response to question 6
Macmillan Cancer Support (MCS)	I have no specific information or examples of this, although there have been general discussions related to the management of patient care when a patient’s condition has deteriorated and yet the family have relayed that the patient did not wish to be resuscitated and admitted, but procedure/policy led to this happening.

8. **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 which overruled the DNACPR decision?**

Organisation	**Response**
Yorkshire Ambulance Service (YAS)	Please see YAS's response to question 6
Leeds & York Partnership Foundation Trust	This has not occurred
NHS North Yorkshire & York (NHSNYY)	Yes Rapidly deteriorating patient discharged, to fulfil his wish to go home to die DNACPR in place and discussed with patient, the family, the ambulance crew taking him home and the hospice team –agreed what to do if he died during the journey home The GP OOH's Palliative Care Handover Form was completed and faxed When he died his carer rang 999 and a crew was dispatched who went on to attempt CPR This was unsuccessful and the police and the coroner were then involved The ambulance crew had not received their training and therefore wouldn't accept the form
York Teaching Hospital NHS Foundation Trust (YTHFT)	On occasion an out of hours phone call made by family to alert OOH to an unexpected death have resulted in the despatch of paramedic responders and police and telephone advice about starting resuscitation. This is not about compliance with DNACPR form but the appropriate triaging of such

Organisation	Response
	phone calls. Across the SHA commissioners are doing a piece of work with YAS about this and are collating information. The feedback from commissioning is as follows: There have been very few problems in the City of York area that have been brought to the commissioners' attention: • June 2011 – Ambulance crew stated DNACPR form was out of date and refused to transfer the patient with the DNACPR form at the house. They wanted it update and also the section regarding ambulance crew guidance completed • November 2011 – the Director of Clinical Services, St Leonard's Hospice informed the project lead of an incident in November 2011. The patient was also known to the Specialist Palliative Care Team who also raised this as a concern. Rapidly deteriorating patient discharged, to fulfil his wish to go home to die. DNACPR in place and discussed with patient, the family, the ambulance crew taking him home and the hospice team – agreed what to do if he died during the journey home.

Organisation	Response
	The GP Out of Hour's Palliative Care Handover Form was completed and faxed When he died his wife, as family members do, rang 999 and a crew was dispatched who went on to attempt CPR. This was unsuccessful and the police and coroner were then involved. The ambulance crew had not received their training and therefore won't accept the form Across North Yorkshire the main problems have been related to ambulance crews stating the DNACPR form was not a valid document because: 1. The form should have red borders – this is an issue for GPs and nursing homes if they download forms rather than using pre-printed forms, as few offices have colour printers. Discussions underway about GPs using/accessing the printed forms 2. The form is a copy 3. The crew felt the form needed reviewing as the form was several months old (i.e. more than 3 but less than 6 months)
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	No
Independent Care Group – Home 1	A photocopy of the form was given to ambulance

Organisation	Response
	men, but they wouldn't accept it so we spoke to our GP
Independent Care Group – Home 2	No
Independent Care Group – Home 3	See answer given to question 8 And GP refusal to sign
Independent Care Group – Home 4	No
Independent Care Group – Home 5	CPR has not been attempted on anyone in this care setting
Independent Care Group – Home 6	No
Independent Care Group – Home 7	No
Independent Care Group – Home 8	No
St Leonard's Hospice	See Hospice answer to question 6
Macmillan Cancer Support (MCS)	I have no information related to this

9. **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)?**

Organisation	**Response**
Yorkshire Ambulance Service (YAS)	No
Leeds & York Partnership Foundation Trust	In our experience the main issue for end of life care is not whether resuscitation is provided when someone arrests but whether active treatment e.g. intravenous infusions or admission to a general hospital, should be given when a patient is dying. We believe the emphasis should be on maintaining comfort and dignity for the dying person. This may mean that active treatment is not appropriate. Raising awareness of the use of Advance Directives would assist in this
NHS North Yorkshire & York (NHSNYY)	No
York Teaching Hospital NHS Foundation Trust (YTHFT)	After discussion with social services colleagues and the community matron who works in nursing homes there are several issues regarding embedding the use of the form in a community setting. Nursing homes are trying to use them, (and community matron has taken forms to nursing homes), and get them signed by visiting GPs, however when a patient comes into hospital the form seems to get lost en route/in ED (Emergency Department) and rarely returns to the nursing

Organisation	Response
	homes. This causes them more work as they then have to start again requesting the form to be completed by a non-resident doctor. An awareness raising exercise in the importance of returning the original form after a hospital admission/appointment needs to be ongoing. Social services residential home managers would after discussion only feel comfortable using a DNACPR form completed by a doctor where it can be evidenced that a discussion has taken place with family, carers or a best interest decision is clearly documented. Whilst acknowledging best practice is to have this conversation, there are occasions when they are signed by the doctor without discussion, and there are concerns expressed by social service colleagues about the appropriateness of this. This reflects a lay assumption that family or patient has to consent to the DNACPR being in place. This will need to be followed up with further discussions of all parties. After discussion at dementia workshops etc social services staff have proactively completed DNACPR

Organisation	Response
	forms with all appropriate new residents and are now considering retrospectively doing the same for existing residents. Further joint working on this issue will be very positive
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	We are uncertain how far the requirements of the Mental Capacity Act are embedded in clinical practice to inform judgements around DNACPR
Independent Care Group – Home 1	No
Independent Care Group – Home 2	We had a resident who was discharged from York Hospital who had a form with him on his return to the Nursing Home, however despite the fact that he had capacity it had not been discussed with him or his family
Independent Care Group – Home 3	Provide more publicity to the public. Have discussions with GPs and perhaps have an appeal process to go through when GPs refuse to sign
Independent Care Group – Home 4	When a form comes back with a service user after being in hospital and it is not filled in correctly what to do and how long does it last, the GP thought 6 months then he would need to speak to the service user and family to do another one
Independent Care Group – Home 5	We feel that DNACPR wishes should be made while the person has capacity to make the decision for themselves. We find the forms a little worrying as people's emotional state changes especially at the loss of a loved one and then start to express feelings

Organisation	Response
	of guilt which can lead to recriminations
Independent Care Group – Home 6	No
Independent Care Group – Home 7	We do need to know when a new version has come out
Independent Care Group – Home 8	No comment provided
St Leonard's Hospice	Our Hospice at Home Team (H & H) have cared for a patient in the community who was at the end of life and died over a night time. The H & H Team were not present at the time of death however the family had been informed to contact the out of hours GP team when the patient died. At the time of death the family called 999 rather than the out of hours team and an ambulance attended. The patient did not have a DNACPR form and the ambulance crew attempted to resuscitate. The family intervened and removed the crew from the house and were obviously distressed by the situation. The ambulance crew contacted the police as they had been removed from the property and the police then attended. The family were traumatised by the situation. The concern is that the H & H Team were called to support the patient at the very end of life and the patient had no other prior contact with the Hospice Team. The DNACPR form had not been completed by health professionals involved with the patient's

Organisation	Response
	care. It is vital that all health professionals are aware of their responsibility to have the difficult conversations with patients and their loved ones in a timely manner to avoid situations such as this one
Macmillan Cancer Support (MCS)	MCS is in agreement that the development and use of DNACPR forms is essential for quality of life and quality of death and should be core in all patient pathways.

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

Organisation	**Response**
Yorkshire Ambulance Service (YAS)	See YAS's answer to question 8
Leeds & York Partnership Foundation Trust	We have no experience of this
NHS North Yorkshire & York (NHSNYY)	Yes Ambulance crews have stated it was not a valid document because: • The form should have red borders • The form is a copy • The crew felt the form needed reviewing as the form was several months old (i.e. more than 3 but less than 6 months) • There are no instructions for ambulance crews
York Teaching Hospital NHS Foundation Trust (YTHFT)	Anecdotal evidence, although may be able to ascertain more information from commissioners who are doing a piece of work with YAS about this and are collating information. See other comments from YTHFT
CYC – Adults Children's Education (ACE) Directorate – Assessment & Safeguarding	N/A
Independent Care Group – Home 1	Because it was a photocopy, not the original
Independent Care Group – Home 2	No comment provided
Independent Care Group – Home 3	In the early stages the ambulance crew were not aware of them so we did have a couple of instances of CPR given when the person had been dead for

Organisation	Response
	many minutes
Independent Care Group – Home 4	No
Independent Care Group – Home 5	No comment provided
Independent Care Group – Home 6	No comment provided
Independent Care Group – Home 7	Because it was not an up to date version
Independent Care Group – Home 8	Very recently a member of the YAS reluctantly agreed to use it after complaining that it wasn't outlined in red (it was just a black and white version)
St Leonard's Hospice	As per answer 6 from the Hospice, I do not know why it is not accepted. There has been no feedback to me. However, I have only recently come into post at St Leonard's
Macmillan Cancer Support (MCS)	No information related to this operational issue.

Other Information/Comments

Comment from LINKs – The following comment was received as part of e-mail correspondence regarding today's meeting
'We don't use the form but have received several complaints from relatives of people who had the form but were still actively treated - possibly not CPR but the effect is the same as life is prolonged' (Annie Thompson; Links Partnership Co-ordinator)

Comment from York Teaching hospital NHS Foundation Trust – The following comment was received as part of e-mail correspondence regarding today's meeting
'We are pleased to be able to feedback to you about a large amount of work that has been undertaken in the Trust recently with the launch of our new policy and ongoing training for staff.
Looking forward there remains a great deal of work to do around this area of end of life care, and one of the issues it would be interesting to explore collaboratively is how to influence the culture of the general population to engage in discussions about their end of life wishes and plans, whilst they are well and able to discuss these things with families and friends. It would be ideal if the general social acceptance of sex education by the general population could be replicated in similar education about death and dying, and this would lead to a very helpful public airing of these issues and help support development of this work.' (Elizabeth McManus; Chief Nurse)

Information from the Chief Executive of the Independent Care Group

York Health Overview & Scrutiny Committee - DNACPR Forms
I am very sorry not to be able to attend the meeting. I would like to make one or two points.

Background
I think any discussion on CPR should begin by looking at the subject objectively.
The General Medical Council says:
'CPR has a reasonable success rate in some circumstances. Generally, however, CPR has a very low success rate and the burdens and risks of CPR include harmful side effects such as rib fracture and damage to internal organs; adverse clinical outcomes such as hypoxic brain damage; and other consequences for the patient such as increased physical disability. If the use of CPR is not successful in restarting the heart or breathing, and in restoring circulation, it may mean that the patient dies in an undignified and traumatic manner.'

I think it's important not to forget this. One of the reasons why we have worked to have a Do Not Resuscitate Form is because the Ambulance Service has been (historically) obliged to perform CPR and this has caused distress to everyone where a client is at the end of their life or is frail and has no wish to be resuscitated.

In the past care homes who telephone for advice and support for a client whose condition has worsened have on occasion inadvertently triggered an Ambulance. The person who is at the end of their life and their relatives would not want CPR to be performed but once the ambulance arrived there was no choice.

From talking to Independent Care Group members (care homes in York) and from the forms I have received back I think the following points should be addressed.

The Form
The DNACPR Form has been designed with a red border. Most care homes do not have a colour printer. We have been told that forms do not have to have a red border but there still seems to be a problem with the Ambulance Service accepting this.

GPs being willing to sign forms on the wishes of the patient
Some homes have a very good relationship with the numerous GP practices with whom they work. However, I do still get reports of homes having difficulty engaging GPs in getting the forms signed.

The validity of the Form

If a patient in hospital has a DNACPR Form put into place there remains confusion over what happens to it when the patient is discharged. We need guidance on this. I have been told that the DNACPR Form is location specific – but is this true. If the form has not been discussed in hospital with the person and their relatives then it needs to be discussed by their GP if they are discharged with a DNACPR Form.

People with dementia

Homes which look after people with dementia would like more guidance. Often relatives will say that they do not want their loved ones to undergo resuscitation. This places the home in a difficult position as DNACPR would have to be agreed with the person who lacks capacity.

Summary of discussions from the meeting held on 29th February 2012

1. It was acknowledged very early on in the meeting that the discussions around and the completion of a DNACPR form were only a small part of establishing an End of Life Care pathway; however DNACPR was the chosen focus for this review

2. The Commissioning Manager, Specialist Commissioning, from NHS North Yorkshire & York said that there had only been a couple of incidences in York where the form had not been used properly and he was aware of these

3. In relation to the Acute Trust (the hospital) concerns had been raised by the Care Quality Commission (CQC) [**Annex A refers]** about the use of the form. The Medical Director from the Acute Trust acknowledged that there had been times when the form had not been correctly used within the hospital environment. Training programmes in relation to the use and completion of the form had now been implemented and there had been a shift in practice and more importantly a shift and increase in awareness of the form and its purpose. The CQC had visited the hospital again recently and had noticed a real change in practice and now regarded them as being compliant in the use of the DNACPR form

4. The Chair of the Health Overview & Scrutiny Committee acknowledged that the focus for this review had been partly triggered by the CQC report and it was excellent to know that improvements had been made and concerns addressed within the hospital environment

5. The Medical Director from the Acute Trust said that he sits down with staff every week to review all deaths that have taken place in the hospital over the past 7 days. They look at factors such as age, length of time in hospital and anything that could have been managed differently. He gave an example of an elderly person having been admitted to the hospital; she was very poorly, had dementia and heart disease and was admitted acutely to the hospital from a nursing home; She died 2 hours later. DNACPR was discussed with the patient and they chose not to be resuscitated. However, this was an unnecessary admission to hospital resulting in an undignified death in a place the patient did not want to be.

The process could have been made simpler and more dignified for the patient had DNACPR been discussed within the nursing home, especially as in this case the death would have been foreseen

6. It was acknowledged that some nursing homes do a fantastic job in relation to all aspects of End of Life Care; however there were others where improvements needed to be made. Yorkshire Cancer Network was rolling out a process to enable access to a training programme for staff in nursing homes across the city.

7. A local GP also raised concerns as to why the above mentioned patient was admitted to hospital in the first instance. He said that often admissions like those above happened when the Out of Hours Service (OOH) admitted a patient, however in the instance stated above the patient was *not* admitted by OOH and neither was there any evidence that DNACPR had ever been discussed with the patient

8. A representative of North Yorkshire Police also raised concerns about the OOH service and suggested that the improvements being made to the way DNACPR forms were dealt with were being undermined by inconsistent practice within the OOH service, and a failure to identify patients where death was expected from those in need of urgent medical attention, and consequently the failure to deliver support to the services caring for a patient whose death was expected. Representatives from York Hospital agreed that there had been issues where the Police have been called to expected deaths. If the death is expected with a DNACPR form in place then there is no need to inform the Police. There needs to be more joined up working with the OOH providers and Yorkshire Ambulance Service around these issues along with more education and more robust pathways put in place.

9. A Social Worker told a story of a patient in a nursing home who had a DNACPR in place; the nursing home telephoned the OOH service but instead of coming out to visit the patient they had sent a paramedic, the patient subsequently died and this led to the Police becoming involved which was distressing for the family

10. The Chair of the Committee commented that the OOH service was being mentioned with regularity in what appeared to be a negative light.

The OOH had not been invited to the meeting on 29th February but it was clear that the Committee would need to speak to them in the future and include them in any further discussions. To date, it was acknowledged that all comments received about the OOH were anecdotal and these were only one part of the jigsaw.

11. The Committee indicated that they would like to know more about how the OOH dealt with these situations, such as: If a GP was aware that death was imminent for a particular patient was there a process in place that could alert OOH to this and thus avoid YAS and/or the Police being called? The GP present at the meeting on 29th February was confident that this was the case if the patient was dying from cancer as robust end of life care pathways were usually in place. However, this was not always the case if the person was just elderly and/or in a care home rather than suffering from cancer

12. He felt that OOH should be asking 'is this an expected death' and if the answer is yes then there would be no need to call YAS. If the death occurs in a nursing home then a registered nurse, who has completed the appropriate training, can verify[1] death. An unexpected death would be handled in a different way. However when a telephone call comes through to OOH electronic systems should provide them with all information they need whether the death is expected or not. The GP confirmed that, internally, they were being asked to be more aware of which patients had a DNACPR form in place

13. A representative from a residential care home raised the point that in residential care homes there was not always a registered nurse on the premises. Therefore if someone does die there is not always someone on site to verify death. It had sometimes been a struggle for them to get a GP to attend to verify death, especially an OOH GP. There had been an instance in the past when there had been an expected death in a residential home and the GP would not attend, instead advising the nursing home to ring YAS and the Police. This unfortunately ended up in the Coroner's Court which was distressing for all concerned.

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[1] Verification of death is when the death is confirmed by a staff member who is trained in verification. Certification of death is when a Doctor documents the cause of death on a death certificate. This is a legal document required by the informant to be able to register the death at the Registrar's office.

This is an area that needs to be looked at further as residential homes do not always have registered nurses that can verify a death.

14. A consultant in palliative medicine from York Hospital mentioned that a GP did not have to be present to verify a death that was expected. However, there may be issues around this process that needed to be made clearer and more widely understood. It was important that people had a dignified death and distressing situations, such as the unnecessary involvement of YAS and/or the Police, needed to be avoided at all costs. It was therefore acknowledged that there was work to be done around managing the 'verification of death' process in both residential care homes and some nursing homes.

