

**Patient Participation Group
Central Chair's Welcome & Questions
13th December 2012**

The Meeting was introduced by Dr Greg Battle and Dr Sue Blake

1. Welcome from Central Chair – Dr Greg Battle

Dr Greg Battle introduced himself as Chair of Central Locality of 4 years' standing and welcomed everyone to the meeting. In response to a patient request, time allocated on the agenda for item 3, "Developing the Patient Groups" was extended.

2. Developing the Patient Groups – Dr Greg Battle

Feedback from patient meetings at locality and practice level indicates that patients would like to retain locality groups (smaller, more intimate) as well as the larger Islington-wide meetings. Proposal is two Islington meetings per year and two Locality meetings per year – with suggestion that some meetings could be held in less formal settings.

A patient called for elected representatives to run the agenda and meetings, as well as patient representation on the CCG Board. He expressed his view that CCGs are there to carry out the Government vision, the NHS is in real danger and the democratic involvement of patients is needed in order to monitor the CCG.

Dr Katie Coleman spoke about the lay representatives on the Board and their function; patient meetings are a voice that feeds in to the Board. A patient who attended the last Board meeting reported that the patient groups were not referenced. A discussion followed in regards to the best way to structure the patient groups. Although, the new structure was devised out of patient feedback, there were patient members present who were keen to also see an elected patient reference group.

Sorrell Brookes (CCG Lay Representative) informed the meeting that she is an Islington resident, patient and user of services, and is committed to a non-privatised NHS and to getting voices heard. She is committed to using language everyone can understand – no acronyms, and to hearing the voices of the community.

A patient requested information on when and where Board meetings are held – he held the view that meetings were too secretive; patients need to witness meetings and be party to decisions. Dr Katie Coleman feedback that the Board meetings were actually publicised through adverts in the local press and on the website.

Dr Batte recapped that patient groups did not have 'democratic' elections to decide their own patient representatives, and appealed for ways to translate the energy of the meeting into positive outcomes.

Action:

Please see attached response re: the setting up of a patient reference group which has some kind of electoral system to determine membership.

The meeting continued with presentations and questions on:

Integrated Care Programme

It was explained that the Integrated Care Programme is a local programme which aims to help health and social care services work together.

- A cost analysis was requested.
- A LTC patient commented it was important care was not fragmented.
- Sharing information and basic patient education was seen as important.
- It was also highlighted that preventative work must not be forgotten.

There was groups discussion about several areas of the new Integrated Care programme.

The discussions focused on particular topics.

Sharing of patient records between health and social care professionals:

- Information sharing is a good idea and should be given a chance
- Advantage of not having to repeat info again Sharing information is a good way to try and minimise abuse of the system
- System for all clinicians involved to be able to change the info held
- This is already used by social workers

- Get GPs, consultants, hospitals to share info and communicate first
- Integrate medical side first
- Integrated care musn't dilute healthcare

- Concerns of the information being shared with private (health / social) companies
- They like the idea of sharing with social care but must be clear what it is for

- 'I would like to address my records via an online link.'
- 'I would like to see all GP records about me.'

- Info sharing must have explicit patient consent
- Would want to look at who would receive it and why
- Confidentiality should be maintained

- Online or other access to records for patients
- System for patients to approve the info that is being shared?
- Patients to be able to say which agency they want or don't want to share with
- Confusion about what exactly they are being asked to consent to
- Who is responsible for updating the info e.g. medication changes updated
- What standards of confidentiality operate across the services?
- Patients are worried about where / what their electronic records are – 'in a cloud'

Care plans:

There was some positive feedback on care plans. These were:

- Agree with principle of care plan but some real key concerns
- How long does it take to get care plans into action
- Medicines – no clear instructions
- Cut time and costs

- Understand need for integration for people leaving hospital
- Don't reinvent the wheel – look at hospital care plans
- Crucial is partnership and there has to be agreement and commitment for each partner to carry through

However, there were some key concerns which came out of the discussion. These focused around how ready a patient would feel to take on the idea of care planning. The points were:

- Patient may be blamed when things go wrong. Care plans feel intimidating. Scared about patient responsibility
- Worried about costs
- It won't be for everyone – some people who have the most complex needs can't come or participate in these meetings
- People a bit scared of 'expert' patient programme
- People need not to *have* to be an expert patient
- Care plan – don't like you're created care plan
- Need to be very sensitive about how care planning is presented.
- Some people who are most in need don't attend the surgery and won't be able to use the plans.
- What happens to patients who don't go to their GP surgery
- Patient advocates at all surgeries to help explain systematic things to patients e.g. helping to understand care planning.
- Patients need to know who is going to assist them in their care
- Could be confusing need to remember one size does not fit all.

Some interesting areas came out of the discussion of care plans which looked at how health services could support the wellbeing of the person.

- This was summed up by this point: GP practice as a community hub so drop off point for food, clothes etc. engaging people in the actual practice.

Other points raised were:

- People are suffering with hardship
- Outreach to people
Especially those who don't have a neighbour
- How will community cope in supporting people?

Other concerns which came out of the discussion were:

- Still a lot of people without internet so info needs to be provided in paper form as well
- Barriers to accessing GP services – language barriers at receptionist/PM to have interpreters.
- Visual: video screen at surgery, picture images stand out, posters, easy read leaflets
- Word of mouth – people's experience

Commissioning Intentions

Given Whittington Health is an integrated care organisation are the tariffs for the community setting the same as those for the acute setting?

Acute – (hospital based) is a national tariff whereas community is local tariff.

Dementia care:

How do they work out patient population? Can feel like GPs don't want to diagnose patients with dementia.

- Islington works with public health to identify the expected level of dementia patients (taking into account those not diagnosed or late diagnosed).

Measures to deal with rising dementia population?

- Memory clinics
- Dementia advisors in community
- Increasing community geriatrician support.
- Additional resources in community should help to delay late diagnosis and early onset.

Other points made in regards to this topic were:

- LINk have considered looking at domiciliary care and will be on agenda in HealthWatch.
- Will any choice be offered to patients? Yes there will be choice – community service will just be an additional option.

A&E department's 4 hour deadline is not going up.

Certainly looking to support people to manage in their own homes.

Single Point of Access

Physios it can be felt do not give people enough help. Just a piece of paper with instructions is not enough.

As part of this process they are looking at services to consider if they are effective.

The professional who is to be the assessor? Who will that be – and how will that work, will they have enough skills to assess both health and social care? This is currently being worked through – and they are not quite sure. So this would be a multi skilled assessor but they would clearly have a specialism.

Highlighted by several members that the medical staff are working hard under pressure to deliver services to meet the local community's needs.