



## **Why bother about user engagement in primary health care?**

I have to confess I do sometimes wonder why we bother with trying to engage users in health care. You would think it would be easy. The NHS is our most important - certainly our most expensive – social service. Virtually everyone uses it and we all have opinions about it. And yet, the literacy level of the great British public about the health care arrangements their taxes pay for is pretty dismal. Most people only seem interested in how the NHS works when it doesn't. I can only speak about England here. Maybe health consumers in the other UK nations are better at this, but somehow I doubt it.

Primary health care is the face of the NHS for most people. You would think that would make it fertile ground for engaging users. You might expect that primary care practices would come with patient participation groups as standard features. But no. Years working as public involvement consultants has taught me and my partners that we aren't exactly pushing at an open door with many practitioners when it comes to developing user engagement. Sometimes the practice door's not only closed, it's firmly bolted from the inside. Even if that metaphorical door is unlocked and has a "welcome" sign on it, patients (not a word I like but I'll use it for convenience) aren't generally stampeding to get through it to share in the responsibilities of decision making.

It's not that patients are disinterested in what happens in their practice. You can interest most patients in things to do with services and changes that would affect them personally: things like clinic access, waiting times for appointments, telephone consultations, waiting room TV content, information display boards, arrangements for repeat prescriptions, online appointments, and where to store buggies and brollies. Of course the real magnets for engagement are bricks and mortar questions - a planning application or blueprints guarantee standing room only.

Concrete issues aside, when it comes to whipping up interest in commissioning, as opposed to service issues, our experience is that we might as well be describing life on Mars. This is very frustrating because commissioning not only determines what happens today in primary care, it

dictates what will happen tomorrow and long after that. Reflecting on how hard it is to “sell commissioning” to service users, I think we need to go back to basics. Maybe we’ve got our expectations wrong? Maybe we are using the wrong language? Maybe we don’t understand how to align the ideas we think are important with the experience of users? Maybe we don’t know what success looks like so we overlook it when it happens in a small way? I don’t have pat answers to these questions, which is why I’ll keep coming back to them in this series of articles about engaging people in primary care and what we’ve learned from trying to do it.

### **What’s in a word?**

Let’s look at the language we use about engagement. As Humpty Dumpty said to Alice in *Through the Looking Glass*, “‘When I use a word, it means just what I choose it to mean -- neither more nor less.’ ‘The question is,’ said Alice, ‘whether you can make words mean so many different things?’

Take “involvement” and “engagement” as examples of words which are used in confusing ways. They aren’t synonyms, though they are frequently blurred in policy statements which leads to confusion in practice and fuzzy communications.

Locally, our commissioners have sorted out the difference between involvement, engagement and communications. The Chief Executive’s introduction to our Board’s engagement policy says: *“Throughout this document we refer to involvement, engagement and communications for patient and public empowerment. Involvement for empowerment is the overall objective. Engagement is a tool used for specific purposes, including formal consultations. Communications is the range of techniques and tools used to interact with people, listen, understand their feelings, and communicate with them appropriately and feed back to them what they said. The result of this is helping people feel that they are continually involved in our business.”*<sup>1</sup>

### **Together on a journey**

We made these distinctions between words because we understand that patient and public involvement in health and social care is only a process leading us somewhere. The real destination is shared power in decision-making and genuine partnerships with people who use services we commission. *“Involvement is key and the PCT needs to develop processes to*

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<sup>1</sup> Wandsworth PCT. *Communications and Engagement Strategy 2008-2013* (October 2008) [www.wandsworth-pct.nhs.uk](http://www.wandsworth-pct.nhs.uk) (accessed January 2010)

*make sure that we listen to patients and the public as we shape ideas for new service delivery models – we need to make sure patients and the public are with us on the journey of service re-design as we consult, develop service specifications, consider tenders, and monitor contracts.”<sup>2</sup>*

“Taking patients with us on a journey” is a pretty good description of what user participation in primary care could also be about. If we promoted it like that, staff might be more enthusiastic. My local experience as a PEC member suggests that user participation groups in primary care practices offer learning opportunities about mutual trust, responsibility and partnership which can overcome the “professional vs patient” barrier.

When added together across practices small initiatives have real cumulative benefit in creating a local culture about working together. We will need that as things get tighter financially and some hard choices have to be made. Supporting practice-based participation opens new channels for compliance with consultation and involvement duties enshrined in law. Neglecting the opportunity to create “bottom up” building blocks of user engagement is risky - just remember the fate that befell Humpty Dumpty.

### **Being a “patientologist”**

Patients get different things out of engaging with a practice. Staff are often surprised by what participants say about this. A member of a new patient participation group at one of our large group practices told me what she thought was the most important factor in getting the group off the ground.

This is what she said: *“The doctors at the surgery became aware that their patients were a valuable and under utilised resource. We are experts too, each and every one of us, including the underprivileged, the refugees and the asylum seekers. They appreciated that we have all attained a degree, an “ology”: we are all “patientologists”.*<sup>3</sup>

Another group participant added rather wryly, *“Patients have experiences that doctors know nothing about, experiences that can have immediate consequences on our health. How the approach to the premises can influence opinions and expectations of our treatment; how the dirty, dying or dead plants will confirm any niggling worries we may have about the doctor’s abilities; how the receptionist’s curt greeting can increase our nervous tension or raise our*

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<sup>2</sup> *Ibid.*

<sup>3</sup> Unpublished notes

*blood pressure or how the ambience of the waiting area can determine the way we experience the rest of our visit.*<sup>4</sup>

### **Creating value through user participation**

We evaluated what motivated members of the practice participation group where two of MAC's partners are also patients. We found quite a sophisticated understanding of the value which user participation created for patients as individuals and for the practice as a whole. We used a Delphi-type approach over several sessions to help group members (who were the "experts") identify and rank values of participation.<sup>5</sup>

What emerged surprised us. The two most important values from participation came out as *"We can make a difference as a group better than as individuals"* and *"I get to hear about local and national NHS developments and policies that affect us locally"*.<sup>6</sup>

Our starting assumption was that most patient participants would say the most important thing they got out of participation was interacting with other patients and learning more about their own health. These things were important, of course, but they came well down in the final ranking. It was the collective difference the group could make and the benefit that would make to the practice which really motivated them to get involved and stay involved.

If we could only replicate that appreciation of the value of participation in every practice, then the answer "why bother?" with user engagement would answer itself so obviously that no one would even think of asking the question.

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*The Moore Adamson Craig Partnership supports user and public participation, trains lay representatives and develops responsive health, care and education organisations.*

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<sup>4</sup> *Ibid.*

<sup>5</sup> Craig AG. *A Framework for Evaluating Patient Participation Group in Primary Care Practices in Wandsworth* (2004) [www.mooreadamsoncraig.co.uk/pdf/evaluating\\_patient\\_participation\\_groups.pdf](http://www.mooreadamsoncraig.co.uk/pdf/evaluating_patient_participation_groups.pdf) (accessed January 2010)

<sup>6</sup> *Ibid.*