15. It was acknowledged that some GPs still had their own OOH service but only very few. The current, main OOH service was commissioned by NHS North Yorkshire & York. It was not clear from discussions at this meeting what policies and guidelines were in place for the OOH service in relation to DNACPR forms; however it was generally understood that they would be aware of them but clarity needed to be sought at a future meeting. Neither was it known what training they had had in relation to DNACPR forms. The Committee asked that further information be provided on this for a future meeting, especially in relation to what training is provided to the OOH GPs in relation to DNACPR forms. However it was stated that discussion around and completion of the DNACPR form should take place 'in hours' with patients, families and appropriate medical staff. The 'paperwork' should be in place by the time a death occurs. It was noted that commissioning of this service would be moved from NHS North Yorkshire & York to the Vale of York GP Commissioning Consortium and they should be involved in further discussions around this.

16. Representatives from York Hospital said that 25% of deaths are from cancer and 75% are from a non-cancer related illness. 60% of all deaths happen in hospital and only 20% of deaths will have a palliative care pathway in place with their GP. The Hospital representatives were very supportive of DNACPR forms being embedded across the community to allow all a dignified death. Of the 60% mentioned above many would have preferred to die at home so there is still work to be done and it is clear that we aren't getting things completely right yet.

17. It also appeared that in some instances communication in relation to end of life care was breaking down when a patient left the hospital. There had been instances when the DNACPR form had not left the hospital with the patient, with the hospital saying that the form belonged to them.

    The Medical Director said that this was unlikely to happen now as issues around DNACPR forms had been addressed and staff had been provided with training and thus had a much better understanding of how the form was used. It was now known that when a patient left hospital with a DNACPR form, their form should go with them. The electronic discharge notice issued to a patient's GP should include information on any current DNACPR form so they are aware of a patient's wishes.

18. In the past some DNACPR forms had not clearly shown whether there had been any consultation with the patient and/or their family. Whilst the subject matter being discussed was acknowledged as being sensitive, patients were often very happy to discuss it with medical staff and were keen to be involved in making decisions about their own death. The Medical Director at the Acute Trust said that it was good practice to discuss end of life issues with a patient. If patients are competent they can refuse cardiopulmonary resuscitation (CPR); if patients who lack capacity have a valid advance decision to refuse treatment which includes 'not for CPR', these patients will not be resuscitated and will have a DNACPR order put in place. A patient has a right to make a decision on whether they want to be resuscitated or not after being fully appraised of their medical condition around quality of life issues. (The CPR may well be successful but the outcome following CPR may be that the patient has a very poor functional state.)The patient understanding this may wish, on quality of life grounds to be resuscitated. However, if resuscitating the patient were considered to be medically futile then the decision on whether to resuscitate or not would be made by a clinician. Patients can also change their minds about DNACPR; if a competent patient had previously made a decision to not be resuscitated, but then changed their mind, providing it is not deemed a medically futile treatment then the patient would be resuscitated; but if CPR is deemed to be medically futile and not in the patient's best interest the DNACPR order will remain in place.

19. Sometimes there may be evidence of discussions around DNACPR in a patient's care notes – it was important that these were clearly

documented on the DNACPR form. Improvements needed to be made around documentation, although indications show that this is now happening. The Acute Trust had a leaflet produced by the Strategic Health Authority entitled ‘What happens if my heart stops’ and this could be used to provide information to and prompt discussion with patients and their families. A copy of this leaflet is attached at **Annex G** to this report

20. A Service Manager at one of York’s Residential Care Homes said that there was tangible evidence to show that DNACPR forms had generally been used in an excellent way and there were only a few instances where things had gone wrong, however it was still very important to address these. It was confirmed that training on DNACPR forms was mandatory for all staff working in City of York Council residential care homes and it was not usual practice to move patients to hospital to die if at all avoidable

21. A representative of YAS acknowledged that there had been some training and staffing issues which were being addressed; however there had been a vast improvement and a quantum leap with this. The procedures and protocols used within the Ambulance Service around DNACPR were becoming stronger and stronger and bad experiences were occurring less and less. There had been a noticeable improvement within the last 2 or 3 years. He also acknowledged that unnecessarily calling YAS and/or the Police to a death was not only distressing for families but also for staff within YAS as well who wanted to do the best for the patient and their family.

ANNEX G

Yorkshire and the Humber region

What happens if my heart stops?

Do not attempt cardiopulmonary resuscitation (CPR) decision making.
Information for patients, family, friends and carers.

 ANNEX G

This is a general leaflet for all patients but it may also be useful to your relatives, friends and carers.

It tries to explain:

- what cardiopulmonary resuscitation (CPR) is;
- how you will know whether it is relevant to you; and
- how decisions about CPR are made.

It may not answer all your questions about CPR, but it should help you to think about the issue. One of the doctors or nurses caring for you may discuss CPR with you and if you have any questions after reading this information, they will be able to provide answers for you.

What is CPR?

If someone's heart or breathing stops suddenly, the brain can only live for about three to four minutes before death could result. When this happens it may be possible to try to restart the heart and breathing with emergency treatment called CPR or cardiopulmonary resuscitation.

What happens in CPR?

CPR usually includes:

- 'mouth-to-mouth' breathing to get air in the lungs; and
- repeatedly pushing down very firmly on the chest to pump blood round the body, until further help arrives.

In hospital, or healthcare premises, the emergency team may then:

- use a machine to give electric shocks to try to restart the heart;
- insert a tube into the windpipe to give oxygen; and
- give drugs to help the heart and lungs work properly.

Is my heart likely to stop suddenly?

The healthcare team caring for you are the best people to discuss the likelihood of your heart or breathing stopping suddenly. People with the same illness or symptoms do not always respond to their treatment in the same way, so it is usual for professionals and patients to discuss what might happen in advance.

Is CPR tried on everybody whose heart and breathing stop?

Yes, in an emergency and if the medical decision is that there is a chance that it will work and the person has not refused CPR.

When the heart and breathing stop without warning, for example if a person has a serious injury or heart attack, the healthcare team will try to revive the patient.

Some members of the public are also trained to do CPR. The priority is to try to save the person's life. However, a person's heart and breathing also stop working as part of the natural and expected process of dying. If people are already very seriously ill and near the end of their life, there may be no benefit in trying to revive them each time their heart and breathing stop. This is particularly true when patients have other things wrong with them that mean they don't have much longer to live. In these cases, restarting their heart and breathing may do more harm than good by prolonging the pain or suffering of someone who is soon to die naturally.

Does CPR work?

The chance of CPR being successful will depend on:

- why your heart and breathing have stopped;
- any illnesses or medical problems you have (or have had in the past); and
- the overall condition of your heart and lungs.

Fewer than 2 out of 10 patients who have received CPR leave hospital alive. The figures are much lower for patients with serious underlying conditions. It is important to remember that this is a general picture. Everybody is different and the healthcare team will explain whether they think CPR will help you.

Do people get back to normal after CPR?

Each person is different. Patients with many medical problems are less likely to make a full recovery. A few patients do make a full recovery, some recover but have health problems. Unfortunately, most attempts at CPR do not restart the heart and breathing despite the best efforts of everyone concerned. It depends on why the heart and breathing stopped working and the general health of the person. It also depends on how quickly the heart and breathing can be restarted. Patients who are revived are often still very unwell and need further treatment afterwards, usually in a coronary care or intensive care unit. The techniques used to restart the heart and breathing also sometimes cause side effects, for example, bruising or broken ribs and punctured lungs. Some patients never get back the level of physical or mental health they enjoyed before the cardiopulmonary arrest. Some may end up with brain damage or go into a coma.

Who makes the decision about CPR?

The doctor in charge of your care is responsible for this decision. However, the team looking after you will look at all the medical issues, including whether CPR is likely to be able to restart your heart and breathing if they stop, and for how long. Sometimes, restarting a person's heart and breathing leaves them with a severe disability or only prolongs their suffering because of the injuries that CPR itself can cause. Prolonging life in these circumstances is not always beneficial; your doctor will discuss this with you. Your wishes are very important, and the healthcare team will want to know what you think. In most cases, doctors and their patients agree about their treatment when there has been good communication.

Does my age or the fact that I have a disability affect the decision about CPR?

No, your age does not affect the decision, nor does the fact that you may have a disability. What is important is:

- your state of health;
- the likelihood of you getting back to a life that you can enjoy; and
- your wishes.

Will someone talk to me about CPR?

Yes, if you would like them to. Your healthcare professional will usually talk to you about:

- your illness;
- what you can expect to happen; and
- what can be done to help you.

If you want, your family and close friends can be involved in these discussions. You can also ask someone who shares your religious faith to join you. If you are in a hospital or hospice, the chaplaincy service may be able to arrange for a leader of your faith to visit you to discuss this.

What if I don't want to talk about it?

You do not have to talk about CPR at all if you don't want to, or you can put a discussion off if you feel you are being asked to think about too much, too quickly. If you really do not want to talk about CPR at all the doctor in charge of your care will decide whether or not CPR should be attempted, considering your medical condition and taking into account things you may have said.

If you are under 18, your parents may be able to contribute to the decision for you or if you are 16 or 17 they may be involved in the decision making process, with you. If you and your parents disagree, help from a legal professional should be sought.

What if I am too poorly to think about CPR?

If you are not able to contribute to the decision due to your illness, the doctor in charge of your care is responsible in law for deciding on your behalf. Your family and friends are not allowed to make a decision to refuse CPR for you. If you have granted someone with a lasting power of attorney for health, it can be helpful for the healthcare team to talk to that person and to your family about your wishes. However, if there are people you do not want to be asked about your wishes, you should let the healthcare team know.

What happens if it is decided that CPR won't be attempted?

If it is your decision that you do not want CPR and if you have made an advance decision to refuse treatment, your decision should be recorded in the advance decision to refuse treatment. Further information about advance decisions to refuse treatment can be found at the end of this leaflet.

If you do not have an advance decision to refuse treatment you can still refuse CPR and the healthcare team must respect your wishes. You must inform them of your wishes so they can record it in your medical notes.

If you are in agreement with your doctor that an attempt at CPR would not be right for you then your doctor will complete a dated and signed form which will be kept at the front of your confidential health record. This is called a DNACPR form, a Do Not Attempt Cardio Pulmonary Resuscitation form.

The doctor will also make sure that other members of the healthcare team are informed and may tell your family and carers about the decision, unless you don't want this to happen.

The healthcare team will continue to give you the best possible care and other treatments will be provided where appropriate.

What if I want CPR to be attempted, but my doctor says it won't work?

Although nobody can insist on having treatment that will not work, no doctor would refuse your wish for CPR if there was any real possibility of it being successful. If CPR might restart your heart and breathing, but is likely to leave you severely ill or disabled, your opinion about whether these chances are worth taking is very important. The healthcare team will listen to your opinions and to the people close to you, if you want them to be involved in the discussion. If there is doubt whether CPR might work for you, the healthcare team can arrange a second medical opinion if you would like one.

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How will I know if I have got a DNACPR form?

The signed, original DNACPR form should be kept with you in whichever place that you are receiving care. It will be stored in the front of your health record if you are in a hospital, hospice, care or nursing home. It will be kept in your hand held notes if you are under the care of a community nurse at home.

The DNACPR form will need to travel with you if you are being transferred by ambulance or if you attend different health care facilities for appointments or tests and the ambulance staff or patient transfer staff will need to look at it.

When you go home, the DNACPR form should go home with you so that any health care staff who may visit you at home know that this decision has been made.

Where a copy is made of your form for one of your healthcare services to keep, it will be clearly marked as a copy.

The original form must be seen in order for CPR not to be attempted, this is in case there has been a change in your health or to the decision.

Who should I tell about the DNACPR decision?

Your doctor may have already asked you if they can talk to your family or carers about the decision. This is an important conversation because your family or carers may be with you when you die and they will need to know what decision has been made. It can be very helpful for your family or carers to know what they need to tell the community nurses or the ambulance staff when they ring them.

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Will I need an ambulance if I'm at home?

You can help your family by letting them know about your end of life care decisions and by sharing your thoughts with them if you would prefer to remain at home when you die.

When that time comes, your community nurse will support you and your family at home, if it is safe to do so. An ambulance will rarely be needed, but if one is called the ambulance crew can also support you and your family at this time.

What if a decision hasn't been made and my heart stops?

The doctor in charge of your care will make a decision about what is right for you at the time.

If you are at home or in a nursing home and an ambulance is called and a DNACPR decision has not been made or a signed form is not available to show the ambulance crew, then CPR will be attempted. The ambulance crew cannot choose not to attempt CPR even if your relatives ask them not to. They must see a valid, documented DNACPR decision in order not to attempt CPR.

What if my condition changes?

If your condition changes at any time for better or worse, the healthcare team will review any decisions about CPR and make the necessary written changes in your records. They will also be expected to discuss any changes with you.

What if I change my mind?

If you want to reconsider the decision that has been made you should ask to talk to any of the healthcare team caring for you. They will be able to review the reasons for the decision and help you to understand the options. The healthcare team can arrange a second medical opinion if you would like one.

Will this decision affect any other treatment I receive?

No, not at all.

A DNACPR decision does not influence the decisions of the healthcare professionals looking after you about any other treatments or medications they think would be right for you.

A DNACPR decision is about CPR only. You will still receive the best possible treatment for your illness even if you, or the team looking after you, have decided against CPR.

Can I talk to anyone else about this?

If you feel that you have not had the chance to have a proper discussion with the healthcare team, or you are not happy with the discussions you have had, please tell a member of the team caring for you.

If you have specific concerns or a complaint you can also ask someone to contact the PALS (Patient Advice and Liaison Service) Officer or Patient Services Team in the hospital, care trust or primary care trust.

You may wish to request spiritual advice from the hospital or hospice chaplaincy or your preferred minister. Additionally, there are patient support organisations for example, Macmillan Cancer Support or Age UK, who you can discuss this with.

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If you are happy for your family or carers to have further information from your healthcare team, they can speak to a member of the team caring for you who will help them to understand the decision that has been made.

Advance Decisions to Refuse Treatment

The Mental Capacity Act confirmed that if you wish to make a formal decision to refuse CPR in advance, it will be legally binding on the healthcare team if:

- You were 18 years old or over when the decision was made
- You had the mental capacity to make such a decision
- Your decision is in writing, signed and witnessed
- Your decision states that it should apply even if your life is at risk
- You have not withdrawn or contradicted your advance decision
- You have not given someone power of attorney to make CPR decisions
- Your circumstances match those envisaged in your advance decision

If your advance decision to refuse treatment does not meet those criteria it will not be legally binding, but it will be considered when deciding what treatment is in your best interests, if you lose the mental capacity to make such decisions for yourself.

An advance decision to refuse treatment form can be obtained from the National Council of Palliative Care: *www.dyingmatters.org/page/planning-your-future-care*

ANNEX G

This leaflet has been adapted from a model information leaflet created by:

The British Medical Association;
The Resuscitation Council (UK);
The Royal College of Nursing; and
Age Concern.

Other languages and formats

If you need the information in this leaflet to be provided in other languages or formats, please ask a member of your healthcare team for more details.

Approved by the Yorkshire and Humber DNACPR strategic group.

Publication date: November 2011
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Annex H

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24th July 2012

Dear Councilor Funnell,

Many thanks for your letter dated the 2nd July and for the copy of your interim report of the End of Life Care Review with a focus on the Use and Effectiveness of DNACPR forms. The report clearly raises some very important issues and I am very happy to contribute to this process. I am slightly disappointed that the comments about the Out of Hours Service in the report, at this stage, seem to be based largely on anecdotal evidence and lack any real data to support them. I must also express disappointment that the OOH service has not been asked to contribute earlier in the process. That having been said, I fully understand the need to get this process right and I hope the OOH service can contribute to a positive conclusion.

In addressing the issues I thought it would be useful to try to break things down and present opinion and evidence under the following headings;
1. The pathway by which DNACPR forms are received into our service and communicated to our staff.
2. An overview of the difficult issues relating to the use of the forms
3. The Verification of Death Process
4. Evidence supporting the use of DNACPR forms in the OOH period
5. Current Action

1. Pathway;

Currently information relating to patients that are approaching the end of life is sent in to the OOH service from GPs via our YAS call handling service. They process the information and it is attached electronically to a patients OOH computer record on the Adastra System (Adastra is the IT system used by the OOH service). There is a proforma designed for this purpose and all practices have it. It can be faxed and some practices have the ability to send the information electronically. Once the information is on the system it is visible to a clinician when they open the clinical record prior to contacting or consulting with a patient.

If this process is not completed by the in-hours clinicians responsible for a patient's care then the information will not be available to the OOH clinicians at all.

One of the difficulties of the OOH system is that the clinicians working in our service do not (usually) have any prior knowledge of the patients accessing the service. It is therefore very difficult for them to actually put a DNACPR order in place if it has not been done and the feeling is that it is not particularly appropriate. We have considered the need for this and the attached letter sent out in May 2010 is provided as evidence for this (**Annex H1**), however the responsibility for this process must lie either with the patient's GP practice or indeed a Hospital team if the patient has recently been in hospital. We currently do not receive communication from Hospitals – the information would go back to the GP and then it would be forwarded to OOH – perhaps this is something that could be improved upon. I will present data re the number of forms received into the service in section 4.

