



Appendix 10: MAC Associates “recruiter and recruited” briefing for Department of Health *Learning from Pilot Patients’ Forums* (March 2003)

Here are some thoughts on Patients’ Forums as a contribution to developing guidance. They are based on our work with the national sample of Pilot Patients’ Forums and our local experience of providing the ongoing training and development programme for the Wandsworth PPF.

This note supplements the detail in our previously-submitted research report ***Building Capacity for Pilot Patients’ Forums: the Experience of Recruiter and Recruited*** (November 2002).

1. Advocate or Watchdog?

There is a real debate in the pilot Patients’ Forums centred on whether the Patients’ Forum should be seen as a gathering of citizen advocates speaking for the benefit of users of the Health Service, as against the Patients’ Forum functioning as a watchdog and auditing the performance of the local Health Service. The latter is the traditional guardian role adopted by consumer representative bodies such as Postwatch and indeed by the CHCs. The group monitors and where appropriate criticises the performance of the body in question. The advocates, in contrast, see this as too narrow a function. They seek to imbed the user view in the governance and ethos of the service deliverer and then play a role in this body as an active and engaged citizen/user of the UK’s most important public service.

Both arguments have their attractions and are not mutually exclusive. However when we consider the idea of a ‘win’ and how local people recognise “wins”, we have to conclude that the watchdog role should precede the advocate role because it is better at generating early and measurable achievements in service improvement. In addition, the proofs of effectiveness will generate the wider loyalty and support to underpin the advocacy and generalised citizen support that the health service needs.

Embedding user perspectives and values in the thinking and behaviour of the commissioners and providers is a longer term objective about changing “professional culture” and cannot be achieved by the PFs alone. While we embrace the goals of citizen participation, we look to the smaller victories on the day to day issues to sustain the Patients’ Forum members in their commitment.

2. Building capacity

Our report concluded that the term ‘recruitment’ was inadequate to describe the process of building capacity and securing the engagement of those with something to contribute. Those who were interested by the thought of being part of a Patients’ Forum had a strong need for clarity about ends and means.

The discussion in point 1 was prompted in part by this need. We have come to believe that the Forum must manage a very open and diverse set of inputs where the issue determines those inputs from what could be a panel of people – each contributing in the way that they find practical and satisfying.

We do not think that the model of the standing committee discussing the papers prepared by the secretariat meets the PF needs. Choices must be offered to those thinking of getting involved. The choices would be about both the degree of involvement and the type of issue to get involved with. The word 'recruitment' does not do justice to the choices offered for degrees of participation and issue selection.

The phrases 'building capacity' and "following a pathway" are truer reflections of the process. It is also essential that the participant voice in the new PFs from the very beginning does not get lost amid the din of the construction site as the new structures of participation get built. The PFs must be learning organisations from the time the first steps are taken to create them.

3. Penalty Free Participation

In encouraging a wide range of participants and the means of participating, we were very concerned by the current policies of the Benefits Agency. The most vulnerable and excluded had this status confirmed by the Agency withdrawing or threatening to withdraw benefit for those who were giving time to PF activities. The guidance administrative principle must be penalty free participation.

Our experience with training lay members for pilot Patients' Forums has shown that the organisers must be prepared to make immediate cash reimbursements to those requesting it for things such as return transport costs (including use of taxis where public transport cannot be used), child care costs, and the cost of providing alternative carers where needed.

4. Building Best Practice

We think that our recommendations on this as set out in the research report we did bear repeating in this context because they offer a practical set of actions to stimulate and underwrite progress in this area. We reproduce them in the next paragraphs.

Building Capacity – Best Practice

Building capacity is not a game with a prize for the highest numbers signed up. There is a need to build a sustainable community around a common purpose and a promise of achievement. The management process will recognise the value of the human resource and work towards maintaining enthusiasm and a sense of useful contribution to the NHS, so retaining those who have come forward.

Values, Processes and Metrics

We can begin to see the basis for a best practice template built around a framework of values, processes and metrics. All elements will be built around the principle of respecting and recognising the resource of the individual participant and the reason that prompted her or him to come forward.

Best practice will be based on the values of honesty and clarity about roles, remuneration, demands on time and goals. Independence is prized as is a degree of autonomy in appointing chairs or agreeing agenda issues. The survey revealed great differences both in how the money was spent and the amount of money spent. Some have appointed development managers – others have accomplished much without a dedicated resource. Ideas of the budgets to be needed vary greatly.

This will be reflected in building capacity:-

- 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, eg 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 the drivers of participant satisfaction which may be quite different from professional expectations
- To assess effectiveness in terms of cost.

Seven Step Process

Based on the responses received, we see a best practice seven step "recruitment process" as follows:-

1 Direct Marketing and Advertising - Develop as large as possible mailing list using GP lists and use the GP in the recruitment process as a valued and trusted person in the eyes of patients. All material to give means of getting

more info or volunteering to participate. Consider use of local press. This is the big trawl – large nets to scoop up as big a catch as possible: can be costly in above the line costs but if successful, a low cost per head gathered in

2 Local Promotion Leaflet - Use local health-related premises to distribute news of the initiative and brief health staff on the initiative, using the material distributed. Print costs can be controlled: display disciplines and pick-up cannot. Negotiate handout perhaps with a prescription form or on presentation at reception. Mail to voluntary organisations.

3 Collate and record responses received by paper, electronically and on the phone and give those whose interest has been aroused the chance to attend an event or meet an involved human being to make clear the nature of the commitment. IT support may be needed to build database and temporary help to key in data. Check data protection legislation. Waste nothing.

4 Targeted Approaches – approach groups in the community from whom nothing has been heard and seek to supplement the responses received from the trawl to make sure a full range of patient experience is connected to the network. This is the single line fishing or small nets with fine mesh – low in above the line cost but heavy demands on organiser time.

5 Training - For those whose interest is confirmed offer a specific introductory training session about the user representative role in health and instil an appreciation of the local health situation, including health inequalities and what might be done to address them. Develop goals and intentions amongst those attending training sessions. Training carries a cost but recipients may recognise it as a valuable non-cash benefit. Offering training as part of the inducement to engage worked well for several of the pilots. Training as a “way in” for traditionally excluded groups, taken to and delivered where they are, also has potential.

6 Choices -Following the training, offer choices about ways of making a contribution. For those who seem most interested in the commitment needed for a Patient Forum member, organise a formal interview and appointment process. Others will be used informally in the ways they have suggested themselves. The database if competently set up will support and ease this process.

7 Expectation and Reality Check – research attendees/ participants asking ‘have expectations been met?’ and ‘would you recommend friends and colleagues to join in?’. What is the ‘burn out’ rate? To increase retention, understand what a win looks and feels like and make sure members recognise one when they see one.

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Web site: www.mooreadamsoncraig.co.uk

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