

University College London Hospitals NHS Foundation Trust Listening Event April 2017

Introduction

On Thursday 12th April 2017, the Trust held a Listening Event from 5:30pm until 7:30pm. The focus of the event was to explore and work to improve the ways in which UCLH engages with and involves patients and the public, through understanding what matters most when it comes to being involved with NHS services.

The event was hosted by University College London Hospitals (Healthcare provider) and included a representative from University College London (Education) regarding involvement in healthcare research.

Chief Nurse, Flo Panel-Coates, introduced the event and it was facilitated by Fiona McKenzie (Independent Patient and Public Involvement expert). Thirty-eight patients and members attended the Listening Event. The event started by asking attendees to outline the topics that mattered most to them. Four staff members present then gave brief presentations on current opportunities for involvement. For the remainder of the session, nominated staff facilitated table discussions on how attendees would like to be involved with the hospital and how we can support this. The agenda for the evening can be found in Appendix 1.

‘What involvement opportunities are already available?’

UCLH talked; patients and members listened

Four staff members gave brief presentations on opportunities for involvement, representing volunteering, research, membership and service improvement. Key points are outlined here, along with contact details:

Volunteering

Volunteering roles fall into three categories:

- Ward based volunteering: interacting with patients, facilitating activities, helping with shopping and meal times
- Welcome teams: greeting people as they arrive at the hospital, helping with way-finding and supporting more vulnerable visitors
- Information and support: giving information about our services and helping behind the scenes, and providing emotional support for patients

All volunteers go through an application process and have CRB checks.

volunteering@uclh.nhs.uk or 020 3447 9828

Research

Patient members can join the lay panels of the Biomedical Research Centre to provide valuable insights into:

- How specific research studies should be designed and delivered
- Which research questions to prioritise
- Suitability of outcome measures
- Plain English summaries
- How and where to present research findings to a patient and public audience

erin.walker@ucl.ac.uk or 0203 108 2418

Membership

Opportunities to get involved through the UCLH membership include:

- MembersMeets: seminars on services provided by the Trust
- Patient Led Assessments of the Care Environment (PLACE Inspections)
- Becoming a Governor
- Web chats: ask an expert questions on a specific health topic
- Joining the Membership Development and Strategy Steering Group

foundation.trust@uclh.nhs.uk or 020 3447 9290

Service improvement

Opportunities to be involved in the design of services include:

- Committee meetings
- Service improvement planning and work
- Improving accessibility
- Involvement in the new Electronic Health Records System
- The design of new facilities
- Experience of carers

ppi@uclh.nhs.uk or 020 3447 2672

‘What matters to you?’

Patients and members talked; UCLH listened

A number of topics that are important to patients and the public were identified, through post-it comments and table-group discussions. The main themes that emerged are presented below; the full list of post-it comments can be found in Appendix 2. A number of issues were raised about the NHS in general, specifically concerns regarding the lack of funding and the impact of this on how services are run. These issues are beyond the scope of this work and are not discussed further here:

Staff attitude

Several comments reflected the importance of staff being cheerful and helpful, and the concern when this is not the case. Some attendees reported experiencing or witnessing a dismissive and patronising attitude towards older patients, and felt there is sometimes a lack of respect shown by some healthcare professionals.

Communication

The need for better communication between the hospital and its patients was a prominent theme. Hospital letters can be outdated and difficult to understand, with inaccuracies and jargon words. There can be a delay in receiving information and results; poor communication between healthcare professionals and clinical departments; and frustration over the telephone system.

Acting on feedback

Attendees would like their feedback acknowledged and acted upon for service improvement, and for involvement opportunities to be communicated in a way that is accessible to all. Providing a platform for two-way conversations and exchange of feedback to occur, and giving an explanation when action cannot or has not yet been taken following feedback were of great importance.

Care

Attendees felt it important that patients be involved in decisions made about their own treatment plan from the start, with better awareness from clinical staff of the patient's location (i.e. at home, in respite) when planning appointments. There was a call for more consistent advice to be given on discharge from the hospital, with information on services available to help patients in their recovery. Other comments were about a need for improved care for patients with dementia and cancer, and the importance of being seen on time by a doctor who is familiar with the patient and their case. Better training for staff on less common conditions was also cited.

