END OF LIFE CLINICAL REFERENCE GROUP

Notes of a meeting held on 11 June 2015 at Balham Park Surgery

Present:  
Stephen Deas (Chair)  
Sue Tappenden  
Marietta Swanne  
Lizzie Lloyd-Dehler  
Stephanie Schlingensiepen  
Cathy Maylin  
Megan Cambridge  
Lizzie Dehler  
Stephanie Schlingensiepen  
Cathy Maylin  
Megan Cambridge  
Lizzie Dehler

Apologies/not present:  
Catherine McGowan  
Saby Apetroie  
Chloe Longmore  
Gilly Best  
Karen Haviland  
Alison Tye  
Gill Thompson  
Martin Powell  
Dallas Pounds  
Hannah Gill  
Phillipa Brookes  
Vedrana Ilic  
Rebecca Wellburn  
Alison Kirby  
Caroline Warren  
Susie MacAllister  
Camilla Barber  
Rachel Corry

1. Welcome, apologies and introductions

Introductions took place.

2. Minutes of the last meeting (30 April 2015)

The minutes of the last meeting were agreed as a correct record.

3. Matters arising not on the agenda

- PACT Social Work Service: The group was advised that Saby had now started in her new role as Community Adult Health Service (CAHS) Social Work Team Leader, based in the Access and Coordination Hub in Stormont. IT issues remain unresolved which are causing some difficulties! Social Workers within the team will take direct referrals from GPs for PACT patients, although referral criteria will be widened to include all patients via GPs. Other healthcare professionals (eg community nurses) can contact the new team with a patient referral, provided the patient has been discussed within the CAHS multi-disciplinary team meetings. There is a Social Worker and Social Work Office in each of the 4 localities. Secondments in to the new team are initially for a 12 month period with an evaluation of benefit taking place during the initial phase.
• Update on the Frailty Pathway work: SD updated the meeting on developments with the Frailty Pathway. A further multi-agency workshop had taken place on 18 May. Main points of note were:
  
  ▶ An alternative name for "frailty" was under consideration as it was recognized that this was not a term that all patients would be comfortable with nor did it necessarily reflect patient health;
  
  ▶ 2 interesting presentations had been made at the meeting. The first was on the role of the Facilitated and Supported Discharge service of the new Community Adult Health Service (CAHS), in terms of its team configuration, links with the CAHS Access & Coordination Hub, working within the acute sector and improving liaison with Social Care to arrange packages of care for patients going home. The second was the St George’s Frailty Model, comprising functions such as the front door assessment service and earlier access to intensive therapy, both aiming to reduce length of stay in hospital and to reduce readmissions;
  
  ▶ A Frailty Pathway algorithm/map was being developed. Several significant end of life care services had been added to complement the first draft, in particular the role of our new End of Life Care Coordination Centre;
  
  ▶ Discussions had taken place around the importance of coordinating the whole system, and being inclusive of dementia services, enhancing the equipment service and rapid response.

4. Patient and Public Involvement (PPI) Action Plan

A discussion took place about how the group might continue to make contact with some of the “hard to reach” groups to ensure that end of life care services were known about and able to respond to all those nearing the end of their life. Specific groups to follow-up were Homeless/Hostels (ACTION: Sue T to ask within the CCG about who leads on this area) and Wandsworth Prison (ACTION: Sue T to contact community services who remain the health service provider to identify a contact). In addition, a meeting was taking place with the Wandsworth Community Empowerment Network (Malik Gul and colleagues) at the end of June to discuss how they and the CRG might work together to improve knowledge about EOLC services across the wider community. Lizzie, Stephen, Cathy and Megan would be attending and would report back at the July meeting. In addition, Sue would contact Sally Hale (community services) to find out who might be the best person to invite to a future meeting to discuss end of life care for people with a Learning Disability (ACTION: Sue).

