

## **People's Board Notes**

**15 November 2018, Hillside Bridge**

### **Persons present:**

*Sam Samociuk (Chair), Abdul Ismail, Stella Hall, Karol Wysznski, Rosema Nawaz, Claire Weaver, Mike Frazer, Mohammed Mahboob*

**In attendance:** *Saeed Khan, Max McLean, Dr Fenwick, Polly Masson and Victoria Simmons*

### **Apologies:**

Emma Stafford, Huma Malik, Adam Deacon

### **Welcome**

Sam Samociuk (ES) welcomed the group and introductions were made.

### **Conflict of Interest**

No one declared any conflicts of interest.

### **Minutes from Previous meeting and action log:**

All agreed with minutes from the previous meeting.

Claire mentioned she would like to get involved in any carers work that was referred in the meeting.

It was suggested that the PMCS be taken to the PN for feedback.

### **Attendance at other meetings:**

Victoria informed the group that if any members wish to get involved in any other piece of work outside the People's Board, it should be discussed at the People's Board and agreed.

### **End of Life Care:**

Polly talked about End of Life Care and said she wanted to engage with local people regarding the End of Life Care strategy.

Polly asked how we can engage local people to inform the strategy.

Polly talked about the National Guidance, but is this right for our local population.

Dr Fenwick said that if you look at the National Guidance we are doing quite well. But when you look at it deeper at local level you will see that AWC CCG is doing really well whereas, City CCG is doing not so well. So when you average it out we look quite good.

Polly explained to the group that she has four questions she would like to work on with them, the questions are:

1. Your thoughts / experiences of end of life care – when talking to your communities
2. How do create an environment where people would be comfortable discussing end of life care?
3. What approaches / tools would be most effective in gathering this sort of feedback?

4. What would be the best way to split the wider population in smaller groups to enable focussed conversation to ensure various voices are heard?

Mike said, he has personal experience of AWC involving Marie Curie and Airedale Hospital, the care was excellent, he felt if it was BRI it wouldn't have been so good.

Abdul - the number of people the different areas serve could make a difference. Also culturally it is quite difficult to approach this topic. You have to think about the right time and right person to initiate the topic.

Claire said in the current set up where you don't really have a family doctor where you can build up a relationship it's quite difficult to discuss such sensitive issues.

Mike said he feels it's unfair to expect the main carer to have this discussion with the terminally ill person – its best if a specialist can have this conversation with the patient.

Abdul - some communities lack confidence to engage with organisations.

Rosema – Agrees that it would be best to have a specialist organisation to deal with this. But felt for someone like her grandparents and their generation it would be best for one of their carers to have this discussion to help the patient understand.

Sam – felt that generally older people do talk about their death.

Claire – talked about personal experience – she gave example of her father – who has terminal cancer and has survived 7yrs with it. But he would not talk about his death even when his wife would ask him he would get very upset. Everyone is different so any future policy would need to be very flexible.

Mike – All carers should be offered this specialist service and it should be up to them to take it or not – the offer should be there.

Stella – the offer needs to be made not imposed.

Sam – what is the baseline offer of the service? How would people know about it?

Polly asked so how do we approach this?

Sam – Wilsden PPG ran an end of life course – this helped people think about it.

Abdul – Tag this topic onto something else – piggyback on an existing health event – also work with the Chaplaincy service.

Mahboob – agreed with Abdul's idea of tagging onto other topics

Claire – Benefit in explaining to people what is end of life care – people think it is only for people who are terminally ill – quality of care is important throughout life.

Sam- suggested that Polly speaks to Community Centre leads – Community Centres know their communities.

Polly talked about the different End of Life Care:

- Out of the blue
- Frailty – elderly
- Long term illness
  - Frailty and long term illness – these two groups will be the most difficult to speak to.

Polly asked how can we target groups/segments of the population –  
Mike suggested Community Centres would be the best place to start

Karol – it would be best to speak to people currently on the End of Life pathways – and ask them where they heard about this service.

The group also came up with the following ideas:

- Specialist organisations would be good to get involved – leaflets can be given to the main carer to make them aware that this service is available
- Maybe look outside the NHS for ideas
- Also look into different communities and cultures and how they see death
- Look at faith centres/leaders and use to disseminate information to people.

### **Role of the People's Board members**

Emma was meant to lead on this - so Sam suggested that if any members have any questions send them in and we can discuss this as a proper agenda item next time.

The group put forward some questions:

- When are we representing the People's Board?
- How are we influence policy and strategy?
- Do we have annual report of impact?
- How do people outside know what we are doing?
- What is our future plan/expectations?

Karol said he would like to see a proper structure for his role showing which meetings he should/can attend as a People's Board member etc.

### **Future Meetings schedule:**

The most popular options was to stay with the Thursday afternoon slot, as everyone said they could make Thursday afternoons.

Victoria – Once Jean is back she will book 2019 meetings in advance – venues will be rotated.

### **Blog Post & Social Media:**

Sam asked if someone would volunteer to write some thoughts of today's meeting?  
Mike volunteered to write this.

**A.O.B:**

Victoria briefly talked about Talk Cancer Workshops and asked if anyone would be interested.

Rosema - promoted/talked about the Women of the World event this weekend – a load of different activities, singers, speaker and workshops will be there.

**Actions:**

- Sam to email Poly to ask her what she got out of this meeting and what the next steps are
- Mike to write the blog
- Jean to book 2019 meetings – in advance
- New members to be added to the People's Board WhatsApp group