2. Difficult Issues;

- Following on from the last section the OOH service uses the Adastra IT platform which currently does not allow the OOH clinicians to view the patients GP or Hospital records. At some of our sites (including York Primary Care Centre (PCC)) we are able to view the Hospital record, however this is not available when the clinician is out in one of our mobile units. **Improvement in IT and access to the in-hours GP record would in my opinion enhance the care that is given to patients.**

- Sometimes when carers or care home staff call into the service and they are assessed via the call handlers algorithms the presenting complaint can trigger an inappropriate response – ie an ambulance is called – when often they just want to talk to a clinician. I realize that I too am bordering on anecdotal but there is a paucity of robust evidence for how often this is happening. **Introduction of a pathway enabling algorithms to be bypassed would improve the management of this group of patients.**
- DNACPR orders do not mean Do Not Treat. It is difficult for clinicians who have no prior knowledge of patients to refuse all treatment. If the treatment recommended by the OOH GP for example for conditions such as a UTI or a chest infection constitutes a course of IV antibiotics then are there not occasions when a short admission to hospital may not be appropriate (as things stand currently – as IV treatment is not really possible in the community at present). **Development of protocols for administering IV antibiotics in the community may help in this situation.**
- The OOH service is supported by a District Nurse Service provided by York Hospital Foundation Trust in the Selby and York Area – it is worth stating that HDFT provide the nurses in the Harrogate area. Recently the service in York has faced staffing difficulties and this has resulted in many District Nursing shifts being unfilled – this has resulted in a lack of support for palliative patients during the overnight period and may have contributed to some of the issues. **More robust staffing would be ideal – perhaps even developing a dedicated OOH palliative care team.**
- There is an issue of care homes taking responsibility for their patients – particularly in residential homes. If a patient deteriorates there can be a perceived pressure that because the staff aren't 'trained' they are not appropriate to look after the patient and therefore the patient should be moved – it is unclear the exact origin of this pressure but it is felt that it is related to fear of retribution or litigation if something untoward were to happen to a patient. **We need to work closely with the care homes to develop treatment pathways that give staff the confidence/support to continue to look after patients if they deteriorate. We also need to look at staffing levels and consider innovative ways to augment staffing levels when patients require more intensive input.**
- Of course we must consider resources/finances. Whilst it is easy to hide behind this it cannot be ignored. My feeling is that the OOH service as it currently stands is under resourced.

It has faced budgetary cuts annually for at least the last 4 years, the activity is increasing year on year (9% increase in 2010-2011), there are fewer clinicians working in the service and there has been an increase in skill mix ie less qualified staff. The morale is low as further change is on the way – NHS111 is coming in 2013 and this will reduce the clinician's control over the workload and it is feared that the workload will increase as a result with, of course, no increase in resources. In my opinion this is a serious issue and one that cannot be ignored – the PCT have already suggested there will be a procurement process in the near future which will introduce yet more uncertainty and, possibly, yet another provider – in my opinion a huge issue. **Pressure must be put on commissioners to give stability and adequate resource to the service by ensuring the commissioned service is reviewed against its budget enabling the creation of a fit for purpose, sustainable service for the future.**

3. Verification of Death;

This has been a topic of much debate for many years within the OOH service particularly whether a GP is required to visit a patient, who has been seen recently by their own GP and is 'expected' to die, in order to confirm death. The feeling and current guidance is that it does not need to be a GP that visits. In reality this can cause some problems as your anecdotes reveal. Usually it is not a simple decision, not always black and white – each decision is different and needs to be put into context. However as a general rule if there is an expected death in a nursing home we would ask the staff if they are able to confirm death and if so then the GP would not visit. If the death occurred in a non-nursing home environment then there would be an expectation that a health care professional needs to confirm the death. We have worked with our District Nursing Service and developed a policy that provided governance for them to confirm death under particular circumstances including expected deaths. The policy is attached (**Annex H2**). Whilst the OOH service and the DN service were under the same provider the system was working well, however since the services now have different providers and are experiencing the staffing pressures as described above the District Nurses are no longer confirming death on a reliable basis. This has put further pressure on the OOH service and whilst I absolutely would expect GPs to behave appropriately and sensitively when faced with the situation I do understand why there is a reluctance to visit when the guidance is clear that there is no legal requirement for the Dr to do this. However I must make it clear that if needed I would expect a GP working in our service to visit to confirm death.

I think the circumstances that necessitate reporting a death to the coroner are very clear and I would expect all GPs working within the service to be aware of this. Some of the anecdotes in your report do sound alarming however I can assure you this is not a common occurrence and if the source of the anecdote would like to provide me with more information I would be happy to investigate individual cases.

4. Evidence;

In order to demonstrate some of the issues I have discussed I can provide some evidence;
We record the outcome of all our patient encounters and are able to tell how many deaths have been reported to the service and of those how many were expected or unexpected. I accept that this will only 'capture' those deaths that occurred in the patients' homes so the overall total number of patients that died following contact with our service will be slightly higher. In addition we have a record of the number of DNACPR that are in place for those patients who have died expectedly. This data is captured by the YAS algorithm for expected death. As you can see from the data DNACPR forms/orders were in place for less than half of these patients (43%). Whether or not this figure should be 100% (or close to it) is a point that we should debate.

Deaths in OOH period from July 2011-June2012	Total Number	% of all calls
Died - Expected	968	0.87%
Died - Unexpected	34	0.03%

Expected Deaths Jan - June 2012	No of expected deaths	DNACPR in place	%
January	40	17	42.5
February	32	15	47
March	48	18	37.5
April	39	14	36
May	35	19	54
June	28	12	43
Mean			43

5. Action;

I absolutely concur with the paragraph in your report quoting the York Hospital Medical Director that suggested where tangible outcomes could be achieved;

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

At HDFT we are already working very hard with partners to try to improve this situation. We are working with Harrogate and Rural District Clinical Commissioning Group and YAS looking at reducing avoidable admissions from Care Homes and part of this work is to recognise that patients with DNACPR orders in place need to be managed in a different way – we are trying to develop a pathway with YAS to bypass the current algorithms and give staff direct access to speak to a clinician in order to make a patient centred decision rather than a protocol driven one.

We are gathering data on all of these issues and I have attached some of the data that has been collected so far – I accept that much of it is unrelated to DNACPR forms however it shows what we are looking at and how this is, as always in the modern NHS, linked to making savings and using resources more efficiently (**Annex H3**). I have also attached a presentation given to this group by YAS – this is really to show that the issue of DNACPR forms and End of Life Pathways is something that we are looking at as part of this wider piece of work (**Annex H4**).

I hope this information informs your future discussions and can contribute to the improvement of the effectiveness of DNACPR forms for this group of patients.

Yours Sincerely,

Mike Holmes

Dr M A Holmes

Clinical Director, Unscheduled Care, Harrogate and District Foundation Trust
Chair, Locality Management Group, GP OOH, Selby and York
GP Partner, Haxby Group, York

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21st May 2010

Temporary Guidance re DNAR Forms (Do Not Attempt Resuscitation)

Further guidance from Dr Mike Holmes Clinical Lead

Background Information

1. DNAR forms are necessary if YAS are not to send unnecessary ambulances to patients who are not for resuscitation
2. Certain algorithm responses (known to the call handlers) given when a request is made to access an OOH Dr to contact a patient can initiate an emergency ambulance instead of a GP call back. Only if a DNAR form is held at the patient's house can this be overridden.
3. GPs should issue DNAR forms in working hours after consultation with the patient and/or the relatives or carers. This is a separate issue from the need to inform OOH about terminally ill patients or others with "special notes".
4. YAS only recognise their own agreed DNAR form although a universal form is in development and will be available soon
5. Ordinarily OOH doctors should not have to take on the responsibility of issuing DNAR directives.
6. If a DNAR form is not in place and after assessment it is deemed appropriate then the OOH GP can put a DNAR orde in place.

Recommended Practice

7. Dr Holmes and YAS team leaders have agreed an interim measure whereby OOH doctors can complete DNAR forms after appropriate discussion with carers/ relatives and possibly also with

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the patient where appropriate. The directive will be formalised with the patient's own GP on the next working day.

8. The forms are to be kept in each car and at the PCCs
9. The DNAR form is to be left at the patient's address.
10. The carer is to be told that they should inform the call handler that a DNAR form is available if they have to ring for OOH help
11. If the form is completed OOH the call handlers must be notified in writing (ie fax the forms to the call handlers). If a form is not available for whatever reason the order can be put in place by informing tha call handlers in writing.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Yorkshire & Humber SHA Form for Adults aged 16 and over

Version 3 May 2010

In the event of cardiac or respiratory arrest NO attempts at cardio-pulmonary resuscitation (CPR) will be made. All other active treatment should be given.

NHS No	Hospital No	Next of Kin/Emergency Contact
Name		
Address		Relationship
Postcode	Date of Birth	Tel Number

Section 1 Select as appropriate from A - D (see reverse)

A. ☐ CPR would be inappropriate or unsuccessful because of the following conditions:

....

Discussion with the patient / relevant others is not compulsory in this situation but it is good practice to explain why CPR will not be attempted unless doing so would cause unnecessary distress.

This has been discussed with the patient ☐

This has not been discussed with the patient because it would cause unnecessary distress ☐

This has been discussed with .... (name) Relationship to patient:......................

This has not been discussed with any relevant others ☐

Record details of discussions in the patient's notes

B. ☐ The outcome of CPR would be a length and quality of life which would not be of overall benefit to the patient.

This must have been discussed with the patient and/or relevant others. *Record details in the patient's notes.*

C. ☐ CPR is against the wishes of the patient who has mental capacity to make the decision

D. ☐ CPR is against the wishes of the patient as recorded in a valid advance decision

Section 2 Healthcare professionals completing DNA CPR form (see reverse)

Name & Designation		Name & Designation (Counter Signature)	
Organisation		Organisation	
Signature	Date	Signature	Date

Section 3 Review of DNA CPR decision (if appropriate)

This order is to be reviewed by: Date: ....

Review Date	Full Name and Designation	Signature	Still applies	Next Review Date
			☐ (tick)	
			☐ (tick)	

AMBULANCE CREW INSTRUCTIONS

In the event of a Cardio-Pulmonary Arrest, please do not attempt CPR or defibrillation for this patient. All other active treatment should be given.

Any other specific instructions:...

....

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 ANNEX H2

Title:	**Policy for Verification of Death in the Community**
Reference No:	CMHS 072
Owner:	Director of Operations
Author:	David Hogg, Resuscitation Officer
First Issued On:	February 2010 [v 0.001]
Latest Issue Date:	January 2011 [v1.000]
Operational Date:	November 2010 [draft]
Review Date:	January 2012
Consultation Process:	Palliative Care Leads Adult Governance Group
Policy Sponsor:	Resuscitation Committee
Ratified and Approved by:	CMHS Governance Committee
Distribution:	All staff
Compliance:	Mandatory for all permanent & temporary employees, contractors & sub-contractors of North Yorkshire and York PCT
Equality & Diversity Statement:	This policy has been subject to a full equality and diversity assessment

Please note that the intranet version is the only version that is maintained. Any printed copies should therefore be viewed as 'uncontrolled' and as such, may not necessarily contain the latest updates and amendments.

ANNEX H2

CHANGE RECORD			
DATE	**AUTHOR**	**NATURE OF CHANGE**	**VERSION No**
02 2010	D Hogg, Resusc Officer	First policy draft	0.001
03 2010 to 09 2010		Amendments, comments Community Policy Group, Adult Governance Group, Palliative Care Leads	0.002-0.006
25 01 2011		Ratified CMHS Governance	1.000

Preface

This Policy is made between North Yorkshire and York Primary Care Trust (NYY PCT; "the PCT") and the recognised staff side organisations, using the mechanism of the Joint Negotiation and Consultative Committee (JNCC) and Local Negotiating Committee (LNC). It will remain in force until superseded by a replacement Policy, or until terminated by either management or staff side, giving no less than six months notice. The purpose of the notice to terminate the Policy is to provide the opportunity for both parties to renegotiate a replacement Policy. Withdrawal by one party, giving no less than six months notice, will not of itself invalidate the agreement. If agreement cannot be reached on a revised policy, then the matter will be dealt with through the PCT's Grievance Procedure.

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ANNEX #2

Section 1 Scope and Aims of the Policy

1.1 Scope:

The Policy is of primary interest to all clinical staff working in community teams and in-patient units within NHS North Yorkshire and York Primary Care Trust. The Policy will be implemented for use by Medical and First Level NMC Registered Nurses directly employed by NHS North Yorkshire and York PCT; for whom the Primary Care Trust has a legal responsibility.

1.2 Aims:

- Provide supportive clear guidelines relating to the professional, legal and training requirements for healthcare professionals who in the course of their duties will be required to verify death.
- Provide clear pathways to follow when the policy is implemented in clinical practice in situations of predicted / expected deaths or sudden / unexpected deaths.
- Respectful of the diversity of opinions that exists in the healthcare teams, the policy will ensure a consistent team approach when verifying death.
- Differentiate between Verification of Death and Certification of Death
- Raise awareness and identify conditions which are reportable to the Coroner and / or a post-mortem examination needs to be fulfilled. .
- Identify circumstances where a Registered Nurse is not authorised to verify death
- Ensure the death of a patient is dealt with in a professional timely manner, preventing unnecessary delays in removal of the deceased to an appropriate place, preventing additional stress for either relatives/carers, staff or other patients.
- Ensure the safety of patients is not compromised by provision of competently trained healthcare professionals.
- Ensure that the procedure undertaken following death does not compromise health and safety.
- Raise awareness of responsibilities and the requirement to protect potential forensic evidence in specific circumstances.
- Ensure the dignity and delivery of culturally appropriate care for the deceased and the bereaved is maintained after death.

ANNEX H2

Section 2 Legal Position

2.1 Medical Practitioners

The law requires that:
"A registered medical practitioner, who has attended a deceased person during his/her last illness, is required to give a medical certificate of the cause of death to the best of his knowledge and belief, and to deliver that certificate forthwith to the Registrar. The certificate requires that the doctor state the last date on which he saw the deceased person alive, whether or not he saw the body after death. He is not obliged to view the body, but good practice requires that if he is in any doubt about the fact of death, he should satisfy himself in this way".

Para 5.01 Report of the Committee on the Death Certification and Coroners Home Office (1971)

- While there is no statutory duty on doctors for reporting deaths to the coroner, however doctors have voluntarily assumed the primary responsibility for such reporting.
- However there are certain conditions/ circumstances that require to be reported to the coroner. These are outlined in Appendix A or details can be found in 'Consultation On Improving the Process of Death Certification **(Department of Health 2007).**

2.2 Registered Nurses

Nursing and Midwifery Council (NMC) Advice Sheet : Confirmation of death – for Registered Nurses April 2008:

A Registered Nurse cannot legally certify death – this is one of the few activities required by law to be carried out by a registered medical practitioner. In the event of death, a registered nurse may confirm or verify death has occurred, providing there is an explicit local protocol in place to allow such an action, which includes guidance on when other authorities e.g. the police or the coroner, should be informed prior to removal of the body.

A Registered Nurse undertaking this responsibility must:
- be aware of their accountability when performing this role
- only do so providing they have received appropriate education and training and have been assessed competent.
- recognise and work within the limits of their competence
- keep knowledge and skills up to date

(The Code NMC 2008)

ANNEX H2

Section 3 Terminology

3.1 Certification of Death

3.1.1 Certification of death is the process of completing the 'Medical Certificate of Cause of Death'. Certification of death has to be carried out by a Registered Medical Practitioner as determined by part 11 of the Births and Deaths Registration Act 1953.

3.1.2 In all cases the patient's GP should produce a Death / Medical certificate of the **cause** of death 'to the best of his knowledge and belief' within 24 hours of the patient's death.

3.1.3 If the death occurred during the weekend or on a Bank Holiday, the certificate should be produced on the next working day.

3.1.4 The doctor has to state the date he last saw the deceased and whether or not he saw the body after death

3.1.5 The doctor is not obliged to view the body, but good practice requires if there is any doubt the doctor should see the body (Home Office 1971)

3.1.6 A Registered Nurse cannot legally certify death.

3.2 Verification of Death

3.2.1 Verification of Death can be defined as a healthcare professional clinically examining a patient and deciding whether the patient has actually deceased and life is extinct.

3.2.2 Traditionally a registered medical practitioner was called upon to pronounce life extinct, however English law does not require a medical practitioner to confirm death has occurred

3.2.3 To verify the fact of death the body must not have been moved to any setting in which survival would be compromised e.g. mortuary refrigerator.

3.2.4 A First Level Registered Nurse with current U.K Nursing & Midwifery Registration, working in an area with an explicit local policy in place and having undertaken training and demonstrated the necessary competencies has the authority to verify death, notify relatives and arrange for removal of the body

ANNEX H2

3.3 Expected /Predicted death (Appendix Bi)

3.3.1 For the purpose of this Policy expected death can be defined when the patient's demise is imminent following on from a period of illness that has been identified as terminal and where active interventions to prolong life are deemed to be futile.

3.3.2 A predictable death can be defined as the patient having been diagnosed with a condition which has been identified as terminal. Due to the nature of the condition death will be inevitable in the future may be days/weeks or months; the exact time may be difficult to predict.

3.3.3 Doctors are responsible for identifying patients whose death is expected. Such identification will include the views of the patient (where possible), relatives/carers and the multi-disciplinary team

3.3.4 The prognosis will have been discussed with patient (when possible) relatives/carers and the multi-disciplinary team and will be clearly documented either in the community in-patient / home care records within an Integrated Care Pathway for End of Life Care) or appropriate Out-of-Hours documentation. A DNAR order / Living Will / Advanced Decision or Advanced statement should be in place. (NYYPCT DNAR Policy 2009)

3.3.5 Although an expected death the healthcare practitioner should satisfy themselves there were no unclear or suspicious circumstances just prior to death. In addition consideration should be made to check the ultimate cause of death does not require to be reported to the coroner e.g. asbestosis **(Appendix A – Reportable Deaths)**

3.3.6 It is recognised that in some situations the death was considered to be predictable but may occur suddenly / unexpectedly.

3.3.7 In the event of a predicted death occurring suddenly, it will be necessary for the healthcare practitioner to establish the events just prior to death and satisfy themselves there were no unclear or suspicious circumstances just prior to death. In addition consideration should be made to check the ultimate cause of death does not require to be reported to the coroner e.g. asbestosis **(Appendix A – Reportable Deaths)**

ANNEX H2

3.4 Unexpected/Sudden (Appendix Bii)

3.4.1 n the event of a patient dying suddenly from a predictable death, providing there is a DNAR order, advanced directive or living will in place and no unclear or suspicious circumstances all healthcare professionals may verify the death but inform the Coroners officer (via the police).

