



**BUILDING CAPACITY FOR PILOT PATIENTS' FORUMS:
THE EXPERIENCE OF RECRUITER AND RECRUITED**

A RESEARCH REPORT

from

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A MAC ASSOCIATES RESEARCH REPORT

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1. REPORT LEARNING AND CONCLUSIONS

- 1.1. The summary contains what we have identified as “LEARNING POINTS” designed to state the conclusions and lessons that can be drawn from this exercise. The extracts below are excerpts from the main body of text in Section 2 onwards.
- 1.2. Our start point is an earlier ‘snapshot’ survey done in April 2002 of some pilot patients’ forums and their progress as at that date. These are ‘baseline’ studies. The information we present now draws on that data covering as it did a number of activities to concentrate on the single process of persuading members of the public to become associated with pilot Patients’ Forums. Our goal is the provision of actionable data that will assist the future work of the Commission for Public and Patient Involvement in Health as well as recognising the work already done by the pilot Patients’ Forum pioneers.

LEARNING POINT I

- 1.3. The first learning point about the results of these surveys is that the pilot groups we were in touch with were given a great degree of latitude to develop their own approaches and methods. The pilot paths were uncharted; the milestones not yet laid and no boxes existed to tick signifying that the master plan was being realised. The research therefore could not be an audit of progress towards standardised goals – it remains a description – looking in more depth at one particular activity - that of finding people with something to say about the NHS and giving them an opportunity to say it.

LEARNING POINT II- Users Voices Not to be Lost in the Din of Construction

- 1.4. The new structures for user representation are public statutory bodies and will need therefore to be fully accountable in terms of the work that they do. The mechanisms for such a process have not yet been established but must include a means of measuring effectiveness which draws on the experiences of those taking part. This survey albeit limited in terms of sample size has demonstrated that research amongst participants can provide actionable data. In particular, our survey gave members an opportunity to voice their views on how they had got on. It is essential that the participant voice does not get lost in the din of the construction site as the new structures of participation get built. Our experience is that too often research amongst users is left till the processes are up and running. However new approaches to user participation stress that all avenues for the collection and dissemination of the views of those in the system must be deployed, and deployed from the start of the new Forums and thereafter be continuous.

LEARNING POINT III- Abandon The ‘Recruitment’ Label

- 1.5. We can abandon the label ‘recruitment’ to describe the process by which participants are identified and inducted. This survey confirmed a point that came out of the original ‘Snapshot’ –namely, the importance of offering choices 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. The differences in degree and type of involvement entail different forms of promotion for involvement and room for manoeuvre in what we might call ‘engagement agreements’ between people and organisations seeking their views. These

agreements would begin to answer one of the strongest needs of participants – the need for clarity about ends and means.

LEARNING POINT IV – Participation Difficult To Map

1.6. We have discussed the need for graded and tailored recruitment programmes which embrace a spectrum of approaches and techniques. The extremes of each approach are:-

- Formal <> Informal
- Closed <>Open
- Segmented and Targeted<> Population at Large

The participation map therefore will be both tricky to draw and demanding to manage. An organiser will have to juggle a number of dimensions to create structures and processes that will reflect a diversity of styles, cultures and needs. The process will need to clarify who is available to discuss a particular issue, the experiences and understanding they bring to the issue and the best way of facilitating that input within what will often be a timeline outside their control. All this before we have touched on the question of formal appointment and appropriate rewards and remuneration.

LEARNING POINT V –Penalty Free Participation

1.7. The number of responses prompted by financial support-related questions emphasises the importance of valuing lay time. There must be recognition of the value of that time committed by citizens to PCTPFs and other NHS participation opportunities. It is crucial that any payments in cash or kind are organised so as not to disrupt the lives of those individuals who receive a range of state benefits. We are aware that local Benefits Agency offices have very wide discretion. Through our work with the pilot forums we have become aware of the situation whereby some lay people carrying out NHS representative roles have had their benefits reduced because their benefits office took the view that the role they fulfilled should be remunerated to reflect the time commitment and level of responsibility. This consequence of not recognising the value of lay time could well exclude those who are hardest to reach in the community. The administrative principle must be penalty-free participation.

1.8. 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. Patient representatives are often uncomfortable with form filling and financially embarrassed by delays in payment which assume they have £20 to spare for a taxi in the first place. At the same time, the organiser must account for the disbursement of public funds. The solution lies in adopting wherever possible and in a consistent way, the penalty-free administrative approach – the penalty in this case being the need to payout and wait for payment. The preferred approach makes a settlement in full 'at the time', 'on the spot' and in defined circumstances in advance using the means of payment preferred by the representative. The payment would cover 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. PF members may themselves require a carer when travelling or to assist them in meetings because of the degree of their disability or sensory impairment. Barriers presented by NHS administrative requirements should be identified and addressed in case some individuals are otherwise unable to participate with the work of the PF. Organisers may find it necessary to run a taxi account (or liase

with local Mobility bus services if on-time pick up and arrival can be guaranteed) if the cash float gets too large for safety.

