

## PPG Network Meeting Notes

Date: 16 May 2018

6pm – 8pm

336 Brixton Road, SW9 7AA



### Present:

PPG representatives from Brixton Hill, Clapham Family, Clapham Park, Corner Surgery, Dr Masterton & Partners, Edith Cavell, Grantham, Herne Hill Group, Hetherington Group, Hetherington at Pavilion, Hurley Clinic, Minet Green, Paxton Green, Springfield, Streatham Hill, Streatham Place, The Vale, Valley Road, Vassall

### Guests:

Verena Hewat, Compassion in Dying

### Apologies:

Beckett House, Exchange, Herne Hill Road, Knights Hill, Riverside, Stockwell

Meeting commenced at 6.05pm, opened by Sharon Hudswell

#### 1. Welcome & Network Update

Sharon Hudswell welcomed attendees. Two new members were attending for the first time from Hetherington at the Pavilion and Brixton Hill practices. Cheryl Alfred gave the Network's update:

- Confirmation of the appointment of Patricia Ross as Treasurer to the Network's board
- Data protection training for PPGs mentioned at the March meeting has been delayed. The network is in communication with the Information Governance Team at the CCG to finalise the spec. Members will be notified once a date has been agreed.  
Cheryl also mentioned that members would shortly be receiving communication to give consent to continue to remain on the Network's mailing list to receive information. She encouraged all members to respond to the communication, so that they could continue to be kept informed, as without consent the Network could not retain their contact information.
- The Network's board had an away day in early May to plan and prioritise for year ahead. A number of project groups will be set up to do time limited discrete pieces of work, like reviewing the PPG Toolkit, looking at how we communicate with members. Once the groups are confirmed members will be asked to join them.
- Future network meeting dates are given on tonight's agenda. The Network was invited to address Kings College Hospitals Patient experience committee. The committee are keen to get patient feedback on their experiences of using services Kings run in the community. They will be coming to the July meeting to talk about their services and to get feedback from patients.

2. **Starting the Conversation – Advanced Care Planning**

Guest speaker Verena Hewat, Community Outreach & Training Officer from Compassion in Dying (CiD) joins the meeting. Click [here](#) for presentation.

Compassion in Dying is a national charity which helps people prepare for end of life; how to talk about it, plan for it, and record their wishes.

They can support you to plan for your treatment and care, in case a time comes when you can't make decisions. This helps you get the support that's right for you, when you need it. When what matters most to you is known and recorded, it makes it easier for your family, friends and healthcare professionals to follow your wishes, giving everyone peace of mind.

Help can be provided through their free information line, publications and resources, and their work with diverse communities. They specialise in supporting people to make Advance Decisions ('Living Wills') and to talk about their goals and priorities when living with a life-changing illness. Their free *MyDecisions* website helps people to record their wishes for care in a legally binding way. They are keen to raise awareness about planning ahead and are currently focusing their support in Lambeth.

Advanced care planning is about making informed decisions and there is a lot of free support and advice available. There are three tools to help when thinking about planning ahead:

**1. Advance Decision to Refuse Treatment (ADRT)** is a legal document where individuals outline the treatment they do not want to receive in the future if they lose the capacity to make decisions or communicate their needs. There is no national database, however some people have them included in their medical records.

**Question:** Are photocopies of these documents accepted?

**Response:** Yes, copies are accepted, as long as it is clear where the original is kept

**Question:** Does this replace living wills?

**Response:** The big difference is that living wills have no legal meaning, so it is suggested that you update your living will to an ADRT. It is good practice to update and review your ADRT regularly (i.e. every couple of years, or if your health situation changes).

Compassion in Dying has good guidance on how to prepare an Advance Decision.

**2. Advance Statement** (*free*)

An Advance Statement allows you to write down your wishes, feelings, beliefs and values, in case you later become unwell and need care or medical treatment. For example, you can include your food preferences, religious or spiritual beliefs, your daily routine and where you would like to be cared for.

**Lasting Power of Attorney for Health (LPAH)** came into being in 2007. It is where individuals nominate someone to act on their behalf if they lose capacity. It is a myth that family members have the right to make decision about treatment in the absence of a lasting power of attorney. The healthcare professional will make

the decision they believe is in the best interest of the patient. You do not need a solicitor to prepare a LPAH. It currently costs £82 to register the LPAH with the solicitor to make one. It costs nothing if you are on some means tested benefits, so can be free to prepare and register. You can also complete them online through The Office of The Public Guardian.

**Do Not Attempt Resuscitation (DNAR)** is an advisory document, so not legal and is clinician led. When preparing one it should always be done in conversation with the patient.

**Why is it important to have the conversation?** It enables the support and the care given to be person centred, gives individuals choice and peace of mind and to avoid unnecessary expense.

Compassion in Dying wants to encourage engagement in a number of ways and use a variety of tools and visual aids to help with having these conversations. Want to raise awareness and promote the choices that are available in practices with the support of PPGs.