Information about services

A number of comments revealed a need for more accessible information on the different services UCLH provides and how to use them, to help manage demand and encourage the use of the right services at the right time, for example the Accident and Emergency department. Making a range of services available that support the care pathway, and increasing staff awareness of such services was suggested. The services mentioned were advocates, care navigators, interpreting services, blue parking badges for free

parking and the option of using an online web-chat that is not limited to the English language only. Understanding the Complaints service was also important to several attendees.

‘What other involvement opportunities could we offer?’

Patients and members talked; UCLH listened

The third part of the Event centred on table-facilitated discussions about other ways to be involved with UCLH. Ideas were presented and key themes generated about how UCLH can incorporate what matters most to patients and the public in the involvement opportunities we offer, and support individuals in their involvement. Some other issues unrelated to involvement were raised, such as improving access to patient records for clinicians, the waiting experience and keeping notice boards updated. There is work on-going throughout the Trust in these areas, which we will communicate more clearly via the Members’ newsletter and website.

Events

Listening events and open days on specific topics were thought to be a good idea, specifically frequent events for small groups with a focused area of interest, to share information and raise awareness. Health seminars and forums that offer an opportunity for patients to speak with healthcare professionals and share their experiences and views were discussed.

Auditing

A number of attendees liked the idea of having secret shoppers and inspections as a different approach to involvement, and contributing to the setting and measuring of targets across the Trust. The suggestion of being able to independently review processes remotely, for example reviewing the complaint process via an online forum, was made.

Providing a patient perspective

The idea of a patient-staff collaboration was prominent, with the endorsement of having patients on interview panels to influence recruitment, and the need to utilise ‘experts by experience’ in clinical training to provide staff with a patient perspective. Opportunities to volunteer as a peer supporter were mentioned. Some attendees would like the chance to influence strategic development and be involved in talks about planning and design for the two new buildings (Phase 4 and Phase 5), along with more opportunities for involvement with research projects.

Support needed

Attendees were asked what support, resources and preparation would be needed to facilitate their involvement. Suggestions included:

- Training for volunteers to develop skills and help them to feel better informed and equipped to take part in involvement activities
- Attracting a wider age demographic as volunteers, with a diverse range of skills to offer
- Having a single point of contact for involvement opportunities and possibilities
- Being flexible in terms of time commitments for involvement and offering options, e.g. holding the same event more than once at different times and locations to accommodate as many potential attendees as possible
- Adding visual representations and alternative language options to the UCLH website to ensure that information and opportunities are accessible to all
- Using an online calendar to sign up to involvement events, but also providing alternative means of communicating as not everybody has or can use a computer to complete online forms
- Transparency from staff around discussions, decisions, accountability and conflicts of interest
- Offering payment for the services of 'experts by experience' – although others felt that payment is not needed as individuals choose to volunteer their time and expertise. It was agreed this is down to the individual but the Trust should review its approach to expenses and reward for involvement.

Summary and next steps

Patients and members talked; UCLH responded

The Listening Event allowed the Trust to collect a large amount of positive and constructive feedback. Comments varied between topics and tables; however there were common themes raised and an over-arching theme of communication which ran throughout each discussion.

Actions we are taking

Closing the feedback loop

- The Trust will share the feedback collected with all attendees to inform of what was said and what the Trust is now doing with this information. A copy of this report will be made available to all who attended; it will also be displayed on the UCLH website and included in the members' newsletter

- The feedback will be used to inform the 2017-2018 Patient and Public Involvement Strategy and Membership Development Strategy
- Feedback collected more generally across the Trust is being acted upon; teams are being encouraged to use the 'You said, we did' boards more frequently, and actions taken based on feedback received will be communicated via the Members' newsletter
- Ensure that people who do not use computers are also able to access the feedback.