LEARNING POINT VI – Sharing The Accumulated Experience

- 1.9. The Wandsworth Pilot Patients' Forum organiser had already submitted his comments to the Transition Advisory Board and made them available for this survey also. We quote the passage dealing with Success, Problems and Lessons Learned since they make a number of points on the process which have been echoed by others and a second broader point that the knowledge held by those involved is much more extensive than can be captured by a single questionnaire on one particular aspect of that experience. The documentation that Lincolnshire shared with us is another proof of the richness of that seam. MAC has long recommended a second event which will gather participants to glean such knowledge at an early stage of the CPPIH's life. Self-evaluation by experienced organisers is recommended in conjunction with member research.

OVERALL CONCLUSIONS – PILOT RESEARCH LEARNING AND BEST PRACTICE

Pilot Research Learning

- 1.10. Both the recruitment practices and this piece of subsequent research are pilot exercises. What has been the overall learning and what conclusions can be drawn? We set out below both the principal learning points for future research and a best practice approach to build capacity. Both are for discussion.

The Limits Of This Work

- 1.11. The numbers of responses both from the groups and the individual members are small. The survey takes its approach from the overall context of the work with what are pilot organisations. So it is with the surveys to a degree. The fact of carrying out the research at this stage offers some good pointers for the future which we will discuss later. The 'technical' point to be made at this point in our report is that the numbers fall some way short of statistical significance and would need to be validated by a larger survey in the future. In these initial surveys, we have not identified 'recruited member' comments with those that made them nor the part of the country they came from. We have however quoted freely from the remarks that they made in order to underline the essentially qualitative and subjective nature of the work. The data from the 'recruiters' questionnaire are by contrast essentially factual compared to the responses of the 'recruited' to questions that asked about their perceptions, feelings and intentions. We have identified the organising area where appropriate and useful.

Questionnaire Respondents

- 1.12. A further methodological point has to be made about the 'recruited' member surveys. Based on their personal details, it is clear that we have heard back from a particular group of participants who are mainly British, middle-aged or older and who have been involved before in similar representative organisations, often in health or related fields. This is not proof of the success or lack of it in involving other social groups in the representational network. Here it is primarily a measure of those who fill in self-completion questionnaires and secondly of the sample of people to whom organisers or forums

BUILDING CAPACITY

sent the questionnaires in the first place- a choice we left them free to make within certain very broad criteria.

Diverse Research Approaches for Diverse Membership

- 1.13. Any future study of member views will have to construct a more variegated sample of potential respondents to reflect the full diversity of the forum members. Such a study would use either a face to face or a telephone interview technique to achieve the collection of views from a fully representative cross-section of forum or other network members. Just as the means of attracting users and the role they are asked to fulfil will vary according to their needs and experience, so will the means of researching their representative experience.

BUILDING CAPACITY – BEST PRACTICE

- 1.14. 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

- 1.15. 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.
- 1.16. 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.
 - To assist in the identification of issues where patient representatives can make a difference
 - To assess effectiveness in terms of impact on standards of health care
 - To minimise waste by maximising retention amongst those who come forward
 - To understand the drivers of participant satisfaction

- To assess effectiveness in terms of cost.

SEVEN STEP PROCESS

1.17. 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 representative role and develop goals and intentions amongst those attending. Training carries a cost but recipients may recognise it as a valuable non-cash benefit.
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.

A Continuous Process

- 1.18. Organisers should recognise that building capacity and interest is a continuous process. People will drift away and become unavailable for many different reasons. How can the process of promotion and invitation be sustained over time? Will there be regular campaigns at particular times of year? Campaigns for particular groups?

One Stage in the Management Process

- 1.19. Building capacity is just one element in the management process of creating an effective public and patient representative network. It does however offer a number of strong clues as to the characteristics of that management approach. It must be user-centred and adopt administrative procedures that are indeed public and patient centred. The procedures must be tailored to differing circumstances; they must assume little and be ready to learn a lot. Some formality and structure must remain in the structure in the way that records are kept and protected; in the handling of funds and in the way in which opinion is solicited, gathered and transmitted. The system will not be stable, comfortable or easy to manage at all let alone well. We can anticipate great variations in levels of accomplishment. Some forums will fail and disappear, as will managers. Participation remains a choice for users. How will the official and permanent structures of the Health Service react?

The Permanent Pilot – the Continuous Learning Organism

- 1.20. Experiment, adaptation and evaluation will be abiding features of what may well be an organism in permanent evolution from which we will be able to take new ideas aimed at reviving and revolutionising citizen participation in the national life. In this sense the pilot will be permanent.

