

Patient & Public Involvement Guidance for new Forum Members and Managers - your Starter for Ten

If you have recently joined or are thinking of becoming a member of a new Patients Forum, as part of the Patient and Public Involvement (PPI) programme at a local primary care or foundation trust, then I would guess that you are looking for a challenge - the NHS can be very difficult for outsiders to understand and navigate their way through. Part of that challenge is about the facts and figures which can be a headache to learn. There is a wish to be seen as being good at the job and have fun and make friends at the same time. This can take people into new areas and involve new ways of looking at things that may be a long way away from where they feel comfortable and at home.

So what will make that process easier and more fun? We have some ideas about that based on research and public involvement training that we have conducted amongst consumer and user representative bodies.

Getting Ready for Patient and Public Involvement

When we asked people what they thought was important, they told us that it was important to get as wide a selection of people as possible including that most difficult to recruit group - young people. Also we were told "we need to recruit people who are just patients on their own who are not just representatives of organisations and who are experts". Another person made it short and simple saying what was needed was "1. Some teambuilding work. 2. More mentoring. 3. More resources".

Many made the point that they would like more training and briefing on the health service. We got a very detailed description of the information pack they would like to receive:

- ❑ **Index of health care centres, hospitals and trusts in the area**
To include all the local health organisations, be it a primary care trust, foundation trust, surgery, etc. with brief details of sizes, functions and objectives and audit reports
- ❑ **Demographics and Statistics for the primary care/foundation trust**
A briefing pack of the area covering demographic data, doctor to patient ratios,

special problems especially deprivation, how the area compares with similar areas in the UK and with national data. How much poor health costs the area.

❑ **NHS Statistics**

Health care statistics Particularly waiting times by speciality, premature death rates, emergency re-admissions and costs of service provision, current plans for NHS improvements and how the area's statistics compare with national data over a 5 year running period.

Overall people were interested in being independent, well organised, developing a sense of purpose and knowledge with good training tailored to the individual and the job with some suspicion of the 'expert' representative committed to things as they were done in the past. They need to be respected for what they are and be reassured that their time is valued. Does this strike a chord with you?

If those we questioned did not get results, then there was always a remedy as one forum member reminded us: "Terrific potential for forum - needs political support/ more clout. If this does not happen, (I) will resign." Get some early wins and celebrate them - even the little ones. The big ones will take a long time to arrive - if they ever do.

Barriers to Successful Patient Forums

Organisers in their turn have to make sure that the barriers to success are identified and overcome. These include:

- ❑ No understanding of the purpose of involvement amongst Forum members or health service managers - "what is the job we are supposed to be doing?"
- ❑ Finding it hard communicating with the patient population - "no one ever tells us anything and if they do, it is generally too late in the day to do anything about it".
- ❑ Being so afraid of raising unrealistic expectations that they do not create any - "Everybody is very busy and I don't suppose they will be able to come to the meeting"
- ❑ Not creating the means to identify and then address poor attitudes and lack of skills on the part of either side - "no training budget this year I'm afraid. I am sure that with a bit of good will, we'll all muddle through somehow"
- ❑ Not anticipating that patients and health professionals will have different agendas and approaches and not being able to cope with disagreement - " With respect, we really had expected you to take a more positive view about..."

- ❑ Professional or organisational territorialism i.e. everyone just concentrates on their own patch "Never mind them, what about us?"
- ❑ Lack of resources (time and money) or support. "Sorry its all a bit of a rush - see you what you can do by Thursday." (waving 200 page consultative report)
- ❑ Anxiety about the cost of involving users and not paying out expenses which will exclude some members of the public and patients. "Can you wait till next month for the money to pay today's taxi bill? I am afraid our accounts office are a bit slow".

A Route to Effective Participation in Patient Forums

The prerequisites of effective participation and contribution for Patient Forums to take on board seem to us to be:

- ❑ To reflect all strands of circumstance and opinion in the community;
- ❑ To offer a wide range of choices to participants in terms of the way in which they contribute and the issues on which they wish to make their opinions known;
- ❑ To develop means of stimulating and gathering opinion which reflect the individual's circumstances e.g. mobility, access to IT/internet.
- ❑ To assist in the identification of issues where patient representatives can make a difference, e.g. issues like cleanliness, noise, food, staff attitudes, information provision
- ❑ To assess effectiveness in terms of impact on standards of health care
- ❑ To minimise waste by maximising retention amongst those who come forward and quickly giving them something meaningful to do
- ❑ To understand that what creates participant or representative satisfaction can be quite different from professional expectations
- ❑ To assess effectiveness in terms of cost.

Easy peasy really.

Colin Adamson

This article was downloaded from <http://www.publicinvolvement.co.uk/patient-forums.html>

Send any questions and comments to

Colin Adamson
Partner
The Moore Adamson Craig Partnership
12 Clevedon Court
Clive Road
London SE21 8BT

Tel. 020 8670 0505
email colin@mooreadamsoncraig.co.uk



www.mooreadamsoncraig.co.uk