3.4.2 If the patient is an in-patient and no advance decision has been made and there is no documentation about the appropriate or otherwise of attempting resuscitation, should they suffer a cardiac or respiratory arrest, basic life support should commence immediately (NYYPCT Resuscitation Policy 2010). In the event of an unsuccessful resuscitation the death is unexpected.

3.4.3 If a patient dies suddenly whilst an in-patient in the community hospital and there is no DNAR in place, no diagnosis or clear documentation a medical practitioner must verify death and inform the coroner via the police. If there are any unclear / suspicious circumstances care must be taken to preserve forensic evidence.

3.4.4 Healthcare professionals visiting the patient at home may be faced with very different situations regarding unexpected death to those experienced by staff working within the in-patient facilities. For example staff making a planned visit to a patient may find the patient has died hours or days before and obviously not appropriate for the initiation of resuscitation procedures.

3.4.5 In the event of a healthcare professional finding one of their patients has deceased and the body shows **signs unequivocally associated with death,** Do not move the body, preserve forensic evidence.

3.4.6 Conditions unequivocally associated with death in all age groups

- **Hypostasis**
- **Rigor mortis**
- **Decomposition**

3.4.7 Verification of death must be done by a medical practitioner who will inform the coroner via the police, with care being taken to preserve scene forensic evidence.

3.4.8 Alternatively the community nurses or OOH service may be contacted by relatives/carers to inform them that a death has occurred unexpectedly. The relatives /carers may or may not have been present at the time of the death they are reporting.

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Section 4 Role of the General Practitioner

4.1 Visit the deceased to verify death if no other competent healthcare professional is available

4.2 Verify death if the circumstances /conditions surrounding the death preclude a Registered Nurse from undertaking the process (Section 7)

4.3 In support of good practice the GP should arrange to see the deceased as soon as practical. To prevent additional distress to the bereaved, the nursing staff and other patients this process need not delay the removal of the body to the chosen undertakers premises / mortuary.

4.4 Consider the needs of living persons including relatives/carers of the deceased and other patient's in the clinical vicinity of the deceased.

4.5 Where the deceased's own general practitioner is not available, another doctor should access whether a visit is needed to meet the needs of living patients (e.g. bereaved)

4.6 Issue the Death / Medical Certificate for the cause of death

Further Guidance can be found at Confirmation & Certification of Death: Guidance for GP's in England and Wales (1999)

www.bma.ork.uk/health_promption_ethics/end_life_issues/GeneralguidanceConfirmationandcertificationOfDeath/April1999.jsp

Section 5 Role of the Out-of-Hours Service or Deputy General Practitioner

5.1 The deputy GP/OOH doctor will not be the certifying doctor and is unlikely to have any connection with the relatives or any access to the medical records.

5.2 If a deputy GP or Out-of-Hours organisation is contacted about a death, either by the bereaved relative/carer, community nursing staff or Yorkshire Ambulance personnel, the doctor must make an assessment to decide whether a visit is appropriate. If a visit is deemed appropriate in support of good practice the doctor should see the deceased as soon as practical.

5.3 A visit will be necessary when:

- There is no other health care professional available who is competent to verify death
- The circumstances preclude the nurse from undertaking the procedure
- There is uncertainty surrounding the facts/details of death.

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- A request has been made by relatives or the nursing staff for a visit by a doctor to meet the needs of bereaved relatives/carers.

Although an assessment of the situation may not indicate a visit, the doctor may decide that a visit would be in the interests of the bereaved / carers and this should be arranged.

Further Guidance can be found at Confirmation & Certification of Death: Guidance for GP's in England and Wales (1999)

Section 6 Role of the Registered Nurse

6.1 Verification of Death is only to be undertaken by a First Level Registered Nurse with current NMC Registration who has undertaken appropriate verification of death training and has been assessed as being competent in the knowledge and skills required for safe and effective practice. **(NMC 2008)**.

6.2 Verification of death can be carried out in the home, residential care setting or in the community hospital

6.3 Ensure the relatives / carers understand and accept the verification of death will be undertaken by the nurse and not a doctor. Respect their wishes if they request the procedure to be carried out by a doctor.

6.4 A Registered Nurse must not verify death in a person where there is no clear documentation, when any circumstance surrounding the death is unclear or suspicious, or if the cause of death is reportable to the Coroner (**Appendix A)**

6.5 In the event of the circumstances of a death precluding a nurse from undertaking verification, the patients GP/ On call Locum or Out of Hours Doctor has the responsibility to verify death and refer to the coroner

6.6 Verification of death must be done before last offices commence

6.7 Last offices relates to the care given to a body after death and the nurse must ensure the process demonstrates respect for the deceased and is focused on respecting their religious and cultural beliefs. The wishes of the patient and the bereaved may influence practice, however the nurse must ensure care given and the verification of death process undertaken is compliant with legal guidelines and maintain a high regard for health and safety issues **(Higgins 2008)**.

6.8 In some circumstances the relatives / carers may need support to contact significant others in order to arrange last offices or practice requested by the culture /

religious beliefs of the deceased. (e.g elderly relative with no other close NoK they can approach for support)

6.9 The nurse has responsibility to the deceased patient until the body leaves the clinical environment.

6.10 Excellent documentation standards are required throughout the process

Section 7 Procedure to follow (Expected Death)

- Notify relatives / carers if not present at time of death
- Ensure the correct identity of the patient is confirmed
- Explain the verification of death process to the relatives /carers
- Death must be verified **before** last offices commence

7.1 Examination of the deceased

- Ensure privacy for the procedure and inform other staff to ensure the verification process is free from interruptions
- Collect all equipment necessary before commencing the procedure
- No parenteral drug administration equipment or symptom relieving equipment should be removed prior to verification of death.
- Document the drug /dose/infusion rate of any drug and the amount left in the infusion. Leave all lines, tubes and access devices in situ. Any that remain should be closed or have spigot inserted, then covered with gauze and adhesive dressing
- Using a stethoscope listen for the absence of respiration sounds for one minute and observe for signs of chest movement.
- Using a stethoscope listen for the absence of heart sounds for one minute.
- Check patient's pupil reaction using an independent light source i.e. pen torch, ophthalmoscope, do not use room light only. The pupils will be fixed, dilated and not reacting to light.
- Check there is no response to painful stimuli.

7.2 Documentation

- The Verification of Death Record should be used in all situations **(Appendix C)** All records must be clearly written, clearly signed and the name printed after each entry Document the following:
  - A clear indication of the definitive diagnosis and why death was expected
  - Name and relationship of the person identifying the deceased.
  - Any persons present at the time of death
  - Circumstances of death e.g. place of death

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Date and exact time of death where possible. In cases reported by relatives, the time of death should be established as closely as possible.
- Time of verification of death is made
- Any internal devices left in situ e.g. pace maker, internal defibrillator
- Identify location of tubes, lines and access devices left in situ.
- Time the police / coroners officer was informed (if applicable) and note the name /number of any police officer attending
- Where the body was removed to.
- Any other important or relevant detail for individual circumstances

- Document in the patients clinical notes / home nursing record:
  - Verification of Death Record was completed,
  - Which NoK / carers informed if not present at the death and by whom
  - time and date of death and that death was verified indicating absence of respiratory, heart sounds and papillary reaction.

- The person verifying death should formally communicate to the deceased patients GP as soon as possible. **Appendix C** can be used as a written template at scene to inform the patients GP and/or the information can then be recorded on the Electronic Verification of Death Form and e-mailed to the GP, Out-of-Hours service and Lead Resuscitation Officer.

7.3 Health and Safety Issues

The body following death must be prepared for transfer to the mortuary or funeral directors in a way that does not compromise health and safety.

Reference should be made to relevant Infection, Prevention and Control Policies.

7.4 After verification of death has been made

- Support relatives/carers to arrange last offices or practice requested by the culture / religious beliefs of the deceased
- In the patient died whilst an inpatient provide a quiet area to allow the family to contact their chosen undertaker to collect the deceased or arrange for removal of the body to the hospital mortuary (depends on local arrangements).
- Remove the clinical record from patients home if applicable
- Ensure relatives/carers know what to do e.g. register the death, know who to contact.
- If the deceased is known to have an infection, ensure the shroud is labelled appropriately or the undertakers are informed. Good communication will be essential as the use of danger of infection labels may cause offence or concern.
- If the body has not been moved after verification of death for whatever reason by the time staff change over, the nurse who verified death should ensure full details are handed over to the senior nurse coming on duty and document who the care of the deceased and relatives was handed over to.

Section 8 Training Requirements

Training in the Verification of death should as a minimum cover the following:

- An understanding of the legal requirements for verifying death
- Distinguish difference between Certification of Death and Verification of Death
- Comprehension of the terms used and procedures to follow in the NYYPCT Verification of Death Policy
- Clarification and understanding of individual healthcare professionals roles
- Role of the Funeral Director
- Role of the Coroner / Police
- Documentation for Verification of Death
- Information to be given to the relatives/carers following bereavement
- Registered Nurses will receive the practical clinical skills necessary to verify death by an experienced clinician
- The individual will be responsible for maintaining their competency certification and providing it on request

Section 9 Associated Policies & Documents

NHS North Yorkshire & York PCT (2010) Resuscitation **Policy** Re-ratified date: January 2010

NHS North Yorkshire & York PCT (2009) **Do Not Attempt Resuscitation Policy** Issue date: September 2009

Last Offices for patients with Infection **North Yorkshire Community Infection, Prevention and Control Policies (39 Policy & Guidance Notes)** November 2008

Section 10 Monitoring Compliance and Effectiveness of Policy

The monitoring compliance and effectiveness of this policy will be monitored through the following processes and reported through the PCT Resuscitation Committee:

- Competency training records
- Audit of Verification of Death Records
- Quality and Outcomes Framework in General Practice
- Adverse Incident Reporting Procedure

Section 11 Reviewing, Approving and Archiving this Document

- This document will be reviewed as per the cover page, or when changes are required, whichever occurs first
- The review process will be undertaken primarily by the organisation-wide Resuscitation Committee
- Following review it will be subject to re-ratification by CMHS Governance Committee
- Archiving of this document should be conducted in accordance with the organisation's electronic archiving procedure.

Section 12 Policy dissemination, Implementation

- The Policy will be implemented and disseminated throughout the organisation immediately following ratification
- The Policy document will be published on the Organisations intranet site.
- The Policy document will be open for all to access.
- Managers / Team Leaders will be responsible for distribution within the area of responsibility, keeping a record of distribution and implementation as appropriate.

Section 13 References

Confirmation and Certification of Death- Guidance for GP's in England & Wales (1999) General Practitioner Committee, BMA, London

Confirmation of Death (2008) Nursing and Midwifery Council : London

Department of Health (2007) Consultation on Improving The Process of Death Certification : London

DNAR Do Not Attempt Resuscitation Policy (2009) NHS North Yorkshire & York PCT

Dorries C.P. (2004) Coroner's Courts : A guide to law and practice John Wiley & Sons : Chichester

Higgins D (2008) Carrying out Last Offices Part 1 – Preparing for the Procedure : Nursing Times V 104: no 37 September 2008 pp 20-21

Report of the Committee on Death Certification and Coroners (1971) Home Office, London

Report of the Home Office Review of Death Certification, Executive Summary and Recommendations (2001) Home Office : London

Resuscitation Policy (2010) NHS North Yorkshire & York PCT

The Code : Standards of Conduct, Performance and Ethics for Nurse and Midwives (2008) Nursing and Midwifery Council : London

www.bma.ork.uk/health_promption_ethics/end_life_issues/GeneralguidanceConfirmationandcertificationOfDeath/April1999.jsp

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Appendix A Deaths that must be reported to the coroner

- The person is unidentified
- The cause of death is unknown
- The death of a child
- It cannot readily be certified as being due to natural causes
- The deceased was not attended by a doctor during his last illness or was not seen within the last 14 days or viewed after death
- There are any suspicious circumstances or history of violence
- The death may be linked to an accident (whenever it occurred)
- If there is any question of self neglect or neglect by others
- The death has occurred or the illness arisen during or shortly after detention in police or prison custody (including voluntary attendance at a police station)
- The deceased was detained under the Mental Health Act
- The death is linked to an abortion
- The death might have been contributed to by the actions of the deceased himself e.g. history of drug or solvent abuse, self injury or overdose
- The death could be due to industrial disease or related in any way to the deceased employment e.g. asbestosis or mesothelioma
- The death occurred during an operation or before full recovery within 24hrs of the anaesthetic
- The death may be related to a medical procedure or treatment whether invasive or not
- The death may be due to lack of medical care
- There are any unusual or disturbing features to the case
- The death occurs within 24hrs of admission to hospital (unless the admission was purely for terminal care)
- Dehydration
- Septicaemia
- Any death where there is an allegation of medical mismanagement

N.B. This list is not exhaustive, but essentially one in which most deaths may fall. If in doubt contact the Coroner's Office for further advice

Dorries C.P. (2004) Coroner's Courts : A guide to law and practice
John Wiley & Sons : Chichester

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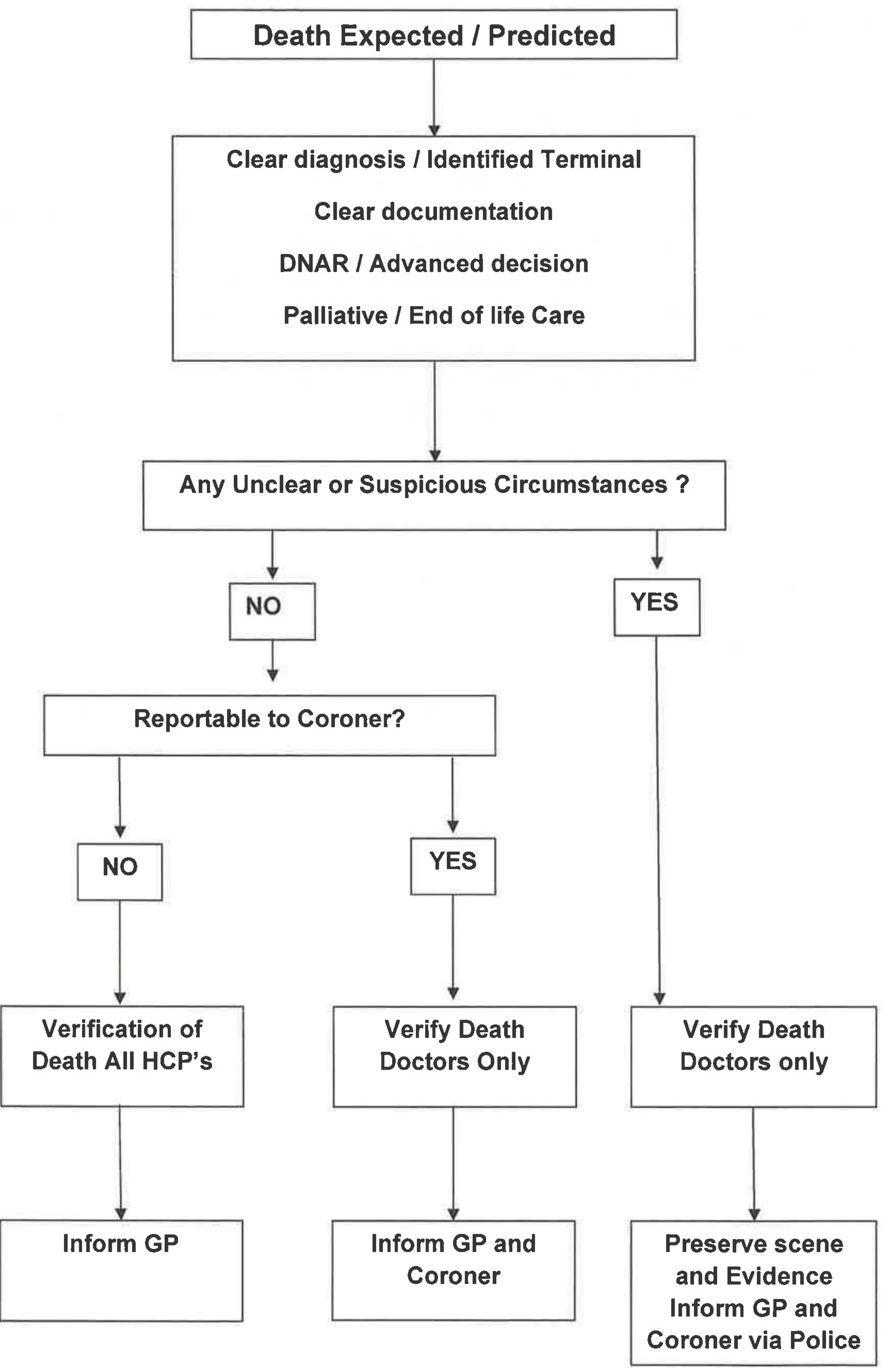
Appendix B i **Verification of Expected Death in the Community**