2. INTRODUCTION TO THE SURVEYS

BACKGROUND

- 2.1. The ways in which members of the public, service users and carers are recruited to take part in NHS patient representative bodies are crucial to the success of these patient and public involvement initiatives. The issue had been identified in an earlier MAC Associates 'Snapshot' study of pilot patient forums in April 2002 when most respondents said there was neither an ideal or an easy approach to finding the right people. At that time all the sites were looking to identify and attract people who reflected a cross section of the communities involved. To give one example from a newsletter 'Wirral Local Network Pilot' for the period January – March 2002, the Wirral Community Health Council described how it had used a series of training sessions "aimed at developing the capacity of local people to engage with the new structures that are to be set up for Patient and Public Involvement in the NHS." This was one of the many approaches used in different pilot groups. In particular, those organising these early initiatives acknowledged that difficulties remained with contacting and recruiting people belonging to the 'traditionally excluded' - the 'hard to reach' groups. The organiser for Southend told us at that time "“We have no representatives **from** ethnic minority or refugee communities, travellers, people under 25, parents and toddlers, schoolchildren or people with learning difficulties. We do however have representatives **of** many of these groups and will work with existing organisations as far as possible”".
- 2.2. There is now in existence a wide range of published information and guidelines on how to work to realise the vision of a patient-centred NHS. We have not attempted to reflect this wider body of work in this version of the report. This study does draw on and is a development of the April survey mentioned above. For example, the first question of the September organisers' survey on avenues and methods of attracting user representatives reflects the means already being deployed in April 2002.
- 2.3. In April, only three of the eight respondent bodies had completed an initial recruitment process. Many had begun to promote membership through four principal channels:
- Consultations with other local interested bodies
 - Consultations with special interest groups e.g. refugee communities
 - Advertising in local media
 - Advertising in 'health-related' premises e.g. doctors' surgeries.
- 2.4. Bexley told us that they were working on "development of membership criteria and appointment process in consultation with DOH" before recruitment itself began. Others like Camden had drawn up a job description for a dedicated co-ordinator for the Forum and said that recruitment would begin once the post was filled. Others like Hertsmere were already far down the track with 160 people coming forward to join the Hertsmere Healthy Network."

LEARNING POINT I

2.5. The first learning point about the results of these surveys is that the pilot groups we were in touch with were given a great degree of latitude to develop their own approaches and methods. The pilot paths were uncharted; the milestones not yet laid and no boxes existed to tick signifying that the master plan was being realised. The research therefore could not be an audit of progress towards standardised goals – it remains a description – looking in more depth at one particular activity - that of finding people with something to say about the NHS and giving them an opportunity to say it.

A NOTE ON RESPONSES TO THE SEPTEMBER 2002 SURVEY

2.6. This second report concentrates on the results of research amongst a small number of pilot sites – essentially the 11 organisations involved in the Experience Exchange organised and facilitated by MAC supplemented by one further area – Lincolnshire which had set up three Forums -which came to our attention during the exercise. Our thanks to those organisations who did participate – filling in questionnaires takes up time and energies which are already very fully committed.

Table 1

√	Bexley CHC
	Brighton and Hove City PCT
√	Camden CHC
	NE London Mental Health Trust
	Salford CHC
√	Hertsmere PCT SW Herts CHC
√	Southend CHC
√	Wandsworth CHC
	Wirral CHC
	Newcastle CHC
	North Tyneside CHC
√	Lincolnshire (new)

2.7. Not all of these organisations were in a position to respond and we received 6 completed questionnaires from those responsible for setting up the Pilot Patient Forums. In addition we received 20 responses from members of the public who had joined Patients’ Forums. All these responses are contained in Appendices A1&A2 (the organisers’ survey) and B1&2 (the user representatives’ survey). Appendix C shows documents developed in Lincolnshire to support the recruitment process.

LEARNING POINT II – Users Voices Not to be Lost in the Din of Construction

2.8. The new structures for user representation are public statutory bodies and will need therefore to be fully accountable in terms of the work that they do. The mechanisms for such a process have not yet been established but must include a means of measuring effectiveness which draws on the experiences of those taking part. This survey albeit limited in terms of sample size has demonstrated that research amongst participants can provide actionable data. In particular, our survey gave members an opportunity to voice their views on how they had got on. It is essential that the participant voice does not get lost in the din of the construction site as the new

structures of participation get built. Our experience is that too often research amongst users is left till the processes are up and running. However new approaches to user participation stress that all avenues for the collection and dissemination of the views of those in the system must be deployed, and deployed from the start of the new Forums and thereafter be continuous.

LEARNING POINT III - Abandon the ‘Recruitment’ Label

- 2.9. We can abandon the label ‘recruitment’ to describe the process by which participants are identified and inducted. This survey confirmed a point that came out of the original ‘Snapshot’ – namely, the importance of offering choices 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. The differences in degree and type of involvement entail different forms of promotion for involvement and room for manoeuvre in what we might call ‘engagement agreements’ between people and organisations seeking their views. These agreements would begin to answer one of the strongest needs of participants – the need for clarity about ends and means.

3. THE FORUM ORGANISER SURVEY

- 3.1. The responses given are set out in Appendices A1 and A2. A1 gives the numerical data based on the question options chosen. A2 sets out comments which complement the responses to the closed questions.

SPREADING THE WORD

- 3.2. Based on information given to our May Snapshot exercise, we offered some 15 identified approaches and techniques for attracting people and an ‘any others’ option.

