



Getting ready for patient participation

“Fools rush in where angels fear to tread” is wise cautionary advice for anyone about to put up the first poster in the surgery waiting room or send out the emails inviting patients to get involved in a primary care practice. Before pressing “send”, pause to consider some key questions:

- Who do you want to come?
- What do you want them to do?
- What will happen afterwards?
- What do my colleagues think about getting patients involved with the practice?

Assessing your team’s readiness to engage

Patient participation isn’t sustainable on the enthusiasm of one person. No matter how keen, a sole enthusiast faces isolation and burn out without wider awareness and peer support. We often hear people say “we tried it, but it didn’t work”. What they really mean is that a keen colleague got tired of trying to push water up hill and gave up. It doesn’t inspire people to try again.

To gauge where you colleagues stand on the “what about involving the patients?” question, try using MAC’s *It’s Easier Said than Done* questionnaire. We paraphrased ten commonly heard staff views about participation to stimulate practice teams to have their say (anonymously if they wish).

1. “They don’t understand how complicated the health service is.”
2. “Patients are not representative and only have their own experiences to tell.”

3. "Groups like younger men don't really want to be involved in their health care."
4. "Patients only talk about their "wants", but we know what they really need."
5. "There will be so many demands that we can't cope and they will want things that the NHS can't afford."
6. "Public involvement in the NHS is too complicated: if we don't understand it, patients won't either."
7. "It will all cost too much if we have to consult patients on everything."
8. "Staff don't have time to do all this as well as meet all our targets."
9. "Participation results cannot be measured anyway, so why are we made to do it?"
10. "Ordinary patients and the public are not really interested in how the system works, they just want a good service."

There's a grain (sometimes more) of truth in each of these statements, so don't be surprised if colleagues produce a mixed response. In our experience, when staff are confident enough to say what they really think about patient involvement, you may hear things like

- GPs aren't interested
- We're all "too busy" to do this too
- Staff can't be available out of hours
- Fears of "demanding" or "heart sink" patients
- Fears of raising expectations that can't be met
- Fears that it will attract the "moaners"
- Conflict between patients and GPs if contentious issues arise

Negative or hesitant views are genuine; don't dismiss them, but file under "persuadable". They won't be the whole story. It's likely that mixed in with negative views are more hopeful views about the benefits of patient participation that works. These are some of the things we frequently hear people say

- It might decrease complaints
- Doctor/patient relationships might improve

- Patients could understand the constraints primary care is working under
- Ways of communicating the practice's views to patients might improve
- Practice meetings could talk about patient feedback
- We could get practical suggestions from patients and try out new ideas
- Staff would not have to 'second guess' what patients think, we could ask them
- We would have a sounding board – maybe even some “critical friends”

The point is that staff views on patient participation are rarely black and white. There are lots of grey areas and “what ifs”. People can hold contradictory views about participation at the same time. Life can be messy like that; involving service users isn't any different.

It's a huge asset to successful participation if there are champions on the practice team and in the patient population. Our experience shows that the core “practice team” for successful participation needs a manager and a clinician who are able to devote time and attention to making it work. Having the Practice Manager and a senior GP waving the participation flag helps keep up morale. So does aligning participation activity with things the practice wants to achieve – more on that in a future article.

Knowing who is out there

Once the practice team knows what its own hopes and fears are about participation, it's time to consider the rest of the people who will be round the table – the users. “Patients” may not be the best term to describe them. Well people who want to get involved may not see themselves as patients because the word has dependency connotations.¹ They might describe themselves as active citizens or just “friends” of the practice. And don't forget to invite carers. They provide a wealth of customer insight from the receiving end of health and social care services.

Appreciating the practice's population demographics is essential. Does the practice have email addresses, especially for more recently registered people? Launching into Facebook and Twitter may be stretching it at first, but don't

¹ Craig AG. “Public involvement in healthcare – every voice counts not just that of patients”
BMJ 2004;328:462 (21 February), www.bmj.com/cgi/content/full/328/7437/462 (accessed March 2010)

discount social networking media for engaging younger users. And make sure the practice website supports interaction to the full. “Virtual groups” can work if there are clear ground rules and moderation. Participation is about much more than meetings – another theme to be explored later in this series.

The 1% solution

Don't get hung up about the “usual suspects”. A few years ago a London NHS guide to patient and public involvement featured a cartoon with one manager confiding to another, “Don't worry – I contacted the usual suspects” as they gazed across a table crowded with biddable sheep. The message was clear: the “usual suspects” were not wanted for serious patient engagement. We find the reverse is often true, and we're not alone in that. A King's Fund report *Every Voice Counts* castigated making distinctions between ‘usual suspects’ and ‘ordinary people’ as ‘spurious and unhelpful’.² The logic was compelling:

‘they disempower individuals who seek to gain confidence through joining collective voices [and] the institutional lay member who puts great effort into understanding the internal agenda of an organisation is ill-served if this is used to question the “authenticity” of their lay perspective.’³

Striving for “representativeness” can be illusory. Rejecting people you already know well in the quest for “real patients” makes quick engagement wins much harder and alienates confident people with skills and knowledge who can be natural allies. There is nothing wrong with picking some low hanging fruit as a way to kick start participation.⁴

And here's more good news. Struggling to win the “numbers game” about patient participation both exhausts and excludes. Accept that fact and you will feel much better. A more productive approach is what the Joseph Rowntree Trust has dubbed “the 1% solution” to participation.⁵ That's about mobilising and supporting a small, well-networked group who are empowered to be a conduit to inform and recruit others so that bedrock participation grows

² Anderson W et al. *Every Voice Counts: primary care organisations and public involvement*. Kings Fund, London: 2002 www.kingsfund.org.uk/research/publications/every_voice.html

³ *Ibid.*

⁴ Craig AG. “Usual suspects provide effective and much needed grit in the NHS oyster” *Health Services Journal* 5 September 2002

⁵ Skidmore P, Bound K and Lownsbrough H. *Community Participation – who benefits?* (York, 2006) www.jrf.org.uk/sites/files/jrf/1802-community-network-governance.pdf

organically and inclusively . Just make sure the practice learns from this experience and can keep it going.

Whatever happens, happens

A recurring participation nightmare is the draughty room with stewed tea, curling sandwiches and a small knot of patients in the corner wondering what they are doing there. We've all seen it, but it doesn't have to be like that. As development consultants working in many settings, we take comfort in the wisdom about meetings built using "open space technology".⁶

- Whoever comes are the right people.
- Whatever happens is the only thing that could have.
- Whenever it starts is the right time.
- When it's over, it's over.

It takes confidence to run unstructured events along these lines. But in our experience they are much more productive than trying to micro-manage a pre-determined format. Power relationships need to be set aside. Some members of the user audience are likely to be professionals themselves, so power sharing the participation process rather than seeking to control it is recommended. That takes confidence too, but the results are worth it.

A final thought before pressing the "send" button on the invitation emails. Successful user participation is a lot like cultivating pearls. The NHS primary care oyster needs a bit of grit in order to produce anything new and useful: no user grit, no pearls for the practice.

Dr Andrew Craig
Partner
© Moore Adamson Craig Partnership LLP

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

An edited version of this paper appeared in *Primary Health Care*, June 2010

⁶ www.openspaceworkshop.com