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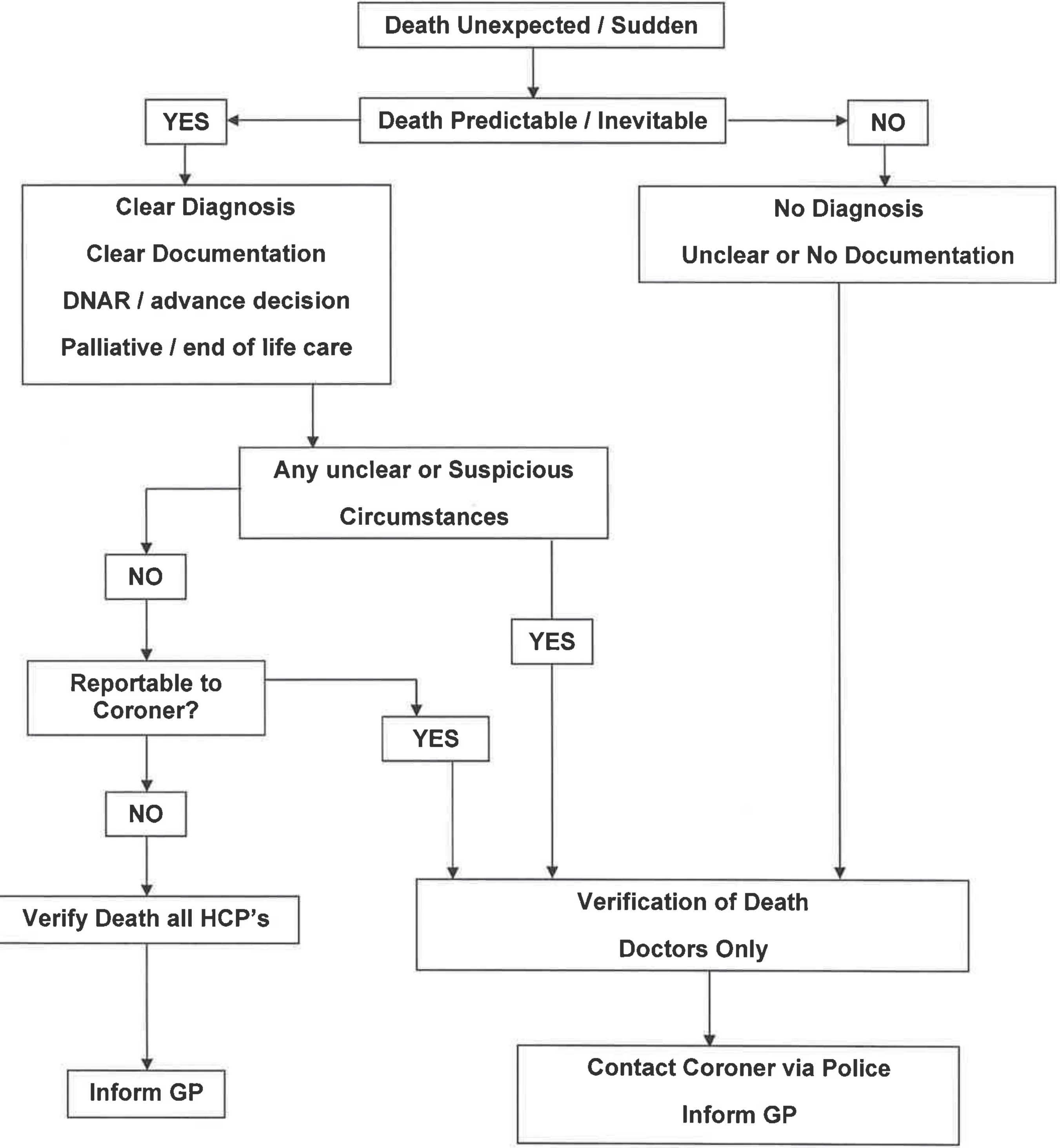
Appendix B ii Verification of Unexpected Death in the Community



In all cases of unexpected and unpredicted deaths consideration must be given to the possibility of suspicious circumstances with preservation of the scene and potential evidence.

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Appendix C Verification of death record

Verification of Death Record		
Full Name of Deceased: Date of Birth:	Address: Sex:	
Place of Death: Who identified body to you		
Persons Present at Death (occupation/position/relationship to the deceased)		
Date & Time Death Recorded (24 hour) Date & Time Death Verified (24hr)		DNAR in place **Yes / No**
Any devices/lines/tubes left in situ:		
Infection present? Where was the body removed to?	Infection control measures in place?	
Is there obvious injury? If "Yes" have the police been informed of the death		**Yes/No**
Has the Coroner been notified?		**Yes/No**
Signs Noted:	Absent Respirations Absent Heart Sounds Pupils Fixed	**Yes/No** **Yes/No** **Yes/No**
Was the patient moved before verification of death made		**Yes / No**
Name of person completing form:		
Position / Occupation	Full Contact details:	
I verify the fact of Death I authorise the removal of the body I have informed the police Signed:	 Date:	**Yes/No** **Yes/No** **Yes/No** Time:

Comments

ANNEX H3

NHS
Harrogate and Rural District
Clinical Commissioning Group

Admissions to Hospital from Care Homes in HaRD CCG

ANNEX H3

NHS

Harrogate and Rural District
Clinical Commissioning Group

Care Homes in HaRD CCG

- Total number of homes = 44
- Total number of beds = 1982

= 1.2% HaRD population

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Harrogate and Rural District
Clinical Commissioning Group

Hospital Admissions to HDFT in 2011 - 12

- Total unplanned admissions = 13,507
- Total from Care Homes = 746

= 5.5% of all unplanned admissions

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Clinical Commissioning Group

Hospital Admissions to HDFT in 2011 - 12

- Total cost of unplanned admissions to HDFT
  = £24, 858,161
- Average cost per admission = £1,840

- Total cost of admissions from Care Homes
  = £2,193,316
  = 8.8% of total cost
- Average cost per admission = £2,940

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Brief Admissions to Hospital

'brief' = admissions for 0-3 days

Total admissions reviewed = 703

Of these

0 – 3 day admissions = 161 (22.9%)

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Brief Admissions to Hospital

Cost of 0 – 3 day admissions = £252,537

= £1,568 per admission

= 10.8% total spend on
Care Home admissions

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Brief Admissions to Hospital

Source of 0 – 3 day admissions

A and E = 78.9%

GP/OOH = 21.1%

Source of admissions >3 days

A and E = 68.2%

GP/OOH = 32.8%

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Brief Admissions to Hospital

Day of the week admitted

Mon	31	19.3%
Tue	24	14.9%
Wed	23	14.3%
Thu	20	12.4%
Fri	25	15.5%
Sat	11	6.8%
Sun	27	16.8%

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Brief Admissions to Hospital

Reason for admission

Chest infection	23
UTI	20
Faint	14
Head injury	12
Senility	10
D and V	10
Fit/convulsion	9
Confused	6
COPD	5
Hypotension	4
Abdominal pain	4
Catheter problems	3
MSK pain	4
AF/palpitations	4
Minor injury	3
Other	30

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Brief Admissions

Home	Beds	Admissions /bed	% 0-3 days	% via A and E	Deaths/ bed
NH	45	0.24	27.3	100	1
RH	29	0.21	0.0	0.0	1
NH	85	0.31	15.4	75	0.85
NH	50	0.62	12.9	75	0.48
RH	23	0.74	23.5	75	0.47
RH	37	0.49	44.4	100	0.44
NH	26	1.04	11.1	100	0.44
NH	44	0.75	15.2	100	0.42
NH	67	0.79	13.2	100	0.42
NH	68	0.78	24.5	76.9	0.42
RH	62	0.66	12.2	100	0.41
NH	25	0.60	13.3	50	0.40
NH	50	0.76	15.8	50	0.39
RH	52	0.62	31.3	80	0.38
NH	42	0.86	16.7	83	0.36
NH	17	0.35	16.7	100	0.33
RH	25	0.72	11.1	100	0.33
NH	45	0.82	13.5	80	0.32
NH	40	0.55	9.1	100	0.32
NH	76	0.99	18.7	79	0.29

Home	Beds	Admissions/ bed	% 0-3 days	% via A&E	Deaths/ bed
NH	114	0.50	29.8	76.5	0.28
RH	76	0.25	21.1	100	0.26
RH	21	0.38	12.5	100	0.25
RH	31	0.65	20.0	75.0	0.25
RH	36	1.03	24.3	55.6	0.24
RH	62	0.76	24.4	81.8	0.23
NH	106	0.65	26.1	72.2	0.22
RH	47	0.81	21.1	75.0	0.21
RH	31	0.32	20.0	100	0.20
NH	33	1.21	9.8	50.0	0.20
NH	49	0.35	52.9	66.7	0.18
NH	66	0.27	22.2	100	0.17
NH	31	0.61	42.1	62.5	0.16
RH	24	0.17	25.0	100	0
RH	85	0.13	27.3	66.7	0
RH	28	0.36	30.0	33.3	0
RH	23	0.22	0.0	0.0	0
RH	14	0.21	0.0	0.0	0
NH	36	0.00			0

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NHS

Harrogate and Rural District Clinical Commissioning Group

Ambulance Calls to Care Homes

Period of time studied March 2010 – August 2011

Total ambulance calls to Care Homes = 1783

Total 999 calls to Care Homes = 1260

71% of calls are for 999 emergency

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Time of 999 Calls to Care Homes

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Calls to 'Nursing' Homes

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Home	Beds	Calls/bed	% Calls999	999 calls/bed
	106	1.14	70	0.80
	85	1.05	57	0.60
	76	1.55	63	0.97
	68	0.75	75	0.56
	67	0.97	83	0.81
	66	0.50	94	0.47
	62	0.97	82	0.79
	52	0.96	78	0.75
	50	0.54	63	0.34
	50	0.42	62	0.26
	45	0.80	69	0.56
	45	0.64	76	0.49
	42	0.57	50	0.29
	41	0.49	65	0.32
	36	0.25	67	0.17
	33	1.03	62	0.64
	32	0.84	70	0.59
	31	0.48	60	0.29
	26	0.46	58	0.27
	25	0.04	100	0.04
	17	0.06	0	0.00

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Calls to 'Residential' Homes

Harrogate and Rural District Clinical Commissioning Group

Home	Beds	Calls/bed	% Calls 999	999 calls/bed
	85	0.52	75	0.39
	76	1.33	83	1.11
	62	1.08	61	0.66
	48	1.50	81	1.21
	47	1.36	67	0.91
	44	1.05	52	0.55
	40	1.65	64	1.05
	40	1.28	73	0.93
	37	1.16	84	0.97
	36	1.58	77	1.22
	31	0.65	90	0.58
	31	0.58	61	0.35
	30	1.80	54	0.97
	29	1.69	71	1.21
	28	0.96	81	0.79
	25	1.20	73	0.88
	25	1.04	73	0.76
	24	0.54	77	0.42
	24	0.54	69	0.38
	23	1.83	71	1.30
	23	0.57	92	0.52
	21	0.86	61	0.52
	14	0.36	60	0.21

ANNEX H3

NHS
Harrogate and Rural District
Clinical Commissioning Group

Summary

- 1.2% of the HaRD population live in Care Homes
- People living in care homes account for 5.5% of the number and 8.8% of the total cost of unplanned admissions
- 22.9% of all admissions from Care Homes stay in hospital for 3 days or less (and a high proportion are potentially avoidable?)
- Admission from care homes of 3 days or less cost 0.95% of the total spend on unplanned admissions (£236,828 per year)
- 70% of admissions from Care Homes follow a 999 call and dispatch to A and E rather than Primary Care assessment and direct admission to a ward
- A greater proportion of 0-3 day admissions occur after 999 call and A and E assessment

ANNEX H3

NHS
Harrogate and Rural District
Clinical Commissioning Group

Summary Continued

- There is wide variation in the number of admissions from Care Homes not entirely accounted for by the morbidity of the residents in the Home
- The timing of 999 calls from Care Homes may be influenced by factors other than the medical condition of the patient
- Homes without qualified nursing staff on duty, and large Nursing Homes are more likely to call generate ambulance calls and more likely to call a 999 ambulance than smaller Nursing Homes. This is not related to the morbidity of the people in their care.

ANNEX H3

Harrogate and Rural District
Clinical Commissioning Group

WHEN TO CALL AN AMBULANCE

A 999 AMBULANCE SHOULD BE CALLED ONLY IN A LIFE THREATENING EMERGENCY, IF SOMEONE IS ILL OR INJURED
AND
THEIR LIFE IS AT RISK

WHAT IS A LIFE THREATENING EMERGENCY?

- **Unconscious person** – doesn't wake or respond with shaken
- **Heart attack** – crushing pain in the chest, possibly radiating to the arms and jaw and lasting more than 5 minutes
- **Breathing difficulty** – unable to speak a whole sentence or has blue lips
- **Bleeding** – major uncontrolled bleeding
- **Choking** – if unable to talk or breathe
- **Convulsions or fitting** – if no previous history of epilepsy or fits
- **Stroke** – numbness or loss of use of arm or leg, slurred speech or facial droop
- **Injury or fall** – which is severe (eg knocked out or severe pain after a fall)
- **Allergic reaction** – with difficulty breathing or loss of consciousness

IF THE PERSON HAS A DO NOT ATTEMPT RESUSCITATION (DNAR) FORM

OR

IF YOU ARE UNSURE WHAT TO DO

OR

IF YOU ARE WORRIED ABOUT ANY OTHER CHANGE TO THE PERSON'S HEALTH

THEN PHONE THEIR GP's SURGERY
OUT OF HOURS YOU WILL BE AUTOMATICALLY PUT THROUGH TO THE DUTY GP
AND ASK FOR URGENT ADVICE.

DRAFT

Angela Harris

Lead nurse urgent care (interim)

26th June

Rationale

Increase admissions

- Increase demand 999
- Increase admissions care homes

Increase in Hcp red calls

- Increase in patients dying in hospital – national target to reduce
- Lack of patient pathways

  Lack of appropriate care

Poor discharge processes

- Lack of integration of services
- Gaps in clinical services provided

Goals

Identify why homes default to 999	Improve process to reduce demand

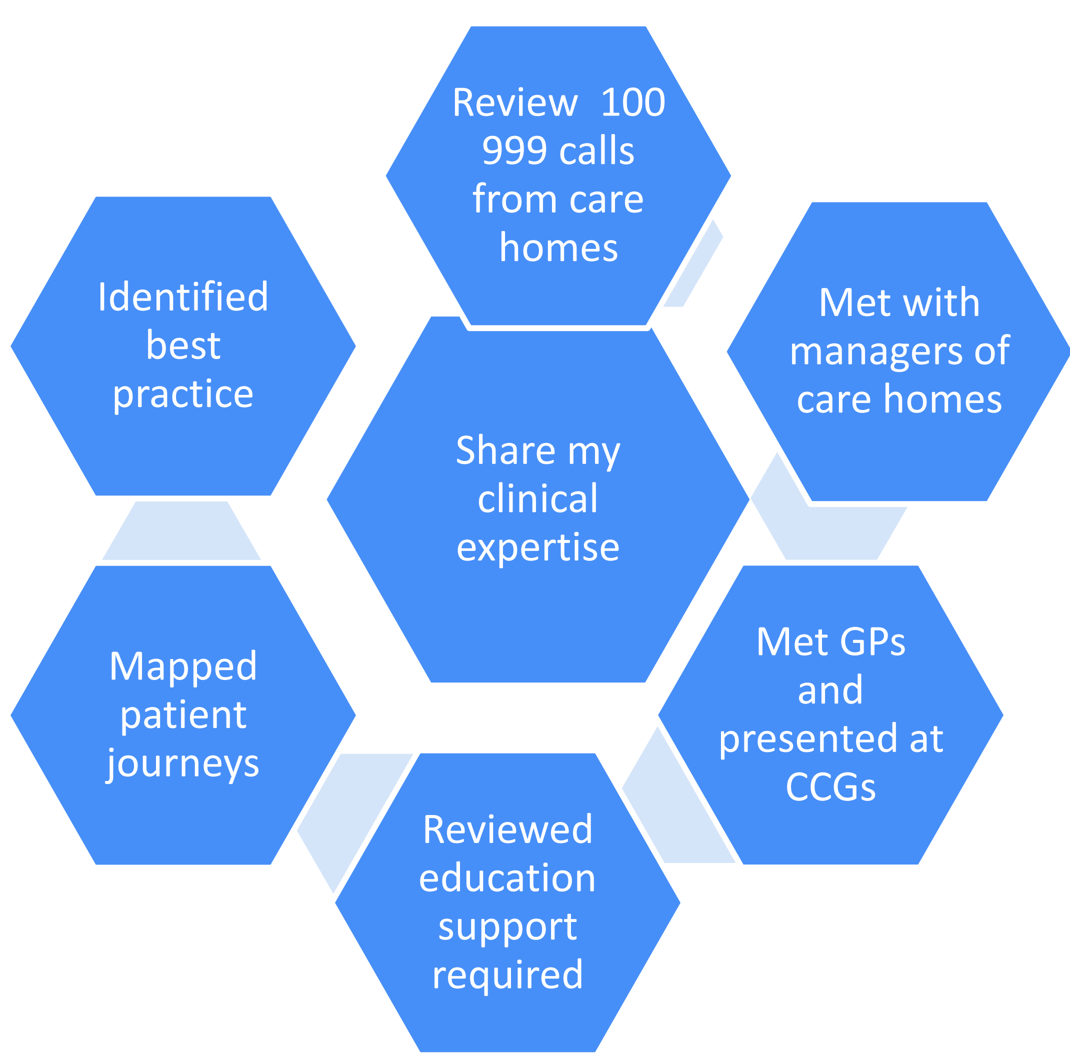
Increase partnership working

Identify clinical gaps in care. Share best practice	Coordinate with commissioners, providers – what is required-

Reduce ED attendance & Increase utilisation of hub

Pathways , education, culture shift	Improve awareness of hub Identify training needs and provide recommendations

What?