Table 2 Recruitment Approaches

0	We recruit by reference to the guidance and principles set out in the OPCA Code (Office of the Commissioner for Public Appointments)
0	We have been able to draw on an existing Consumer or Citizens’ Panel or similar already operating in our part of the world e.g. run by the local authority
3	Advertising in the local media
5	Advertising in ‘health-related’ premises e.g. doctor’s surgeries/ health centres
4	Consultations with other local interested bodies such as community groups/ Council of Voluntary Service or equivalent
3	Consultations with special interest groups e.g. refugee communities; organisations for people with disabilities
3	Mailings to lists and databases of interested and appropriate people held locally by statutory bodies e.g. CHC, PCT, NHS Trust, Local Authority
6	Mailings to lists and databases held locally by voluntary sector bodies e.g. Council of Voluntary Service, local faith groups
2	Contacting expert Patient Groups
4	Stake holder events e.g. with speakers from partner organisations and ‘themed tables’ on diabetes, heart disease, cancer etc

BUILDING CAPACITY

3	Outreach Programmes whereby trained speakers talk to existing community groups
1	Local Strategic Community Health Initiatives
3	Exhibitions in market places, supermarket foyers, shopping malls etc where local people gather
0	Nominations put forward by (name of nominating organisation)
0	Persons chosen by election from the following constituencies
1	Some other method .. detail given below
	SWHerts –direct mail by GPs to individual patients and carers – 7,000 letters sent = 20% GP patient population and 80% core GP business.

3.3. The biggest single exercise was that done by SW Herts which has left them with the largest pool of potential volunteers numbered at between 201 to 500. The exercise was done from the surgeries and the response must reflect a considerable degree of trust in the apparent sender. Lincolnshire put all its eggs into the local newspapers basket and the Table below sets out the titles, the geographic areas covered and the cost.

Table 3 Dispersal of advertising and costs in Lincolnshire

Newspaper	United Lincs Hospital Trust area	SW Lincs PCT area	Lincs Amb. Trust area	cost
Lincolnshire Echo	♦	♦	♦	£269
Rutland & Stamford Mercury	♦	♦	♦	£146
Gainsborough News/Standard	♦		♦	£196.10
Grimsby Evening Telegraph			♦	↓
Scunthorpe Evening Telegraph			♦	£647.5
Louth Leader	♦		♦	↓
Skegness Standard	♦		♦	↓
Horncastle News	♦		♦	↓
Market Rasen Mail	♦		♦	↓
Lincoln Chronicle	♦		♦	↓
Lincs Citizen	♦		♦	£216.30
Bourne Local	♦	♦	♦	£80
Grantham Journal	♦	♦	♦	£329
Sleaford & Boston Standard	♦	♦	♦	£221
Lincs. Free Press	♦	♦	♦	£143
Total cost				£2247.90

3.4. The Lincolnshire manager added with the benefit of hindsight that “In retrospect it would have been appropriate to also place adverts in all other public and NHS locations that would offer a far wider distribution and reach people who do not buy a local newspaper.” The organiser added as a response to the questionnaire “The process used was in hindsight too restrictive but dictated by time constraints. A national profile would help but time to conduct a more inclusive approach i.e. roadshows is important.” As the table indicated mailings to local groups or consultations with them were the methods favoured by most albeit not on the SW Herts scale. The SW Herts model

also organised the mailing to come from the GPs themselves. Examples of the publicity material used is in Appendix D.

- 3.5. The GP channel or their premises were also mentioned by five respondents. Using GPs as a disseminating mechanism, however, has to be undertaken in the knowledge that not all of the local population will be registered patients. However it is a trusted channel. The comments of the recruited picked up on the impact of a personal approach – if they knew and trusted the person making the request to consider joining, they were content to come forward on that basis.

Asking not Telling

- 3.6. In addition to the use of mass mailing techniques and advertising which are techniques that do not involve face to face contacts with potential candidates, we see a number of initiatives which provide that opportunity. Outreach programmes and events with speakers and themed tables or manned exhibitions in supermarket foyers were frequently mentioned. Organisers of such events open themselves up to the risk of disappointment if people stay away but this direct approach can provide valuable and memorable information on the questions potential recruits are asking and the messages to which they respond. Adoption of a graded and tailored approach to public involvement will involve the communication of what could be quite complex messages about the choices available. The fastest way to see if the message is being understood and is capable of inspiring participation is to talk directly to the public. The events are more labour-intensive and to make them at all worthwhile they have to be learning intensive as well. Keep asking and avoid telling is the approach we would recommend at this early stage.

Example Of A Formal Process

- 3.7. Lincolnshire organised seven interview panels which included a member of the Public Involvement Team for Lincolnshire, at least one Non-executive director or Chairman of a NHS Trust Board and on some panels, a patient representative sat as an observer. They used a procedure used by the Human Resources department of Lincolnshire Shared Services- the documentation developed is reproduced as Appendix C. It is an example of an organised and formal process based on a process of advertisement, application, interviews assessed by standardised tools and formal offer and acceptance. 23 people were appointed through this process. It was the most structured approach that we saw.