**Barriers to starting the conversation** – Family and friends assume or misunderstand what loved ones want; perceived expense; assumption that you need to use lawyers to prepare the documents. Healthcare professionals sometimes do not have a thorough understanding of the three Advance Care Planning tools. CiD has a toolkit and other resources that can help.

**Question:** What work is CiD doing in Lambeth?

**Response:** We are part of an Advance Care Planning consortium in Lambeth where we are planning a number of activities including having an Advance Care Planning Tent at the Lambeth Country Show; we have worked on developing bi-lingual literature to support the Portuguese community and are keen to imbed advanced care planning in practices. There is a need for awareness-raising amongst patients and GPs so they can sign-posted to the services on offer.

**Question:** What are the consortium's plans and are GPs aware of these plans?

**Response:** This week is Dying Matters week and a range of activities, events and talks have been taking place. We want to reach out to practices and PPGs might help with this.

**How can PPGs help raise awareness?**

Put posters/leaflets/post cards on PPG notice boards, invite CiD to give a talk to patients and practices, encourage patients to access the free services on offer via the helpline. Suggest showing the [promotional video](#) or information stills on practice TV screens. Promote the information line number for free advice (0800 999 2434)

**Suggestions:**

- Practices could include a link on their website to the CiD site
- Communicate directly with the Local Medical Council as they have links with GPs
- Have conversations with the GP Federations
- All Party Parliamentary Group is a good platform for raising awareness

- Talk with Royal College of GPs
- Involve pharmacists in the discussions

CiD offer accredited training for clinicians

**Question:** There are similar organisations, like Dying Matters offering the same services as CiD. Do you work together?

**Response:** Dying Matters focus on helping people talk more openly about death, dying and bereavement. CiD is the lead organisation for Advance Decisions to Refuse Treatment in the UK and specialise in Advance Care Planning.

The meeting was shown a promotional video from CiD on advanced care planning. Members suggested that it should include subtitles, so that is more widely accessible and could be shown in practices (with the volume down). Some of CiD's literature is available in English, Spanish, and Portuguese and in some south Asian languages.

Verena encouraged those present to contact CiD if they have any ideas around how to raise awareness of Advance Care Planning in practices, if they have any general questions around Advance Care Planning or if they wanted free resources to be sent to practices/PPGs. Call the free information line: 0800 999 2434.

Break

### 3. **PPG Awareness Week (04 – 10 June) & Open Discussion**

This is a national awareness week campaign and is an opportunity for patients to get involved with their PPG, for PPGs to raise awareness and showcase their work and to engage directly with potential new members.

#### **Open discussion**

**Comment:** Getting new members at Streatham Place is difficult. The practice is not engaging with the PPG. We now meet without any practice presence, as they have decided they will attend once every six months. Our meetings times have been reduced from one hour to half an hour because we get no support or acknowledgement from the practice.

**Response:** The Network will work with the PPG to meet with the GPs at that practice to find a way forward.

**Comment:** We want to have more opportunity to network and share with other PPGs and ask for at least one of these network-wide meetings to be given over for just that, so there is sharing across boundaries.

**Response:** We have plans in place for the July meeting, but will consider the request for the September meeting.

**Comment:** Brixton Hill PPG has not functioned for a long time. We are using PPG Awareness week to re-launch the group and raise awareness. We want to know how we can promote the event to practice patients.

**Response:** The practice can use the SMS text messaging service to invite patients, the event can be promoted on the practice website and in local pharmacies.

**Suggestion:** Within the toolkit there are resources and tips on hosting events and working with the practice. Produce posters and flyers to help promote events and meetings.

**Comment:** A recent incentive scheme awarded the practice £2,000 but the PPG can't get any of it. If we want to produce posters or leaflets can the network fund the cost?

**Response:** The Network has no budget to support these costs, but is looking at applying for external funds so will look at ensuring these requests are taken into account. We would encourage PPGs to host an event during PPG Awareness week rather than a meeting, as it is more likely to generate interest and grow momentum.

**Comments:** We want to build PPGs credibility, so whilst there is a week dedicated to raising awareness it should be something we do all the time.

**Suggestion:** Having an open meeting, informal "meet and greet" session or health talk can be considered.

**Comment:** we need patients who are committed and enthusiastic to support the PPG.

**Comment:** Stop using so many acronyms. Keep messages and language simple, otherwise people will be turned off.

**Comment:** Springfield PPG is holding an open event focussing on mental health, which is a follow up from an event held on stress management when over 100 patients attended.

**Comment:** partnership working is vital

**Comments:** This is my first meeting and it is interesting hearing about what PPGs are doing and achieving. It is inspiring and I can go back to my practice and have the conversation about developing a group and looking at what we can do.

**Question:** What resources to PPGs need to help you do the work you are doing locally? Let us know what you do during PPG Awareness week so it can be promoted on the website and in the newsletter.

Meeting closed at 7.55pm