Findings

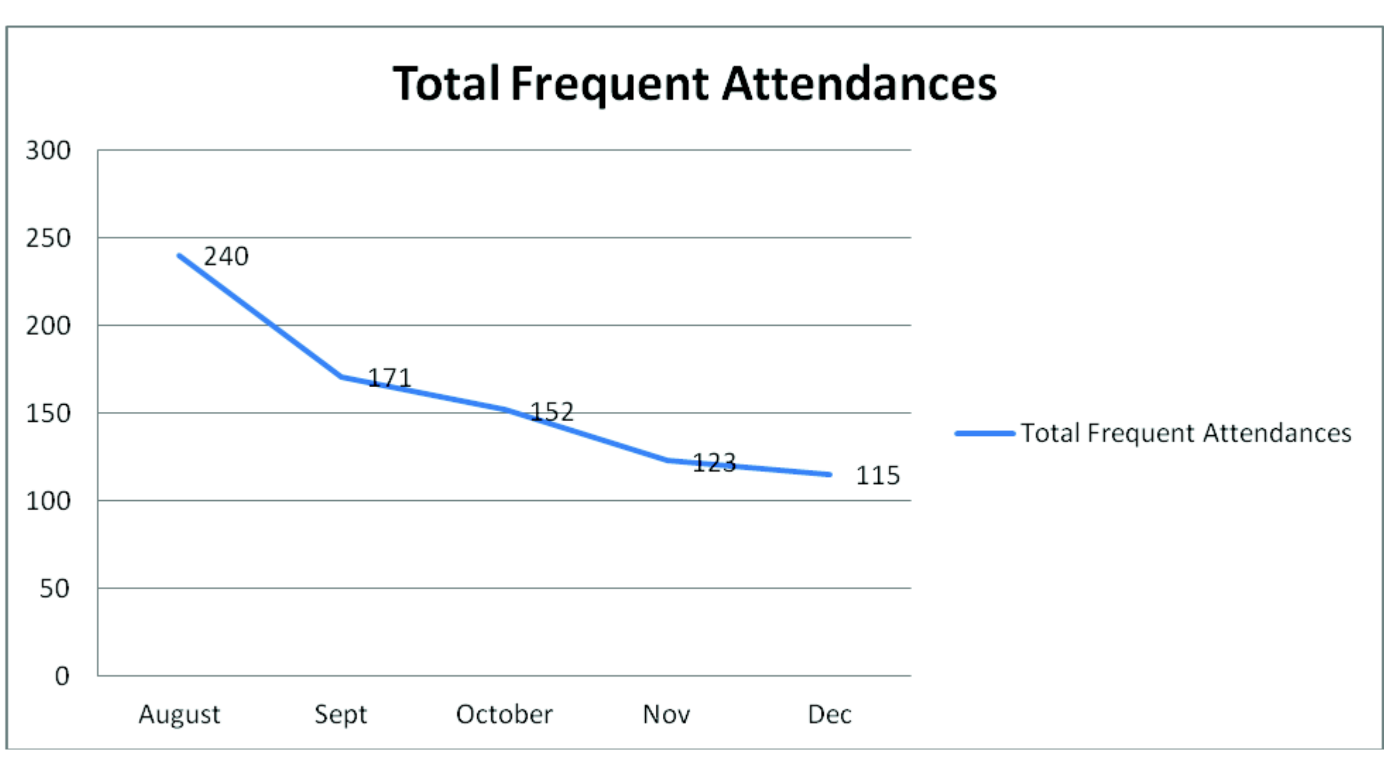
- Approximately 70% of 999 calls “in hours” from care homes
- Data from OOH 15% medication issues
- Gaps – Dehydration, UTIs, End of life planning
- 15% reduction 999 calls(target homes)
- 35% increase urgent calls through clinical hub
- Better utilisation of emergency services
- Improved care
- YAS developments required within hub

Very high intensity users

- The frequent callers group was formed with the purpose of delivering optimal patient care at the right time and place.

- Signposting patients to more appropriate care.

Frequent callers



Cost benefits

Frequent callers cost the NHS in our region over 11m or almost £800,000 per pct.

We can reduce these calls by 50%

Significant benefits accrued reduction in Ed attendance – (£59- £117 tariff per visit)

Why were more patients not managed at home?

- Poor communication channels
- No continuity of care
- Normal ‘abnormal’ parameters for most LTC patients e.g. COPD patient with sats <92%, heart failure patient with low BP
- Unnecessary hospital admissions
- Reactive care
- Often protocol not patient centred care
- Duplication of work / excess paperwork

Emergency care plans

NHS Kirklees

LONG TERM CONDITIONS - EMERGENCY CARE PLAN

Patient details	Name of Community Matron/ Case Manager
Name:	
Dob: GP: NoK Tel:	Tel: 01924 351582 (office 24 hr answering machine) Mobile:
	NHS number............. Care First/ social service ......

ACTION PLAN (self management / signs of deterioration)

Indications for urgent medical attention

INFORMATION FOR EMERGENCY SERVICES

Allergies

Medications (correct as of 20/9/08 please check current meds and/or dossette box)

Past medical history

Normal Baseline observations

Professional network

Name	Address	Phone number	Relationship to client

If you use this form can you please leave a message on office phone number in order to audit its effectiveness in order to improve patient care

"All healthcare information is collected, held, shared and used for the benefit of patients. Everyone working for the NHS has a duty to keep the information we hold about you confidentially. If the purpose for using your information is not for your direct healthcare we would ask your permission before doing so."

Case study

78 year old female patient would call 999 almost daily

Multiple pathology

Reluctant to ask social service support

Quote from paramedic:

"I have on many occasions visited this lady.

Now, with the development of this scheme and emergency care plans,

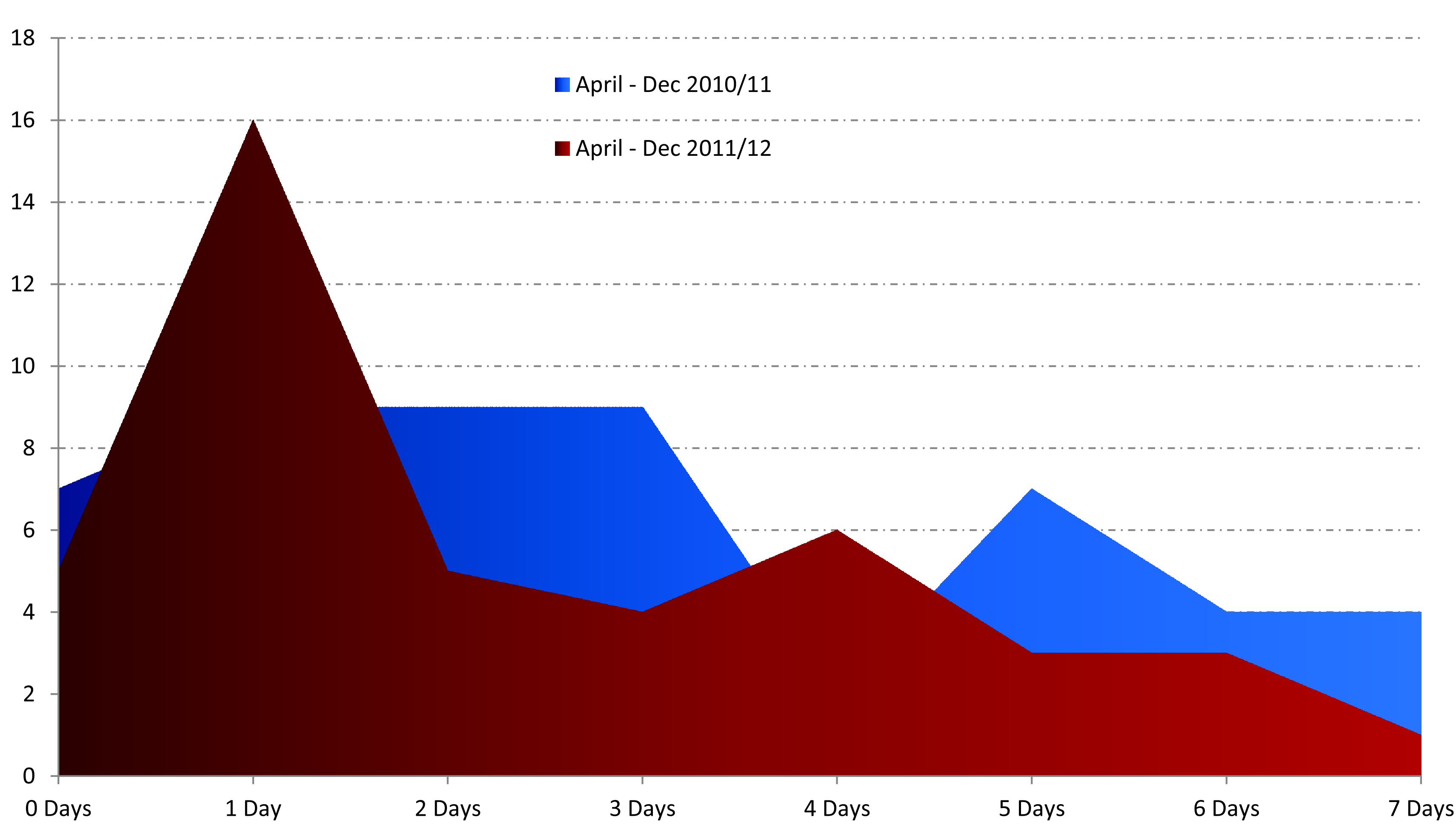
this lady can now be managed at home, therefore reducing hospital admissions"

Cheryl Astbury, (Clinical Team Leader, Dewsbury, Yorkshire Ambulance Service)

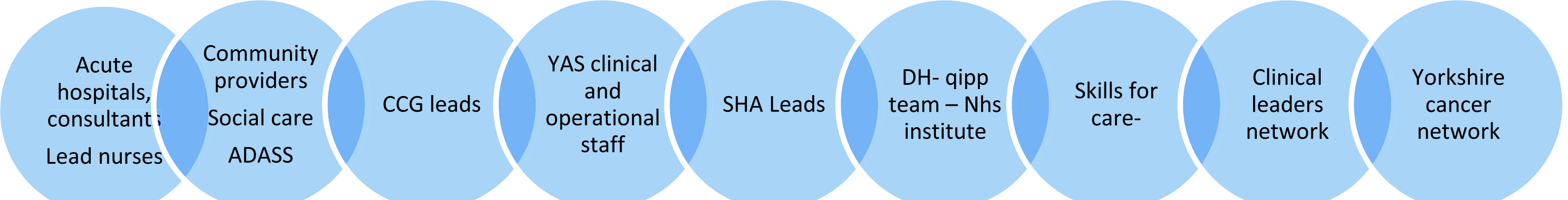
Admission to hospital from nursing homes - Kirklees

	April-Dec 2010/ 2011	April - Dec 2011/ 2012
Total Nursing Home Admissions	2104	1800

Reduction in patients dying within 7 days (nkha)



Key relationships



Pathway for care homes

Worried about a resident?				
999 24 hours	Palliative Care 24 hour advice 01484 557900	GP 24 hours Urgent problem	District nurses 01484 221600 (24 HR NUMBER)	Medicines Management
Chest pain Choking Fitting Severe breathing problems Stroke Unconscious Vomiting / blood	New symptom? Not sure which drug to give? Is it time for a syringe driver? Before you call 999 or local care direct Contact HOSPICE> 830-430 ask for palliative care team All other times ask for nurse in charge on bed area.	Unwell resident Breathing problems Worsening confusion UTI (dipstick first) Worsening pain. Diabetic Emergencies	Catheter problems Constipation Peg problems Palliative care Syringe driver problems Wound care management Ear problems **D/N 24 HR** Urgent nursing problems that will not wait until the following day	Contact local pharmacist for advice. Medication queries 9-5 **01484 464276**
		GP Routine problems General medical concerns Medication concerns Ongoing medical problems		
Clinical Hub YAS – If concerned or you need further advise for new acute health problems only – **01924 584958** Experienced clinicians and support staff –will utilise pathways to provide “Right care, Right time, Right place”				

Evidence

To reduce costs need to release some efficiency savings

- Intelligent use of information

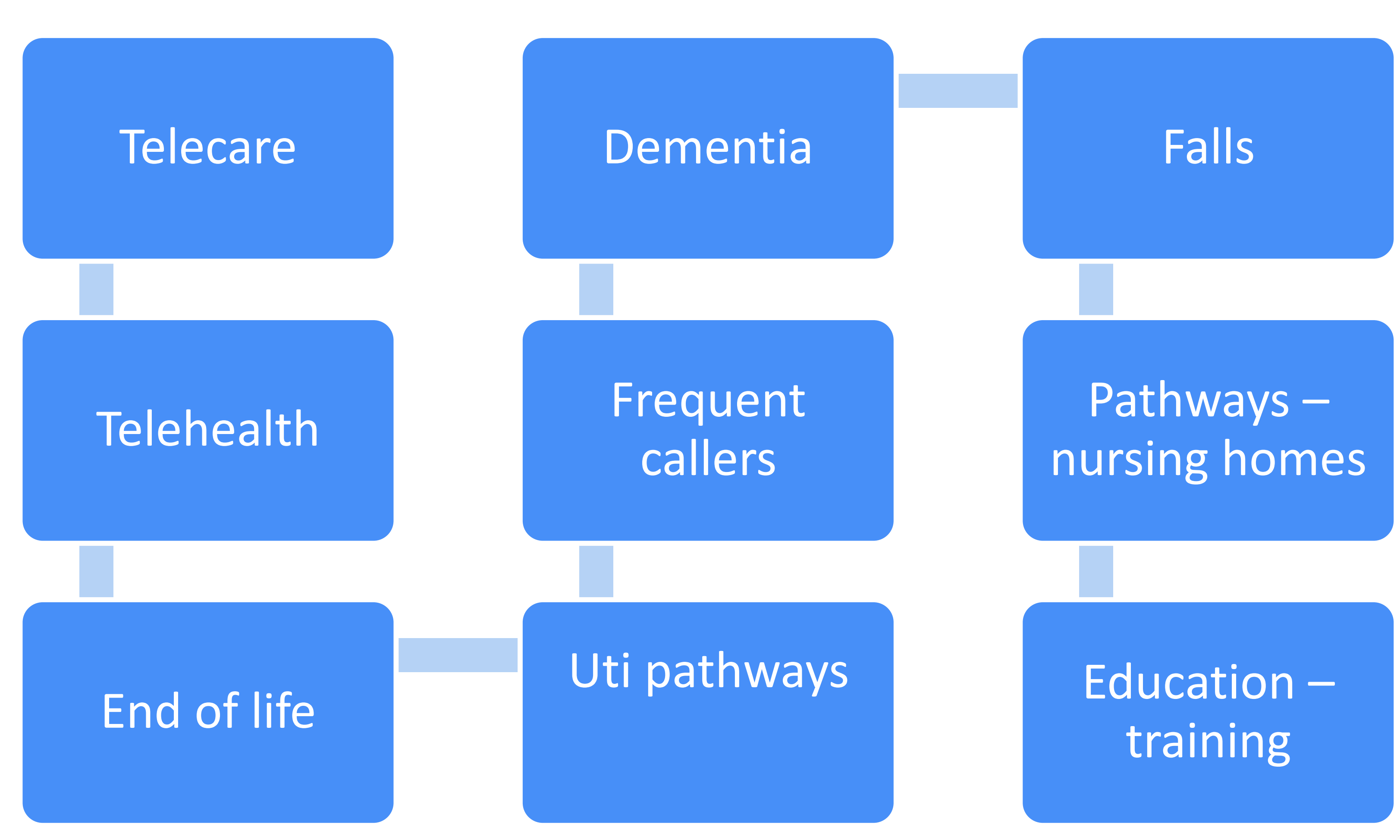
Improve service offered within clinical hub

- Clinical audit of calls
- Understand what can be provided differently
- Encourage commissioners whole system redesign

Model of urgent care

- Share ideas and innovations
- Learn from areas across region –wakefield , calderdale , York, already working with me so that they can use similar methods with ccgs
- mentor across region matrons. – so they can utilise ideas, methods and share learning

overall

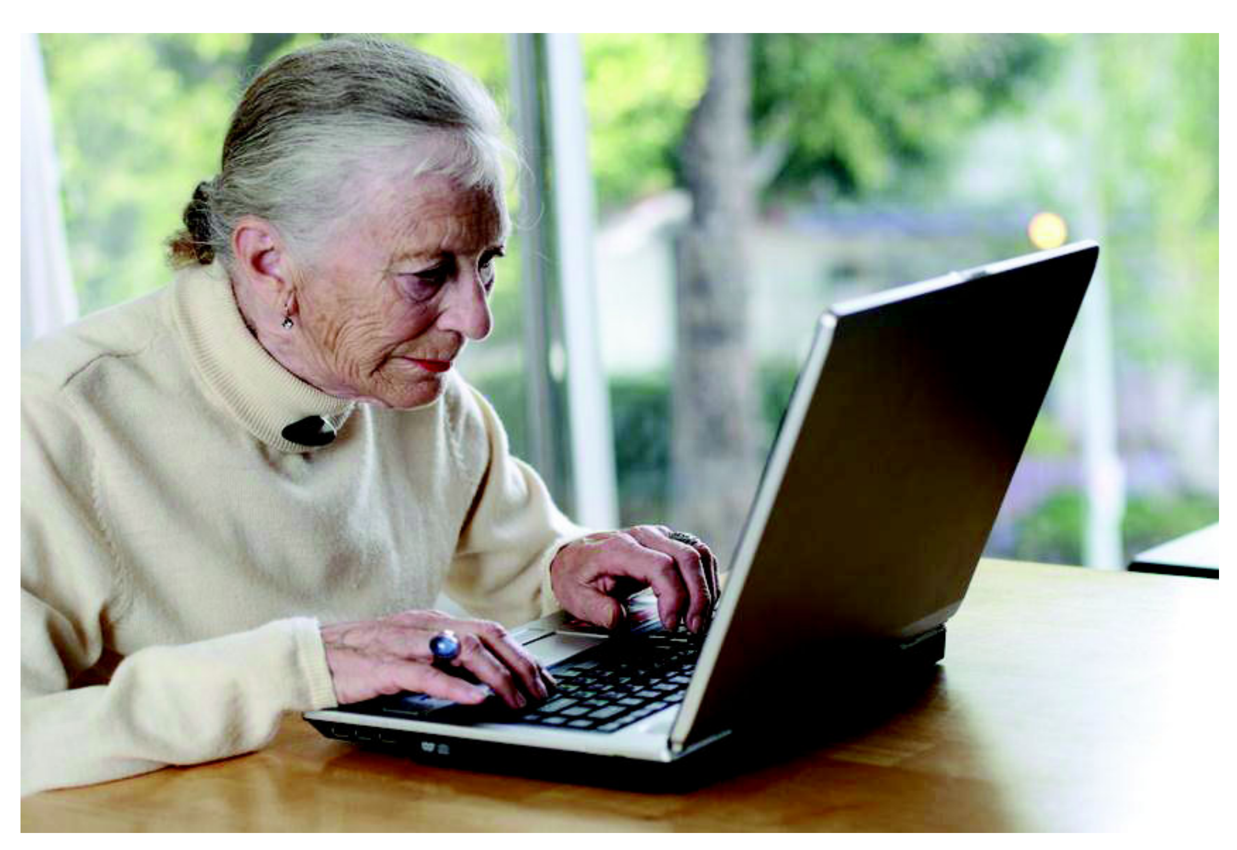


Sustainable models of care

- Uti pathways –care homes
- EOL pathways
- Awareness process for DNACPRs
- Understand what works well
- Stop pilots – sustainability
- Learn from each other

Never too young !