Targeted Initiatives for Inclusion

- 3.8. Half the sample said that they had a specific profile in mind based on local demographics. Many had instituted programmes and initiatives to boost involvement of specific groups such as Black and other ethnic minorities and the answers to question 4 showed some success in recruiting from specific groups in the community. The main successes were amongst the over-60s, the retired and people with serious physical disabilities or their carers. Young people under 25 are difficult to recruit. Southend was addressing this by “discussing progress towards accredited training (as an incentive for young people, refugees and newly arrived people to enhance career prospects”. This approach echoes the Southend commitment to using training as a form of remuneration since it has value. Camden have secured agreement to send representatives to the PPF meetings from a homeless family group and an Asian Woman’s Group and other groups have agreed a looser form of association whereby they will discuss issues and report back to the Forum. Examples of these groups are a parents with learning disabilities group; a group for

parents with children with special needs, central north Community Action Team for rough sleepers and a Cypriot women's centre.

LEARNING POINT IV

3.9. We have discussed the need for graded and tailored recruitment programmes which embrace a spectrum of approaches and techniques. The extremes of each approach are:-

- Formal <> Informal
- Closed <>Open
- Segmented and Targeted<> Population at Large

The participation map therefore will be both tricky to draw and demanding to manage. An organiser will have to juggle a number of dimensions to create structures and processes that will reflect a diversity of styles, cultures and needs. The process will need to clarify who is available to discuss a particular issue, the experiences and understanding they bring to the issue and the best way of facilitating that input within what will often be a timeline outside their control. All this before we have touched on the question of formal appointment and appropriate rewards and remuneration.

LEARNING POINT V –Penalty Free Participation

3.10. The number of responses prompted by financial support-related questions emphasises the importance of valuing lay time. There must be recognition of the value of that time committed by citizens to PCTPFs and other NHS participation opportunities. It is crucial that any payments in cash or kind are organised so as not to disrupt the lives of those individuals who receive a range of state benefits. We are aware that local Benefits Agency offices have very wide discretion. Through our work with the pilot forums we have become aware of the situation whereby some lay people carrying out NHS representative roles have had their benefits reduced because their benefits office took the view that the role they fulfilled should be remunerated to reflect the time commitment and level of responsibility. This consequence of not recognising the value of lay time could well exclude those who are hardest to reach in the community. The administrative principle must be penalty-free participation.

3.11. 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. Patient representatives are often uncomfortable with form filling and financially embarrassed by delays in payment which assume they have £20 to spare for a taxi in the first place. At the same time, the organiser must account for the disbursement of public funds. The solution lies in adopting wherever possible and in a consistent way, the penalty-free administrative approach – the penalty in this case being the need to payout and wait for payment. The preferred approach makes a settlement in full 'at the time', 'on the spot' and in defined circumstances in advance using the means of payment preferred by the representative. The payment would cover 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. PF members may themselves require a carer when travelling or to assist them in meetings because of the degree of their disability or sensory impairment. Barriers presented by NHS administrative requirements should be identified

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and addressed in case some individuals are otherwise unable to participate with the work of the PF. Organisers may find it necessary to run a taxi account (or liase with local Mobility bus services if on-time pick up and arrival can be guaranteed) if the cash float gets too large for safety.

REASONS FOR NOT JOINING

- 3.12. The reasons that organisers hear most often are firstly concerned with time available and fear of over-commitment and then connected with financial support. 5 responses mentioned difficulties with money often benefits connected and one of the five mentioned that the employer would not give the time off.

Table 4 Reasons given for non-participation

4	I do not have the time
3	I am doing enough/too much already in the health field
0	It would not do any good
0	I have not had any problems with the Health Service
1	I would need to have my loss of earnings paid
1	I might lose benefit if expenses and attendance allowance were paid
2	The benefits office say this should be paid work and they would reduce my benefit accordingly
1	My disability makes attendance impossible or very difficult
1	My employer would not give me the time off
	Touch wood, I'm pretty healthy and so use the health service rarely
1	Meetings held at wrong time of day for me
1	Difficult to arrange child care
0	It is too difficult to arrange the right kind of substitute carer to enable me to participate
1	I'm too old to get involved
1	I can't use public transport
1	Other reasons - please describe in the space below

Addressing Shortage of Time Issues

- 3.13. Half of the sample have addressed the time-related points by giving people options. The table lists the type of options available and the extent to which they are offered.

Table 5 Involvement Options

2	Attend all meetings
3	Attend only some meetings of most interest e.g. as an 'expert patient'
2	Respond to questionnaire – but no need to attend forum meetings
2	Attend 'stakeholder' events/community conferences
2	Be available for telephone discussions
1	Join an email group with other pilot forum members
0	Join a small reading group to study and comment on papers in advance of

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	meeting
2	Other options – see below
	1. involvement as needs and circumstances allow – Wandsworth
	2. attend training events – Southend
	3. join an expert patients group – SW Herts

- 3.14. The development of a pool of potential sources of opinion and involvement varies for each area. We have already mentioned the larger numbers that SW Herts have gathered. Southend with two groups has between 75 and 100 on tap. Camden and E Lincolnshire had up to 25. We asked how many had agreed to come to regular forum meetings.

