Annex D1

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) 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. 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.

[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.

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.

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.

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.