Never too old !



Public Awareness & Consultation Event on

End of Life Care services

28 August 2009

Supporting your right to the best health and social services in England

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Introduction from York LINK Steering Group

York LINk (Local Involvement Network) was launched in September 2008 to take over the role of the Patient and Public Involvement in Health Forum (PPI Forum) in the York Area. The PPI Forum was a group of volunteers who inspected health services in York on behalf of the public. The main difference between the LINk and the PPI Forum is that the LINk can inquire about social services issues as well as health services.

The money to fund LINks comes from the Department of Health and is divided between every Local Authority in England with responsibility for providing social services. The City of York Council contracted a 'Host' organisation to help develop the LINk. This is so that the LINk is not directly managed by the Council, giving the staff and volunteers freedom to make recommendations about services without being influenced by council decisions. York LINk's host organisation is North Bank Forum (NBF), based in Hull.

At the LINk launch event in September 2008, an Interim Steering Group was formed to agree the constitution and rules for the LINk before the first Annual General Meeting (AGM).

The AGM was held in March 2009 and a Steering Group made up of individual volunteers and volunteers from York organisations was established.

The Interim Steering Group decided to use a voting system to prioritise the work of the LINk and create the work plan for 2009/10. A debate on the issues that had been referred to the LINk from a variety of sources took place during the AGM, and members then voted for their preferred issues. To try to include as many members of the community as possible, and have a recorded process that provided evidence for LINk

priorities, the voting document was also sent to all registered members prior to the AGM and was available on request from the LINk office. The ‘provision of end of life care services’ was one of the issues with the most votes and so was adopted as part of the LINk work plan for 2009/10.

The role of the LINk is to discover what people in the York area think about health and social services and look into any issues that are affecting more than one person. When the issues have been examined, the LINk can make recommendations to organisations to amend or improve their services. When reports are published, they are sent to the organisations concerned together with a letter outlining the recommendations. The organisations then have 20 working days to reply to the LINk.

York LINk Steering Group

March 2010

Background

The National End of Life Care Strategy

In July 2008 the Department of Health (DoH) published a national End of Life Care Strategy. This is the first such strategy for the UK and it aims to promote consistently high quality of care for all adults at the end of their lives. It acknowledges that, in the past, the profile of end of life care within the NHS and social care services has been relatively low and the quality of care delivered has been very variable.

It is envisaged that implementation of this strategy will make a 'step change' in access to high quality care for all people approaching the end of life. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.

The strategy stresses the need for Primary Care Trusts (PCTs) to work with local authorities, hospitals, hospices, carers etc to agree and implement ways to promote consistently high quality of care for people as they approach the end of their life.

Key areas addressed by the National Strategy

The National Strategy sets out recommendations and actions in a number of key areas:

- PCTs and local authorities need to work in partnership to consider how to engage with their local communities to raise the profile of end of life care. This will involve liaising with schools, faith groups, funeral directors, care homes, hospices, hospitals, home care services, employers etc and agree ways to speak to people about dying and ask their views on current services.

- An integrated approach to planning, contracting and monitoring of service delivery should be taken across health and social care. Improved services should be commissioned as the contracts for present services come to an end, taking the needs of the community into account.

- Health and social care staff need sufficient training to identify people who are approaching the end of life. Workforce training is needed, so that staff have a greater ability to recognise people who are at risk and the correct care can be implemented.

- Everyone who is identified as approaching the end of their life should have their needs assessed. This assessment must include their wishes and preferences about how they are cared for and where they would want to die

- Everyone approaching the end of life should receive coordinated care from all services at all times of day and night. This could be achieved by providing a single point of access through which all services can be co-ordinated.

- Rapid access to care is essential. PCTs must work with local authorities to ensure that medical, nursing, personal care and carers' support services can be made available in the community 24/7 and can be accessed without delay.

- High quality care should be delivered in all locations. These will include services provided in hospitals, in the community, in care homes, sheltered and extra care housing, hospices and ambulance services.

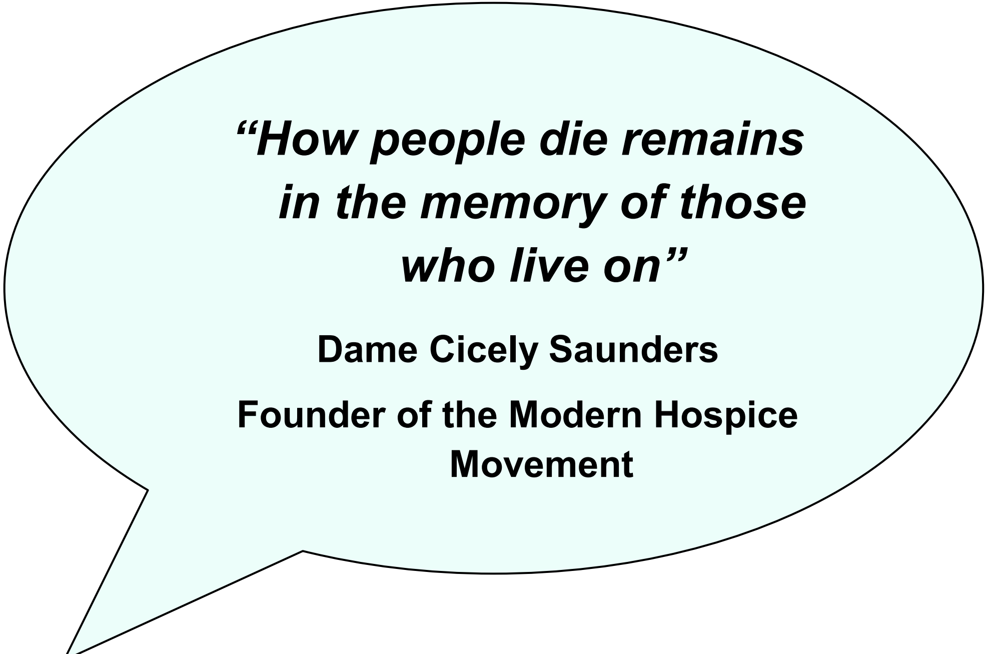
- Increasingly the Liverpool Care Pathway, or an equivalent tool, is being adopted. It was first developed for use with cancer patients but has now been modified for use for people with other conditions. It can be used in hospitals, care homes, hospices and in people's own homes.

- The family and carers of people approaching the end of life have a vital role in the provision of care. They need to be closely involved in decision making, with the recognition that they also have their own needs. Carers already have the right to have their own needs assessed and reviewed and to have a carer's care plan.

- It is critical that health and social care staff at all levels have the necessary knowledge, skills and attitudes needed to care for the dying. Strategic Health Authorities need to consider how training can best be commissioned and provided to ensure that staff have the necessary competencies.

- Measurement of end of life care provision is essential in order to monitor progress. Measurement will largely be through self assessment against quality standards, carried out by the organisations themselves.

- The overall cost of end of life care across health and social care is large and difficult to calculate. The key elements of expenditure are: hospital admissions; hospices and palliative care services; community nursing services; care homes. Increased government resources are committed to implement the strategy - £88m in 2009/10, £198m in 2010/11. Many improvements can be achieved by better use of existing health and social care resources. For example, at least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay.



The Gold Standards Framework

The Gold Standard Framework (GSF) is an approach which is designed to enable a gold standard of care for all people nearing the end of life. 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.

The Department of Health End of Life Care Strategy 2008 says that every organisation involved in providing end of life care will be expected to adopt a co-ordination process, such as the Gold Standards Framework. It is also recommended as best practice by NICE, Royal College of General Practitioners, Royal College of Nurses and other major policy groups.

GSF is extensively used in the UK, by thousands of primary care teams and care homes and increasingly in other settings through cross boundary care and also internationally.

GSF is about:

- Enabling generalists and improving the confidence of generic staff
- Organisational system change - the right care at the right time for the right patient
- Patient led focus on meeting the needs of patients, families and carers
- Care for all those with any end stage condition, non-cancer and cancer
- Pre-planning care in the final year or so of life, proactive rather than reactive care
- Care closer to home - decreasing hospital admissions and deaths
- Cross boundary care and in all settings - care homes, hospitals, hospices etc

Local background

In North Yorkshire and York, deaths are attributable to three main areas of illness:

- Heart and circulatory disease 41%
- Cancer 26%
- Respiratory disease 12%

Of the remaining 21% some deaths will be sudden or unexpected, such as road accidents. Other deaths relate to a range of long term illnesses such as Neurological Disease or Renal Disease. Other deaths relate to frailty and very old age, without a specified diagnosis.

In York, approximately 1,822 people of all ages die each year. Approximately 56% of all deaths take place in hospital, 19% take place in peoples own homes, 5% take place in hospices and 19% take place in nursing and residential homes (PCT End of Life Review/Healthy Ambitions 2008).

In York, NHS North Yorkshire and York (the PCT) staff were already working with City of York Council Social Services staff to review end of life care services before the National Strategy was published. The work began with issues around cancer services but it was recognised that 'end of life' is a much broader area.

The North Yorkshire and York End of Life and Palliative Care Commissioning Strategy 2008-2011 was published in September 2008. An End of Life and Palliative Care work plan has been developed to deliver the strategy.

York LINk Public Awareness and Consultation Event

In order to discover more about End of Life Care services in York, the LINk Steering Group decided to hold a Public Awareness and Consultation Event (PACE) on End of Life Care services. The event took place on 28th August 2009 (see Appendix 1 for the event programme). Speakers from City of York Council Social Services, NHS North Yorkshire and York and York Hospitals NHS Foundation Trust were asked to give information on the services they provide. To include the support available from the voluntary sector a speaker from MacMillan Cancer Support was also invited. Invitations to the event were sent to individuals, local voluntary and community groups and statutory services.

Emma Taylor, End of Life Care Facilitator/ Bereavement Services Manager York Hospitals NHS Foundation Trust

Emma Taylor spoke about both the Liverpool Care Pathway and the Bereavement Suite at York Hospital.

1) The Liverpool Care Pathway

The Liverpool Care Pathway is a document that can be used by all professionals such as nurses, doctors, social workers etc. The document contains templates that doctors, nurses, social workers etc can use to provide the best care possible. This document has been put together from many studies of the evidence available (evidence-based) that has led to the best result possible (best-practice) and has involved the patient's views (patient -centred care).

The Pathway is a tool to help transfer the hospice 'model of care', which promotes patient comfort rather than a cure for their condition, to a hospital setting and will help the staff to have a York Hospital wide structure (pathway) to provide the best care for dying patients and relatives

The role of the End of Life Care Facilitator is to:-

- Lead the development, education and implementation of the Liverpool Care Pathway across York Hospitals NHS Foundation Trust.

- Carry out an audit on the use and the findings of the Pathway.
- Carry out a full review of the Bereavement Care service.
- Develop services to meet preferred priorities of dying patients.

The Pathway is structured in three sections to provide the following:-

1. An 'Initial Assessment' of the patient's needs and the care required
2. An ongoing assessment of needs and care
3. Care for the patient and family after death

When patient care is managed in accordance with the Liverpool Care Pathway, nurses must check patients' physical, psychological, religious or spiritual, and social goals every four hours.

Hospital staff do not need to ask permission from the patient to put them on the Pathway but it is best practice to let them know that staff are helping them as much as possible. Some Doctors still think that a dying patient is a failure of their expertise. This is changing and many now accept that if they have done all they possibly can it is better to help someone to die in comfort than put them through further medical procedures.

How much is the Pathway used in the hospital currently?

- In August 2009 55% of the wards in the Hospital were using a Care of the Dying Pathway - this will be replaced with the Liverpool Care Pathway after staff have received the necessary training.
- There is a roll out development programme for the remaining wards to implement the Liverpool Care Pathway. A large piece of work will be involved prior to the implementation of the Liverpool Care Pathway in the Intensive Care Unit because patients in the unit can have different needs to those on the wards.
- A computer based learning package is being developed for **all** staff including ward clerks, porters and health care assistants as it is recognised that all staff need to have awareness of this area.

- Training on End of Life Care will be incorporated in the hospital staff's mandatory training from April 2010.

An audit of services in York Hospitals NHS Foundation Trust during 2008 found that 55% of all hospital care is about end of life.

Also:-

- 37% of Patients who died were on the Care of the Dying Pathway
- 27% of Patients could have been on the Pathway but weren't
- 36% of Patients were not appropriate for the Pathway

This means that 401 Patients who could have been on the Care of the Dying Pathway were not.

A similar audit carried out in April 2009 after the implementation of the Liverpool Care Pathway in some areas found a small improvement but hopefully this will improve further after all staff have been trained.

Further training is planned for staff who have already been trained on the Liverpool Care Pathway to include documentation and arrangements for sudden or unexpected death.

2) Bereavement Suite at York Hospital

As part of the bereavement care plan to improve services offered to newly bereaved relatives, a new Bereavement Suite is planned for York Hospital. Having been severely delayed, building work is due to commence mid March 2010, with a predicted opening date of August 2010. The project is funded by the Kings Fund Charity and from donations.

Initially the service will be similar to the current service, and will provide an enhanced environment for collection of death certificates, property and valuables. There will be an on-site Registrar of births and deaths, and a room for relatives to be seen by doctors if appropriate. The design also features quiet space outside for bereaved relatives.

Future plans for the suite will involve the use of agencies such as Cruse Bereavement Care and Sands (Stillbirth and Neonatal Death Society) to provide expert counselling and support to the bereaved.

Initially the suite will be open from 8.30am - 4.30pm Monday – Friday.

Ruth Wilson, Macmillan Cancer Support Community Network Development Coordinator

The history of Macmillan

In 1911, a young man named Douglas Macmillan watched his father die of cancer. His father's pain and suffering moved Douglas so much that he founded the 'Society for the Prevention and Relief of Cancer'.

Douglas wanted advice and information to be provided to all people with cancer, homes for patients at low or no cost, and voluntary nurses to attend to patients in their own homes.

The Society provided information on recognising, preventing and treating cancer to patients, doctors and members of the public. In 1924 the Society became a Benevolent Society and changed its name to the 'National Society for Cancer Relief'. As recent as 1975 the first Macmillan nurse was funded and the first Macmillan cancer care unit built**.** The nurses were so successful that only three years later in 1978 their number had increased to ten. By 1980 the Society was able to invest £2.5Million to expand the Macmillan teams throughout the UK primarily focusing on an educational programme to train doctors, nurses and students in advanced pain control and cancer care. In 1986 the first Macmillan doctor was funded. The charity is now called the 'Cancer Relief Macmillan Fund'.

At present, Macmillan directly employs 800 people but includes almost 5,000 people as many nurses etc are sponsored and employed via NHS Trusts. The Development Managers are looking at the gaps in services at present so the interest shown by York LINk is very timely.

Macmillan Grants

The Fund provides grants for travel expenses to hospices, holidays to help recuperation after treatment etc for people who otherwise have difficulty affording them. There are also small grants to support people with the practical impact of cancer such as increased fuel bills.

There are also start-up grants of £500 to help set up local support groups. The support groups can then apply for up to £3,000 in development grants to expand the group or pay for awareness sessions etc. Volunteers can also attend Cancer Voices training and then hold awareness sessions in local areas.

Cancer Networks

Macmillan organises Cancer Networks throughout the country. These are based in grouped NHS areas. In the York area there is the Yorkshire Cancer Network which includes the Huddersfield, Bradford, Wakefield, Harrogate, Leeds and York districts.

Macmillan also has local groups and asks them what they think of services. They come together to meet with professionals at the Network meetings to try to jointly improve services.

Nationally, Macmillan has organised a campaign to get free car parking for cancer patients who attend hospitals for treatment.

At present regionally, there are discussions taking place about moving the main provider of cancer treatment out of Leeds into more local areas, possibly York. Consultation on this is via the Yorkshire Cancer Network and further information is available via Colin Sloane, User Partnership Facilitator. Phone: 01423 555786 E mail: colin.sloan@ycn.nhs.uk.