Table 6 How Many at regular Forum Meetings

20	Wandsworth
40	Southend East
20	Southend West
All	Lincolnshire
30-40	Bexley
8	Camden

- 3.15. Two organisers had offered those joining choices in terms of the issues they wanted to concentrate on. The areas of interest available were evenly distributed over the nine options offered.

Table 7 Choices Available

2	Monitoring primary care plans
2	Inspecting GPs' premises/health centers
2	Visiting local hospitals
1	Getting involved with the commissioning work of PCTs
1	Getting involved with the commissioning work of local NHS Trusts
1	Work to do with complaints and clinical governance
1	Involvement with information services for users and the public
2	Representing patient and public views on PCT or NHS Trust committees or project groups
0	Taking the lead in responding to particular consultations

TIME AND MONEY

- 3.16. We asked the organisers to estimate how much time and money they thought they had spent on this activity. Was it possible to estimate a notional cost per recruited head? If you were starting again with a new patient's forum, what size of budget would you bid for to cover such items as:-
- Staff
 - Premises

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- Recruitment Costs for staff
- Recruitment Costs for members
- Training.

- 3.17. The estimates for time spent varied widely. Those areas like Camden and Bexley which have recruited dedicated development officers show a high proportion of time devoted exclusively to this task at this stage of development. An interesting correlation to be explored further is that the area which spent most time spent least money - £100. The costs incurred were salary-related. The least amount of time spent was 10% and they spent some £3000 above the line on recruitment. The Lincolnshire costs of newspaper advertising are given in Table 1. Cost per recruited member is difficult especially for those areas offering choices about levels and type of participation. Two organisers had a stab at it - £150-£200. If we move to the idea of building capacity to be available to varying degrees, a single figure for 'cost per head recruited' is not a very meaningful measure. Any specific cost has to be attached to a specific task such as recruitment for a specific role such as membership of a Patients' Forum.
- 3.18. When it came to the budget needed to cover the headings listed above, the most ambitious figures advanced by three areas were £200,000 to £250,000. The lowest two thought £40,000 would be enough and the man in the middle would go for £50,400. Lincolnshire had secured funding for one Patient Forum of £25,000 - £5k for advertising costs, £10k for administration support and £10k for members travelling expenses.

Action Plan

- 3.19. The Lincolnshire Communications Action Plan was set out and is reproduced below in the box.

Patients' Forum Communications Action Plan

The aim of the plan is to maximise opportunities to:

- encourage people to come forward to be members of the Patients' Forum,
- publicise the work of the forum.

Timing	Action	Lead person	Resources
May	<ul style="list-style-type: none"> • Pull together information pack to issue to prospective members • Fact sheet for distribution at Lincolnshire Show 		
June	<ul style="list-style-type: none"> • Advertise for members • Feature articles on Patients Forum for print media • Offer broadcast interviews, particularly Radio Lincolnshire action line programmes • Promote at Lincolnshire Show 		
August	<ul style="list-style-type: none"> • In house newsletter articles about forum 		
September	<ul style="list-style-type: none"> • Media invited to meet forum 		
October	<ul style="list-style-type: none"> • Publicise non-executive role of forum 		
November	<ul style="list-style-type: none"> • Promote site visits to staff and public 		
January	<ul style="list-style-type: none"> • Publicise work programme 		
March	<ul style="list-style-type: none"> • Going live PR 	All	

Reimbursement Policies

- 3.20. The organisers summarised their arrangements for reimbursing their members. On current money arrangements to support members, there was a spread of practice with most reimbursing travel costs including taxis and private vehicles. Half reimbursed on the spot.

Table 8 Reimbursement arrangements

2	Remuneration- defined as giving forum members money or something of similar value in return for their attending and participating in the forum
2	Reimbursement of loss of earnings for members who have to take time away from work (including self-employment)
2	Reimbursement of expenses incurred for public transport use only
6	Reimbursement of expenses of all travel costs including private vehicles and taxis if needed
4	Reimbursement of child care costs
5	Reimbursement of costs for providing an alternative carer

Leavers

- 3.21. We asked how many have left over what period? Wandsworth said that 2 had left over 6 months. The organiser had been told in advance both of the fact of their departure and the reason for it. The important point stated by Wandsworth and echoed by others is that “members need to become involved quickly, so that their interest is retained”. Southend commented that because “capacity building” rather than “recruitment” was their objective, they are not worried about numbers at this stage. Ten persons from the Southend East and three or four from West have left over 6 months. What will keep members says Southend is PCTs/Trusts using PPF members as their skills and confidence increase”. Bexley had lost 2 over 6 months. They had been told in advance and the reason given was that the members “considered this transition period a good time to leave and concentrate on other areas”. SW Herts had lost one due to relocation.

ORGANISERS OVERVIEW

- 3.22. We asked organisers to give an overview of the principal issues. Comments that have not already been picked up in the above narrative included:
- “overall the recruitment process should be kept inclusive and simple as possible so not to inhibit those we are hoping to involve” - **Bexley**
 - “many people do not know what Patients’ Forums are, which is an immediate barrier. A nationwide campaign funded by central government might raise public awareness sufficiently to aid local recruitment . Lack of knowledge of and access to computers has precluded the setting up of an e-mail group for pilot Patients’ Forums Members at present.