5. EOLC Coordination Centre (EoLCCC) and HCA service

Cathy Maylin updated the group on the EOLC Coordination Centre:

• The launch event had been successful and well received but so far had not resulted in any increase in referrals. Other ways of publicising the EoLCCC were discussed and A4 sized posters in GP surgeries were suggested and/or a letter to go out to GPs summarising the services carried out by the EoLCCC. (ACTION: Cathy/Megan to action, Marietta happy to support). A similar letter/poster for community services - to remind people – was also agreed (ACTION: Megan/Cathy to organize). The launch had been featured positively on Channel 4 News and Radio Wandsworth in relation to the publication of the Parliamentary Ombudsman’s report into complaints around end of life care;
• Gilly Best has taken up her new role as EOLC Community Nurse. This is great news and is to support the key links between the Coordination Centre and the community nursing service;
• Stephanie Schlingensiepen has been successful in her application for the Lead Nurse role within the Coordination Centre. Stephanie will take this up on a part-time basis (3 days per week) to enable her to continue in her current role for the remainder of the week. This arrangement and Stephanie’s knowledge will continue to benefit both the Coordination Centre and community services;
• Difficulties in accessing some items of equipment for EOLC patients at home, particularly hoists that involve assessments, had been highlighted since the launch of the Coordination Centre. Having a hoist at home involves a very complex procedure and there is a big psychological adjustment to be made by patients whose condition changes such that they require a hoist to move. Sue T is working with colleagues within the community services to resolve the current difficulties and to identify clear pathways for getting assessments undertaken as a matter of urgency when required for this group of patients;
• Cathy is working with Cara (Lead Nurse within St George’s Palliative Care Team) to meet/liaise with the Discharge Coordinators. These links are very important to support patients who wish to return home from
hospital to die;

- Referral data: Cathy reported that there were 20 referrals in April and 21 in May. These levels had not changed significantly since the formal launch of the Centre, hence the drive for further publicity;

- Issues had been identified with arranging assessments for hoists. There is no clear pathway for EOLC patients who are not considered for rehab (likely to be most) and who don’t have a neuro diagnosis. Sue is investigating options and will report back to the next meeting (ACTION: Sue);

- A further issue was raised by Rachel Sibson in relation to specialist equipment for continuing healthcare patients. Such equipment is very expensive but the current process requires that it is returned to the generic equipment store for all consortium users after use, rather than being kept for Wandsworth patients only. Wandsworth has paid for the equipment but neither the equipment nor investment is being retained for Wandsworth patients. A more cost-effective process needs to be in place that still enables access to specialist equipment for patients. (ACTION: Karen H to consider the possibility of hire arrangements for equipment that is not available as part of the standard contract. Sue/Karen to discuss with Mel Rogers, Head of Quality at the CCG);

- Cathy updated on progress with starting the HCA service for fast-track patients. 2 HCAs have started in post with others starting next week (which will enable them to provide a small amount of care) and a further 1.8 wte in July. Chloe confirmed that they all have contracts until the end of the pilot period. Recruitment to the HCA role has been extremely difficult and this will form part of the learning for the pilot and future commissioning. The slow start of this service will result in an underspend for 15/16. Discussions are taking place between the CCG and Trinity (as provider) as how best to utilise this underspend.

6. Frailty Pathway update

This was covered in Matters Arising (see point 3 above).

7. End of Life Care Dashboard

Sue talked the group through the latest Dashboard. A discussion took place about the potential for inaccuracy of the data, particularly around patients achieving their preferred place of death. Patients will often change their mind about where they wish to die and, unless the CMC record is updated with their most recent wishes, the achievement of their PPD may or may not be recorded accurately. Equally, patients do not always have a real choice about where they are cared for eg if they need to go to a nursing home or are discharged out of hospital and so recorded wishes may not necessarily to truly accurate. It is important, therefore, to hold the data “lightly”.

Gilly recounted a recent patient story where the community nursing team had been caring for an end of life care patient at home whose wish was to die at home. Unfortunately, a relative had called an ambulance right at the end of their life and they had been admitted to hospital and died there. The community team had been extremely upset that this had happened, inspite of their efforts to ensure that everyone knew the patient’s wishes and what to do if they needed support at home. Gilly was asked to pass on the CRG’s view that, inspite of everything being in place, such situations would arise. The important thing was to try to learn what else might have been possible, if anything, to avoid it happening in the future with another patient.

8. “What is a Good Death” documentation

The Pan London Clinical Network group has worked to define what a good death would look like. They had wanted to provide a vision statement to inform commissioners. Lizzie advised that she had been involved at an early stage of the discussions. Whilst helpful to some extent, the group felt that the document has greater focus on the services provided by the professionals, rather than answering the question from a patient’s perspective. There was also some concern about the suitability of some of the language.

9. CMC update

CMC have now begun the development of the new system with the new provider InterSystems. Work is underway that should begin to show some useful improvements by September this year, including some limited integration with EMIS by December.

10. Any Other Business
There was no other business.

11. **Dates of future meetings**

- 16 July 2015
- 3 September 2015
- 22 October 2015
- 3 December 2015