Listening to and learning from the patient voice
September 2013

Thank you to all those that were able to participate in this event held at the NMC, Portland Place, on Tuesday 10th September.

The presentation slides from the speakers will be shared with all that attended.

**Simon Gillespie**, CEO BHF chaired the morning. He urged us to be brave and challenge ourselves as to how much we actually listen to our patients and are we truly going to change our services after their feedback.

**Craig Turton**, Health Service Ombudsman’s office, shared some insights into how ombudsman complaints could have been avoided by doing the basics right in the first instance and by taking on-board the complaint’s views. His story of the complaint relating to an elderly lady not being able to reach her water glass was sobering. It’s the little things that matter and can cause the biggest upset if we get them wrong.

**Dr Marc Bush’s**, Healthwatch, presentation walked us through some of the challenges faced by complainants, not least of all the human and society factors which challenge our ability to complain. It was interesting to reflect on the human values map in regards of how the various generations sit with being comfortable and able to complain.

**Jan Gould**, patient, Asthma UK volunteer and advisor to the Berwick review, reminded us all to utilise the time of our patient representatives wisely. She spoke of giving her time freely but wanting to see a return on that time investment. Tokenism does not bring about change, listening and engagement will.

**Panel discussion**

Craig Turton, Dr Marc Bush, Jan Gould, Clare Padley (NMC), Anna Rowland (GMC), and David McNally (NHS England) answered a variety of questions from the floor. These ranged from views of a single complaints system / hub for England to concerns that friends and family tests may not bring the results we would want to see in terms of change in behaviours and culture. Generation differences and their use of social media also featured in the Q&A. Differences in regional responses to complaints was also an item for discussion.

Participants were then split into groups. In these groups they debated and collectively developed a view on six questions;

- How to encourage getting feedback, sharing feedback, and using feedback?
- What does good patient involvement look like? What are the challenges to meaningful patient involvement? And how can we take a more coordinated approach to patient involvement?

The key themes are summarised below

**Getting Feedback**

- Culture and leadership – organisations and staff need to be open to feedback, they need to act on it and promote feedback
• Training and development of staff – communication, confidence to seek feedback, and the ability to use compliments, complaints and complainants to train staff
• Systems and processes – non blame, escalation of concerns easy to navigate for staff and users, responsibility to listen to concerns raised and act on them, transparent - feedback sought and complaint processes well publicised for users

Sharing Feedback
• Systems (micro) – develop internal systems of sharing feedback across departments through newsletters, webcasts, meetings
• Systems (macro) - external systems of sharing with partners and learning from their feedback is important as patients normally utilise more than one system / organisation and expect them to share learning. The process of sharing information should be agreed and be transparent to all
• Communications – if a patient does complain they should have clear lines of communication within the organisation and one person to link in with. Equally the organisation should have clear communication lines between staff to receive complaints / feedback and act on it
• Training – again training staff to use the systems and be open to feedback is vital to support feedback / complaint learning

Using Feedback
• Share feedback – at all levels within the organisation / service, feedback should be known and reflected on. It takes a lot of effort for a complaint to be made and investigated, listening to feedback and collectively changing our responses / actions needs to be faster and more effective. Departments should publish lessons learnt from feedback so others can review and change practice / systems if needed.
• Communication – feeding back to complainants of lessons learnt / changes made, is important. Asking complainants to attend team meetings is one way of closing the loop and making sure staff hear the patient voice.
• Think like a patient – seek patient views in service changes before they are made. Review the themes of complaints / feedback with a patient group to seek direction / support in embedding a new culture. Use “live” complaints in training so staff relate to actual people and events.
• Measurement – make sure reporting on complaints reflects lessons learnt, effectiveness of changes, and improvements not just how many and what themes!

What does good patient involvement look like?
• Patients working with staff to develop services
• Patient representatives training staff in communication
• Themes from complaints used to develop service improvement
• Patient representatives access to Board to share concerns / ideas

What are the challenges to meaningful patient involvement?
• Time
• Ability for staff to listen / hear challenges or feedback
• No action on previous feedback, patients feeling “what’s the point”
• Lack of joined up processes between agencies. Difficult to navigate for patients and staff

**How can we take a more coordinated approach to patient involvement?**

• Utilise existing patient groups rather than set up your own
• Share ideas for changes at an early stage to receive feedback on developments before they cause issues / concerns
• One single complaints hub shared across all e.g. a centralised portal for patients to feed in concerns
• One point of contact for complainants regardless of organisational boundaries
• Share openly what patients are saying about our services. Use websites, twitter, newsletters

**Examples of good practice:**

• Regulators are jointly developing an online consumer panel – for all regulators to access
• Stroke Association - hold feedback events
• Nottinghamshire Healthcare Trust - patient panel members sit on recruitment panels
• Milton Keynes - run after birth service so users can feedback their experience to midwives
• General Pharmaceutical Society - wants patients to be involved in every policy decision
• AGE UK – working with patients to co design services
• Asthma UK - online forums for patients to access, training for patient reps (one has now become a trustee)
• Northumberland Trust – measuring and using patient feedback to develop services
• Scotland – patients are involved as website moderators of health boards
• Healthwatch – patients involved as “enter and view” to find out what’s going on in providers
• Calderdale Healthwatch – took patients to the local Health & Wellbeing Board to feedback on cardiac services
• CCGs working with GP practices, seeking feedback from patient participation groups
• Rotherham Hospital – posters throughout trust giving information how to feedback
• Breakthrough Cancer – patients involved in writing the breast cancer pledge
• General Dental Council – patient feedback newsletter

More examples where shared between participants. We will share participant email addresses so you can keep each other informed of new patient involvement developments; that we can continue to learn from each other.