Since we have only been recruiting members for ONE MONTH, I think we could supply more information for this study at the end of the year.” - **Camden**

- “The project is designed to support the Patients’ Forum not merely to develop the institution of the Forum. It is designed to make the process inclusive of the PCT and its professional networks , e.g. doctors and nurses. The development of the communication process is owned by the members themselves. There is a need for the PCT and NHS to act in a facilitative manner.” - **SW Herts**

LEARNING POINT VI– SELF-EVALUATION

3.23. The Wandsworth Pilot Patients’ Forum organiser had already submitted his comments to the Transition Advisory Board and made them available for this survey also. We quote the passage dealing with Success, Problems and Lessons Learned since they make a number of points on the process which have been echoed by others and a second broader point that the knowledge held by those involved is much more extensive than can be captured by a single questionnaire on one particular aspect of that experience. The documentation that Lincolnshire shared with us is another proof of the richness of that seam. MAC has long recommended a second event which will gather participants to glean such knowledge at an early stage of the CPPIH’s life. Self-evaluation by experienced organisers is recommended in conjunction with member research.

3.24. One organiser’s views are reproduced on the extract below

ONE ORGANISER’S OVERVIEW: WANDSWORTH CHC
Successes:
The Forum has achieved a number of early successes:
• Negotiation to participate in the PCT cleanliness standards group
• Negotiation to participate in the PCT Race Equality Scheme
• Network member appointed PCT Clinical Governance Committee
• Network member appointed to Local Pharmaceutical Committee
• PCT PEC Lay Member is “honorary” network member
• PCT will involve the Forum in drawing up the Strategic Service Development Plan, as part of the LIFT bid
• Member appointed to Elderly Person’s NSF implementation group
• Excellent response to practice-based PPI survey, indicating widespread interest, among surgeries, in the work of the Forum
• The Pilot Forum has produced the only draft in England of the resources required to set up practice-based patients participation groups across an entire PCT. The Forum is working to support the establishment of these groups
• Visiting rights of GP surgeries negotiated – replies to PPI survey indicated almost universal willingness to participate in these visits.
Problems:
A number of difficulties have emerged:
• PCT slow to involve members of the Forum Network
• PCT centre poor at disseminating information to localities

- PCT appears to have problems around “ownership” of the Forum and is reluctant to approach the Forum/CHC for assistance. Unfortunately, a separate PPI agenda seems to be developing, one which seeks to impose standard and strategic direction but which fails to involve the public in these deliberations
- Danger of initial training providing too much information – this is being resolved by updating the training programme
- Payment of members’ time – far more people would have become involved if they could have been reimbursed for giving their time and commitment to the work of the Forum. There is a genuine issue, here.

Lessons Learned:

There is a need to ensure interested members become involved quickly, if they are to be prevented from drifting away. Working directly with PCT localities appears to offer a greater opportunity for genuine patient and public involvement in the NHS. Start small – better to begin by achieving something; don’t be afraid to share information/good practice with others. We are all engaged in a learning process; there is no single best way to involve patients and the public. Is it fair to expect members of the public to give their time without being reimbursed. Above all, don’t be afraid to make mistakes. All we can do is try!

4. THE FORUM MEMBER SURVEY

The Profile of the Respondents

- 4.1. We have already discussed in paragraph 2.9 the profile of the group of respondents. The profile is educative since it shows us what is likely to happen when the call for people to join goes out through the type of channels most used. As many organisers pointed out, models of recruitment on the basis of pro-active policies that identify and then approach personally members of particular social groups or conditions will be needed. These initiatives will need to be supplemented to achieve responses from specific groups on any given topic or to hear from those who are generally under-accessed for this purpose.

A Commitment to Making a Contribution and to the Health Service

- 4.2. The principal source of information about participating was through another body like the CHC. The principal motivations for joining was the feeling that the NHS was very important and people should make a contribution and be more active in their community. There were of course personal reasons such as “I have been a patient in the last 4 years. I also have a daughter with a disability”. One respondent worked for the Health Service and felt the need for more insight into how it works. We asked about being motivated by good or bad experiences with the service. The experience of bad service was only chosen by one respondent as the most important motivation.
- 4.3. 12 of the 20 respondents had previous experience of representing others or working with local and charitable organisations. Many came from the CHC and one such person commented when asked about the recruitment process “as a CHC member, the process was not one of recruitment as such.” One member new to this sort of engagement found the recruitment process all together too unprofessional. “Too relaxed. Not enough information”. Another person wanted “training and education on the system (not guidance and steerage)”. Early training as part of the recruitment process worked to raise enthusiasm and an understanding of what might be involved. Certainly most were satisfied with the way they had been recruited finding it relaxed

and friendly and one that they could recommend to their friends. 14 were satisfied including 6 who were very satisfied with the process and 16 would recommend the process to their friends and colleagues.