The York Cancer and Palliative Care User Partnership Group can be contacted on 01904 631313 (Maggie Clough) and can provide information and advice for people at the end of their lives or their families.

Richard Tassell, Operations Manager, City of York Council Social Services

How does Social Services help?

Most people do not want to die in hospital. The pressure to discharge people from hospital quickly when they are well enough or, if they wish, at the end of their life, is high. There are specific Social Services discharge liaison staff employed to work in the hospital solely to plan discharges. The liaison staff work with Social Services locality managers to ensure a smooth service for people leaving hospital.

Who pays for what service?

Health authorities and councils were requested to agree their respective responsibilities for health and social care services by 1 March 2002. This is an agreement on who pays for social and health care. Councils pay for social care funded via their 'Financial Settlement' from National Government and locally raised rates. Primary Care Trusts pay for health care.

Local agreements on the responsibilities to pay for services have been in place since 1 October 2002. Councils then use Fair Access criteria to determine eligibility for the services for which they are responsible.

Assessing need

Social Services staff assess an individual's needs then prioritise the needs that they are eligible to fund.

The issues and problems that are identified when individuals contact, or are referred to, councils are defined as the "presenting needs".

Those presenting needs for which a council will provide help because they fall within the council's eligibility criteria, are defined as "eligible needs".

When considering needs, councils should not make assumptions about the capacity of family members or close friends to offer support.

City of York Council has agreed to provide End of Life Care to people who require this in their own home as it meets the eligibility criteria used by Social Services.

Fair Access to Services

The eligibility framework is graded into four bands, which describe the seriousness of the risk to independence or other consequences if needs are not addressed. The "Eligibility criteria" describe the full range of eligible needs that will be met by councils having taken their resources into account.

The four bands are:

1 Critical

- when life is, or will be, threatened;
- and/or significant health problems have developed or will develop;
- and/or there is, or will be, little or no choice and control over vital aspects of the immediate environment;
- and/or serious abuse or neglect has occurred or will occur;
- and/or there is, or will be, an inability to carry out vital personal care or domestic routines;
- and/or vital involvement in work, education or learning cannot or will not be sustained;
- and/or vital social support systems and relationships cannot or will not be sustained;
- and/or vital family and other social roles and responsibilities cannot or will not be undertaken.

2 Substantial

- when there is, or will be, only partial choice and control over the immediate environment;
- and/or abuse or neglect has occurred or will occur;
- and/or there is, or will be, an inability to carry out the majority of personal care or domestic routines;
- and/or involvement in many aspects of work, education or learning cannot or will not be sustained;
- and/or the majority of social support systems and relationships cannot or will not be sustained;
- and/or the majority of family and other social roles and responsibilities cannot or will not be undertaken.

3 Moderate

- when there is, or will be, an inability to carry out several personal care or domestic routines;
- and/or involvement in several aspects of work, education or learning cannot or will not be sustained;
- and/or several social support systems and relationships cannot or will not be sustained;
- and/or several family and other social roles and responsibilities cannot or will not be undertaken.

4 Low

- when there is, or will be, an inability to carry out one or two personal care or domestic routines;
- and/or involvement in one or two aspects of work, education or learning cannot or will not be sustained;
- and/or one or two social support systems and relationships cannot or will not be sustained;
- and/or one or two family and other social roles and responsibilities cannot or will not be undertaken.

The City of York Council sets the eligibility criteria at ‘moderate’ so anyone requiring services at a higher level will need to pay towards the cost. The criteria covering when life is threatened is ‘critical’.

Liz Vickerstaff, Senior Commissioning Manager NHS North Yorkshire & York

NHS North Yorkshire and York's End of Life and Palliative Care Strategy was published in September 2008. This strategy reflects national strategy and was developed by patient groups, service providers, statutory and voluntary organisations from across York and North Yorkshire. It also includes information from the following sources:

- NICE Supportive and Palliative Care 2004
- Healthy Ambitions (Darzi Review)

The Strategy includes the following; also contained in the National Strategy for End of Life Care:

Although every individual may have a different idea about what would, for them, constitute a 'good death', for many this involves:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends.

To enable the above, the overall aims of the Strategy are focussed on:-

- Assessment and planning of care (advance care planning). This will be done by discussions between staff and patients as their end of life approaches
- Coordination of care. This will be done by assessing, planning and reviewing care
- Providing specialist care when necessary
- Ensuring quality and dignity in delivery of services
- Providing care for Carers/Bereaved
- Monitoring care/audits surveys to ensure the strategy is working

- Sharing best practice

The aims of NHS North Yorkshire and York are

- That people who are in need of palliative care, or have reached the end of their lives, should receive the best possible care, in the setting of their choice where this is possible, and that when death finally comes, that they are able to die with dignity.
- That carers of those who are receiving palliative care, who are dying or have recently died, should have their needs met throughout the process of caring for their loved one.

The outcomes to be delivered by the strategy are:

- The delivery of person Centred Care – Palliative
- The delivery of person Centred Care – End of Life
- Quality services
- Quality staff performance
- Sustainable services

N.B. Palliative care and end of life care are distinctly different. Palliative care is given to maintain the best quality of life when a cure is not possible – this could be for several years. End of life care is usually in the last weeks of life and involves symptom control, pain relief and meeting spiritual needs.

An End of Life and Palliative Care work plan has been developed to deliver the strategy. The work plan contains the following areas to target:-

- Identify Patients
- Assess documentation
- Coordination of services / policies
- Community/District Nursing and Key worker involvement
- Provision of out of Hours Care

- Provision of specialist Palliative Care
- Ensure access to Equipment and Medication
- Involve Acute Care providers
- Provide treatment in alternative settings
- Provide bereavement care/spiritual care
- Ensure Patient & Carer involvement
- Social Care involvement
- Psychological Care
- Training and Education for staff

The final version of the PCT's strategy was agreed by the board in November 2009, including the above work plan. Following the 'refresh' of the PCT's five year strategic plan, the End of life Care strategy is now part of the delivery of this plan, including the work streams which are now part of the community systems work stream.

St Leonard's Hospice

In order to find out about hospice services in York, the LINk Steering Group arranged an informal visit to St Leonard's Hospice on 15th December 2009.

The Hospice was founded in 1985 It is a registered charity caring for people with life-threatening illness. Its aim is: 'To provide for the needs of patient, carers and families in a setting which is as homely and informal as possible and from which the patient will benefit with enhanced quality of life and greater physical and mental comfort.'

It offers:

- In-patient care in a purpose-built, 20-bed unit. Patients can receive short-term care, respite or terminal care.
- Day care at the hospice for people living in their own homes. This provides a combination of practical help and relaxation.
- A lymphoedema clinic where outpatients can be seen by specialist staff.
- Bereavement support for families and carers after a patient has died.

The Hospice is currently running a one year pilot Hospice at Home scheme to support people in their own homes. Hospice at Home aims to enable patients with advanced illness to be cared for at home, and to die at home if that is their preference. Care may be provided to prevent admission to, or facilitate discharge from, inpatient care.

Doctors and nurses work with a team of other professionals and are supported by volunteers. Referral to the Hospice is made by the patient's own family doctor or hospital consultant. No charge is made to patients or relatives, the Hospice is financially supported almost entirely by the generosity of the local community.

Central to the Hospice philosophy is the care of every patient as an individual. The philosophy of the Hospice is that patients should be consulted about medical treatment and have their questions answered honestly; they should be treated with dignity and sensitivity; they should be cared for as a whole person, with compassion and understanding.

Findings the LINk gathered before, during and after the PACE event:

Information was gathered from 20 individual people, and from a variety of publications and websites (see Bibliography for details of publications and websites).

After the first draft of this report was written, a letter about one family's experience was sent to the LINk office. This was in response to a letter in The Press (24 March 2010) from the Vice Chair of the LINk, asking for experiences (good or bad) of end of life care services. Although this letter was received too late to be included in the main report, the LINk decided to include it because it illustrates Dame Cicely Saunders' quote: "How people die remains in the memory of those who live on". It is published in full (with identity details removed) as Appendix 2.

It is acknowledged that due to unforeseen circumstances this report has taken almost a year to complete therefore services may have improved. Nevertheless, this is what the LINk has found.

Key findings	Source
Home care staff do not know always know how to care for people with MND. For example, one patient was given tablets whole rather than crushed	York Against MND
NICE clinical guidelines on Parkinson's Disease state that that the needs in the palliative care stage of Parkinson's disease are not always identified or satisfied. Their recommendations include that people with PD and their carers should be given the opportunity to discuss end of life issues with appropriate healthcare professionals	NICE clinical guidelines

Qualified nurses are available during the day, but not at night. One patient's partner reported that they stayed up most nights to look after the patient	York Against MND
One patient with MND refused to be admitted to York hospital when she was dying, stating that the care she had received previously was appalling and she would rather "suffer than go into the hospital"	York Against MND
One patients last wishes were not taken into account by a locum GP	York LINk member

Recommendations from York LINk.

1. There is a major mismatch between people's preferences for where they should die and their actual place of death (Department of Health End of Life Care Strategy in England 8 months on by Prof Mike Richards March 2009). Research suggests that the majority of people (between 56 and 74 %) express a preference to die at home. However mortality statistics for 2006 show that 35% of people die at home or in a care home (National Audit Office, End of Life Care, 24 November 2008). However, they may struggle to get services quickly enough to enable this to happen.

    a) 'Fast track' discharge from hospital needs to be available for people wishing to die at home. Hospital and ambulance services need to be able to respond to this.
    b) The 24/7 community nursing service in York needs to provide a rapid response for patients who are nearing the end of their lives. Timely access to advice and medication would mean that people approaching the end of their life are less likely to be unnecessarily admitted to hospital.

2. Hospices are widely agreed to be 'beacons of excellence' in the provision of end of life care. However, in York, there are only 20 beds available at St Leonards Hospice and so can only deal with a minority of patients at the end of their lives.

    a) The Liverpool Care Pathway is being introduced throughout York Hospital and this should be regarded as a starting point to developing 'hospice standard' care (NB St Leonards Hospice do not currently use the Liverpool Care Pathway).
    b) The Hospice should be encouraged to consider what roles it wants to deliver within an integrated local service, responding to local peoples' needs e.g. awareness raising, education and research, co-ordination, specialist outreach services.

3 Patients and carers end of life care needs must be met regardless of who is delivering the service.

a) Co-ordination of resources, and collaborative working across health, social services and the voluntary sector should be a priority. The Marie Curie Cancer Care Delivering Choice Programme demonstrates the effectiveness of establishing a central coordinating facility providing a single point of access through which all services can be co-ordinated. (Recommended in the Department of Health End of Life Care Strategy July 2008).
b) All organisations involved in providing end of life care should adopt a co-ordination process such as the Gold Standards Framework. (Department of Health End of Life Care Strategy – What the End of Life Care Strategy means for patients and carers, July 2008).

4 Improved education and training is needed for all staff involved in End of Life Care, both in health and social care. In addition, for some clinicians and NHS managers a change of culture is necessary so that death is not seen as a failure. Cancer consultants and other cancer services staff in hospitals are now accessing improved communications training which will support this (for cancer service provision). Professionals should not be reluctant to initiate end of life discussions, especially with patients who have long term neurological conditions where the illness may be less predictable than other illnesses such as cancer (NHS Evidence – Supportive and Palliative Care Specialist Collection, National Library for Palliative and Supportive Care, October 2009).

5 Time and an appropriate quiet environment must be available for professionals to have conversations about end of life care planning with patients. (NHS Evidence – Supportive and Palliative Care Specialist Collection, National Library for Palliative and Supportive Care, October 2009)

6 Bereavement care should:
   a) Ensure that counselling and support are available 24/7.
   b) Provide support for those bereaved through sudden death and include the needs of children (The Department of Health End of Life Care Strategy Rationale Chapter 5 – Support for Carers and Families)

7 Local End of Life Care services must include all sections of the community, including those regarded as ‘hard to reach’ such as people in prisons and hostels for the homeless, gypsy and traveller communities. The Department of Health End of Life Care Strategy Rationale (Chapter 4 Care in different settings) says that prisons and hostels for the homeless should be included in local plans and examples of good practice identified.

8 End of Life Care services for people with long term neurological conditions can be more difficult to identify and satisfy. Advance care planning is necessary, in an appropriate quiet environment. In some cases a day hospice environment may be beneficial to patients and carers (NHS Evidence – Supportive and Palliative Care Specialist Collection, National Library for Palliative and Supportive Care, October 2009)

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Department of Health End of Life Care Strategy July 2008

Department of Health End of Life Care Strategy Quality Markers Consultation, November 2008

Department of Health End of Life Care Strategy in England 8 months on, Professor Mike Richards, March 2009

North Yorkshire and York End of Life Palliative Care Commissioning Strategy 2008-2011, September 2008

Palliative care input and advance decision making in patients with long term neurological conditions. NHS Evidence – Supportive and Palliative Care Specialist Collection, National Library for Palliative and Supportive Care, 13 October 2009

National Audit Office End of Life Care, The Stationery Office, 26 November 2008

www.goldstandardsframework.nhs.uk

www.macmillan.org.uk

www.nyypct.nhs.uk

www.york.gov.uk

www.stleonardshospice.org.uk

www.mcpcil.org.uk/liverpool-care-pathway

www.nice.org.uk

Appendix 1

Public Awareness & Consultation Event

End of Life Care Services

Friday 28 August 2009 - City Mills, Skeldergate York

Programme

10.30 – 11.15	The Liverpool Care Pathway in York Hospital, Emma Taylor, End of Life Care Facilitator, York Hospitals NHS Foundation Trust
11.15 – 12.00	Services from Macmillan Cancer Support, Ruth Wilson, Macmillan Community Network Development Coordinator
12.00 – 12.30	Support from City of York Council Social Services, Richard Tassell, Operations Manager, City of York Council Social Services
12.30 – 12.45	Tea / coffee & cake
12.45 – 13.00	NHS North Yorkshire & York and City of York Council Social Services End of Life Care Strategy – Liz Vickerstaff, Senior Commissioning Manager, NHS North Yorkshire & York
13.00 – 13.30	Discussion and recommendations for the future

Appendix 2

Response from a York resident after a letter from York LINk's vice chair was published in the York Press (24th March 2010) asking for feedback about experiences (good or bad) of end of life care services in York.

" My close relative was in York Hospital for many weeks during 2009 suffering from an internal abscess, septicaemia and MRSA. He was also diabetic. In November the doctor at the hospital said that my relative had reached a 'plateau' and would have to leave hospital and go into a nursing home. We were able to have him admitted to Fulford Nursing Home. They treated him with kindness and did all they could to make him comfortable. Unfortunately he was only there for five days before he was re-admitted to York Hospital suffering from pneumonia. We dearly wished that he had been admitted to Fulford Nursing Home much sooner and at least he would have received comfort and care in the last weeks of his life.

There were untoward incidents in the period that my relative was in York Hospital, but there were also positive aspects to his care. We found that general attitudes towards patients were often uncaring, although some of the nurses did help as much as possible. My relative was aware of what was taking place, but he did not complain very much. Occasionally he became upset and exasperated by the way in which he was treated. Some of the staff were quite rigid in their working methods, e.g. sick and elderly patients had to wait for attention if meals were being served. If staff were doing the final bed change in the evening, they would insist on doing everything in a certain sequence, even if a patient needed attention, the patient had to wait.

The separate room that my relative was in was not very warm, especially as the cold winter weather set in. When I visited I needed to keep my overcoat on. My relative was always supplied from home with warm clothing, including jumpers and pyjamas, but often he was wearing none of these things, but just an incontinence pad and a skimpy, short sleeved cotton top (hospital issue). Consequently he often felt cold. This way of dressing a patient may have been an easy method of dealing with patient care, but it did not make the patient warm and comfortable. The food was often unpalatable and eventually we needed to take food in to persuade him to eat.

His next of kin was treated shabbily when she tried to obtain information about his illness. She struggled with this problem the whole time he was in

hospital until his death. When she spoke to a nurse she was often told that he was ’fine’, when this was clearly not the case. The same answer usually came over the telephone. If he had been particularly unwell the previous evening, she tried to phone the ward the next morning. It often took at least six attempts to get through to the ward, and when an answer was finally obtained, it was vague and lacking in information. If she enquired on the ward, the nurse often said she did not know anything or that she had ‘just come on duty’ or that he ‘was not their patient’. No attempt was made to find out what the situation was. A request for an interview with the consultant was granted and although he explained something of my relative’s illness he did not mention MRSA.

I do not believe that we were alone in our difficulties with communication. I often heard relatives trying to speak to staff and not receiving satisfactory answers. On Christmas day 2009 we were at the hospital from mid afternoon until 8pm. My relative was not fully conscious, but a nurse came to take his blood sugar reading. We objected to this being done at that stage in my relative’s life but the nurse said it was ’protocol’ and went ahead and took the sample. Although my relative was on his own in a separate room, no other staff came to see him or talk to us. We did not get any advice about his condition and we did not know what to do. We left him reluctantly. When his next of kin took hold of his hand it was covered in blood. This was the last time we saw him. The hospital phoned the next morning at 6.30am to let us know that he had died at 6.15am. We did not go back to the hospital, we were too upset to do this.

We did not know what to do or where to turn for help and advice in my relative’s last illness. We did wonder if it would have been possible for him to be admitted to St Leonards Hospice but we did not know if it was feasible, or how to take steps to find out. I consider that lack of communication is a big problem for patients and relatives. If a proper system of communication was put in place I think that this would help to clear many problems.”

York's Local Involvement Network

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