

North Tyneside CCG Patient Forum End of Life Working Group Notes

Tuesday 30 January 2018
9.30am-11.30am
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)
Holly Standing	Northumbria University
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 8 August 2017

Agreed as a true record

Matters Arising

The members discussed the possibility of this working group merging with the Older People's working group and it was fully agreed that the two should remain separate. It was also considered whether this meeting should take place at an alternative venue such as the Linskill Centre due to parking and travel issues. It was finally decided to stay at Park Road but adjust the start time from 9.30am to 11am.

Dr Kathryn Hall

Emergency Health Care Plan

The emergency health care plan (EHCP) makes communication easier in the event of a health care emergency. It should include a brief summary of the individual's diagnosis and their understanding of it, a list of regular medication, an indication of any ceilings of care that have been requested by the patient or been recommended by the health care professional and describe actions for emergencies arising at home. A patient with a terminal illness or long term condition can become unpredictably unwell very quickly. The care will differ according to the patients recovery prospects.

Dr Hall is currently working with respiratory colleagues at Northumbria on ways of predicting care and this research has given some indicators on the best methods of care. A bespoke health team have composed a written template on the emergency health care plan.

Holly Standing

Electronic Palliative Care Researcher

Northumbria University

Northumbria University are currently working on an evaluation for the Palliative Care Plane Project liaising with professionals, patients and their families. The attached Participant Information Sheet outlines the purpose of the study and attempts to answer specific questions. This was created by Dr Katie Brittain who has encourage people to contact her on a direct telephone line or email address which is printed at the end of the document.

The intention is to conduct one to one interviews and/or focus groups to gather people's palliative care experiences. There have been complexities sharing information and it has proved to be a huge challenge but the team have recently been given ethical approval. All GPs in North Tyneside have agreed to be involved with the project and agreed to access patients' data with their permission via the GP records. Dr Hall explained that of the 29 surgeries in North Tyneside 15 are on IT System One and 14 on EMIS; these 14 surgeries will be approached first, 1% of their patients are on the palliative register so potentially the target can be met. Patients experiencing palliative care now or previously will be chosen confidentially by the GP who is familiar with the patient. Once this is agreed a letter of invitation will be sent out to the person to attend an interview. This letter will be on the GPs letterhead. This is entirely voluntary and if a person does not want to take part it will not affect the care they receive. Any data gathered will be stored on a password protected computer system at Northumbria University. Dr Brittain and Dr Standing are conducting this evaluation along with another colleague who will be in post in March; all three have previous experience of end of life and bereavement.

Q Will the letter be sent out with a questionnaire attached because if so this does put people off?

A No there will only be the letter.

Q What if people come up with alternative issues?

A They can always go back and discuss these with their GP.

Q Will there be any re-runs of invites to people if they haven't replied?

A If there is no reply it will assumed they don't want to take part, however if there is a poor follow up rate it may be chased it up. We are ultimately hoping for around 20 replies.

Q Why does the CCG logo not appear on the evaluation along with the others?

A As all clinical groups sit under the Northern Clinical Network there are too many logos to fit onto the sheet (incidentally the current logos featured are slightly out of date).

Q Is there an electronic version of this?

A Yes this is available.

Q Regarding the fourth paragraph 'What will happen if I take part – this is a bit inhibiting - should the person be informed they can bring someone with them?

A Yes, that will be noted.

Patient Information Leaflet

The draft leaflet was handed out for the members to read some thought it very dry and also very long. It was explained that the reason for its length is that certain subjects have to be included. The difficulty they have is that it covers Northumbria and North Tyneside and producing this has been a challenge. It was suggested that colour coding the different sections may be useful. All members agreed the information within the leaflet was very helpful. Dr Hall was in agreement that it will be a challenge to keep the information up to date but hoped eventually it would be available on the website. One member thought the professionals listed on page ten should be moved forward to page three. A few other minor adjustments were discussed.

Q Should the leaflet have a section actually explaining what Palliative Care is?

A Yes, this has been noted.

Q Is there an easy-read version for people who have a learning disability or who speak a different language?

A This can be arranged.

Rapid Response

Dr Hall gave a brief feedback from the Rapid Response Team. Everything is going really well and hospital admissions have been reduced to between seven to ten per month in North Tyneside. This is a really good statistic when compared to the national figures. There are still some minor issues about recruitment the staff are not up to full capacity. A short report consisting of three questions was submitted and the response showed that a high level of palliative care patients are dying at home. Dr Hall will bring the officially produced document to the next meeting which shows a validation of the support that is given.

Any other business

Supporting Excellence in End of life care in Dementia (SEED) is a project working within Newcastle University which provides end of life care for people with dementia and complex needs, understanding how end of life care is currently delivered to people with dementia and their families. The aim of this research is to support providers and commissioners to identify and deliver good quality care.

Northumbria University are also currently doing an audit of the Care of the Dying Patient document and when completed Dr Hall will bring a copy to the meeting.

Action

1. Holly to email evaluation letter to Michele.
2. Group members to respond to feedback within two weeks.

Date and time of next meeting

Note new time: 11.00am to 12.30

Tuesday, 1 May 2018

205 Park Road, Wallsend