Prioritising actions based on feedback

- All support, resource and preparation needs listed above will be considered and addressed
- There will be a specific focus on training for patients and the public who would like to be involved. While there is currently a trust-wide induction package for formal volunteers, we will develop a structured training programme for informal volunteers that informs on what it is like to work with us, as well as providing the support required
- We will increase opportunities for involvement as above, and will review the payment of expenses and reward and recognition given.

Holding further listening events

- As previously mentioned, this was the first in a series of events; following events will be arranged on specific topics raised by attendees
- Our aim is to hold an event every six months, therefore the next event will be held in autumn 2017
- The topic for discussion is to be confirmed, and will be discussed at our Improving Experience Group meeting in June.

Appendix 1

Event agenda

- 1) Chief Nurse Flo Panel-Coates opened the event and introduced herself and the event facilitator, Fiona McKenzie (Independent PPI expert). Fiona introduced the staff representatives and table facilitators, and gave an overview of the structure of the event.
- 2) Attendees were asked 'what matters to you', and were invited to discuss, by means of table-group conversations and noting comments on post-its, topics related to involvement. Issues, challenges and experiences could be brought to the attention of UCLH and shared with the room.
- 3) Four staff members gave brief talks on opportunities for involvement with UCLH, representing volunteering, research, membership, and service improvement.
- 4) Through table-facilitated discussions, attendees were asked how they would like to be involved and what support they need to be so (see Appendix 1 for questions and prompts). Attendees were given a hand-out of the Spectrum of Involvement (Appendix 2) to aid the discussion.
- 5) Each table had the opportunity to feedback on points they wanted to reinforce or share more widely. This was followed by a summary of the evening's aims, discussions and next steps, and a group review of the event itself.

Appendix 2

Feedback from the post it exercise – ‘What matters to you?’

Services

- What the services are
- Not sure how to use the UCLH services
- Misuse of A&E
- Improve cancer patient care and survival rates
- Management of demand for services

Equality and diversity

- Governor opportunities for d/Deaf / Disabled
- Where ethnicity is required, I would like the categories to be in alphabetical order

Waiting times

- Not to wait too long
- OPD – Clinic waiting times
- Not to wait long
- To be seen by the Doctor on time
- I am a patient with a learning disability so it is very important to be seen on time
- I need to be seen on time always

Training

- Doctors and hospitals don't know about patients with Williams syndrome

Facilities / processes

- Advocate navigators
- Interpreting services
- Booking (interpreter) knowledge (staff)
- Car parking blue badge free
- Complaint process
- Complaints process pathway
- Technology
- Web chat online barriers for those? BSL / English limitation

Care

- Mental health in practice based services i.e. GPs
- Discharge advice, next steps
- Inconsistent advice / prognosis

- People with learning disabilities want to be part of the decision making from the staff
- Care of those with dementia
- Self-help – what is made available to help and inform themselves on treatment and process
- I want to be seen on time by the doctor that knows me best
- Improve cancer patient care and survival rates
- Patient choice and o.a.l. – awareness of patient location (i.e. their home), in designing treatment plans and appointments

Staff attitude

- Nice staff
- Staff to be happy
- A dismissive attitude to older people sometimes patronising and the suggestion that older people are clogging up the system. Remember we paid our dues, we invested in this service – it's called national insurance
- Frustration of telephone system and rude staff
- Doctors don't listen to or respect patients knowledge of their own bodies
- Nurses don't listen either (I have been given drugs I've already said I'm allergic to – 4 separate times)

Communication

- Getting feedback on our feedback
- Letters of communication after your consultation
- Appointment letters all the same
- Not respecting families when written information is needed within certain timeframes
- Not listening regarding our knowledge within the department
- My experience is that one clinical department doesn't talk to another i.e. cancer and infection
- Jargon words
- Communication between professionals
- Correspondence to patients needs updating
- I want letters and information in easy read
- No jargon words
- I want letters in easy read
- Language line
- Letters or results a) gone missing or b) great delay why letter writers out of London?
- Keep patient informed about their results as well as their GP records

Comments about the wider NHS and personal experience have been excluded from this report.

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www.uclh.nhs.uk/PandV/Getinvolved



We are committed to
delivering top-quality patient
care, excellent education
and world class research

Safety
Kindness
Teamwork
Improving