

## **North Tyneside CCG Patient Forum End of Life Working Group Notes**

Tuesday 1 May 2018  
11.00am – 12.30  
205 Park Road  
Wallsend  
NE28 7NL

### **Attendees**

Gillian Bennett	Wellspring Surgery
Hazel Parrack	49 Marine Avenue
Dr Kathryn Hall	Chair
Donna Sample	Clinical Commissioning Group (CCG)
Michele Spencer	Community and Health Care Forum CHCF
Carole Reed	Community and Health Care Forum (CHCF)

### **Apologies**

David Hall	Northumberland Park
Val Telfer	Wellspring Practice

### **Welcome and Introductions**

#### **Notes of last meeting Tuesday 30 January 2108**

Agreed as a true record

### **Matters Arising**

It was decided that the start time for this meeting should revert back to 9.30am as one of the members is unable to attend at 11.00am. Other members who have difficulty driving to Park Road were given the offer of a complimentary taxi. However the next meeting on 3 July will take place at the Linskill Centre as Dr Hall will do a Powerpoint presentation about the Palliative Care Project.

### **Dr Kathryn Hall**

Dr Hall explained that the Electronic Palliative Care Researcher letter has now been adapted and is available to read; she will send copies out to group members via Michele. Also the Patient Information Leaflet has been modified after feedback from the members was taken on board.

Dr Hall attended an Out of Hours meeting recently which was well attended. Vocare Ltd service providers were in attendance and confirmed their workload has risen significantly as the timescale for each patient is 120 minutes this is proving to be a challenge. Part of the issue is that the Care of Dying Patient document is only being used in certain cases which means the clinicians seeing patients who become suddenly terminally ill may have little or no

information or care plan. Dr Hall confirmed that the document is kept in the patient's home where clinicians, care workers and family all have access to it. This is the process that replaced the Liverpool End of Life Programme along with the production of the five priorities of care. One member informed the group that she had a bad experience with the Care of Dying Patient document about four years ago; Dr Hall agreed that it was around that time when changes began taking place. Dr Hall said people are now recognising the Do Not Resuscitate (DNR) plan but continued education is essential. There is a website from the North East Clinical Network in which members can use a search engine typing in 'Deciding Right'.

The Palliative Care project is progressing really well and Dr Hall informed the members they were now using an IT company called Black Pear who have set up a Sharing Data in Health programme for GPs to use; the contract for this was signed in March 2018. There will be an official evaluation of the EPaCCS project including a formal academic and economic formulation.

Feedback from the Rapid Response Team report that everything is going really well and hospital admissions have been substantially reduced. Patient numbers show 64% are on the Palliative Care register and 62% of people are dying in their place of choice at home or in their care home; the national average is 50%. There is a slow but significant reduction of length of stays in hospital; Donna will chase up the latest figures.

Dr Hall explained to the group that when a patient is at the very end of life and maybe suffering from chest or urine infections they may not wish to go into hospital; in these cases Dr Hall would discuss the situation with the family and prescribe oral antibiotics and any necessary pain relief such as morphine. The main priority is to make sure the patient is comfortable.

Dr Hall has been doing some work with the local authority on fair access to all, the black, ethnic, homeless and LGBTQ members of the public in North Tyneside are in the minority and it is quite difficult to get meaningful figures. She meets up with these groups on an 'as and when' basis.

The members all agreed that amazing progress has been made within the last four and a half years, the working teams involved are very hard working and committed. At present there are no Macmillan Social Workers in post even though the funding is available, this highlights the impact on the service. Local authority social workers now have around 60 people on their caseload.

Members raised and discussed the benefits of a health and care education programme as a joint initiative for staff in relation to end of life and palliative care provision. As a mandatory, jointly resourced training programme the benefits to patients, carers and the multi disciplinary staff team would be extremely valuable if not priceless. Members gave this concept their full support. The work plan for this group will include Electronic Palliative Care Co-ordination

System (EPaCCS) as well as Chronic Obstructive Pulmonary Disease (COPD). The Palliative Care Project in conjunction with Northumbria University will look at patient and carer experiences and how information is shared between families and health professionals, members have had the opportunity to inform the publicity material to be used during the research. All Patient Forum members will be informed and included.

### **Actions**

1. Dr Hall to send out copies of the adapted Patient Information Leaflet, Care of the Dying Audit Report and the End of Life and Palliative Care Data and bring further up to date reports and slides to the next meeting 3 July.
2. Michele to confirm the four dates and venues for the focus groups taking place throughout June and July.
3. Michele to extend an ongoing invitation to members of the Patient Forum to this meeting.