Annex H

Harrogate and District NHS
NHS Foundation Trust

michael.holmes@hdft.nhs.uk
Clinical Director – Unscheduled Care

Unscheduled Care Services
Unit 5
Sovereign House
Kettlestring Lane
Clifton Moor
York
YO30 4GQ

Website: www.hdft.nhs.uk

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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