- 4.4. One area of concern is indicated by the 8 people who replied that they had no very definite expectations about what was involved. This in fact may be rather less of a concern than the 9 people who indicated that it was much as they expected. Given the newness of the organisation and its experimental status, more surprise might have been expected. Other comments were more about the early days of organising the body – one member was concerned that the approach was not sufficiently professional and business-like. That respondent wanted the chairperson to be chosen by the members and not imposed by the system.
- 4.5. Other specific suggestions about improvement of the process was the suggestion that more young people needed to be involved with publicity focused at local sixth form colleges and institutes of higher education, making more use of educational websites. Another was encouraged by the PCT having a communications officer to reach other groups such as the elderly. Carers, care wardens and their representatives were also suggested as people who could spread the word.

Three Specific Things to Improve – Member Suggestions

- 4.6. The views given were various and some were very detailed. Appendix B2 gives all the comments made. They vary from suggestions as to other communities to be approached e.g. young people or “we need to recruit people who are just patients on their own” and, added the same respondent, who “are not just representatives of organisations who are experts”. There was a succinct plea for “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. One respondent gave a very detailed description of the information pack they would like to receive:
- “Provision of an index of all local health organisations together with brief details of sizes, functions and objectives and audit reports
 - 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 especially 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.”
- 4.7. There is a plea for independence, good organisation, a sense of purpose and knowledge with good training tailored to the individual and the job, some suspicion of the ‘expert’ representative committed to things as they were done in the past.

General Suggestions

- 4.8. Finally respondents were given another chance to comment on their overall experience and again a wide range of comments varied from the very focussed request “Some assistance with costs wholly associated with the patient’s forum would be appreciated” to the more visionary

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comment that the experience had “opened new vistas”. Another commented that she hoped the exercise would “give her back her faith in the NHS”. Again all comments are available in the Appendix B2.

- 4.9. There were worries about the scale of the task. The member who was also an NHS manager felt that “my colleagues on the Patients’ Forum are in a ‘rush to get started’ without realising the complexities of the service.” One member devised an auditing process to support effective visiting. She wrote that “I would certainly not appreciate being asked to visit anywhere with my current lack of knowledge.”
- 4.10. Organisers stated the importance of early wins and successes. One member said that “I will reserve my judgement e.g. on recommending others to join (don’t know). Terrific potential for forum – needs political support/ more clout. If this does not happen, will resign.”

5. OVERALL CONCLUSIONS – PILOT RESEARCH LEARNING AND BEST PRACTICE

Pilot Research Learning

- 5.1. Both the recruitment practices and this piece of subsequent research are pilot exercises. What has been the overall learning and what conclusions can be drawn? We set out below both the principal learning points for future research and a best practice approach to build capacity. Both are for discussion.

The Limits Of This Work

- 5.2. The numbers of responses both from the groups and the individual members are small. The survey takes its approach from the overall context of the work with what are pilot organisations. So it is with the surveys to a degree. The fact of carrying out the research at this stage offers some good pointers for the future which we will discuss later. The ‘technical’ point to be made at this point in our report is that the numbers fall some way short of statistical significance and would need to be validated by a larger survey in the future. In these initial surveys, we have not identified ‘recruited member’ comments with those that made them nor the part of the country they came from. We have however quoted freely from the remarks that they made in order to underline the essentially qualitative and subjective nature of the work. The data from the ‘recruiters’ questionnaire are by contrast essentially factual compared to the responses of the ‘recruited’ to questions that asked about their perceptions, feelings and intentions. We have identified the organising area where appropriate and useful.

Questionnaire Respondents

- 5.3. A further methodological point has to be made about the ‘recruited’ member surveys. Based on their personal details, it is clear that we have heard back from a particular group of participants who are mainly British, middle-aged or older and who have been involved before in similar representative organisations, often in health or related fields. This is not proof of the success or lack of it in involving other social groups in the representational network. Here it is primarily a measure of those who fill in self-completion questionnaires and secondly of the sample of people to whom organisers or forums sent the questionnaires in the first place- a choice we left them free to make within certain very broad criteria.

Diverse Research Approaches for Diverse Membership

- 5.4. Any future study of member views will have to construct a more variegated sample of potential respondents to reflect the full diversity of the forum members. Such a study would use either a face to face or a telephone interview technique to achieve the collection of views from a fully representative cross-section of forum or other network members. Just as the means of attracting users and the role they are asked to fulfil will vary according to their needs and experience, so will the means of researching their representative experience.

BUILDING CAPACITY – BEST PRACTICE

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- 5.5. 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

- 5.6. 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.
- 5.7. 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.
 - To assist in the identification of issues where patient representatives can make a difference
 - To assess effectiveness in terms of impact on standards of health care
 - To minimise waste by maximising retention amongst those who come forward
 - To understand the drivers of participant satisfaction
 - To assess effectiveness in terms of cost.

SEVEN STEP PROCESS

- 5.8. 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 representative role and develop goals and intentions amongst those attending. Training carries a cost but recipients may recognise it as a valuable non-cash benefit.
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.

A Continuous Process

- 5.9. Organisers should recognise that building capacity and interest is a continuous process. People will drift away and become unavailable for many different reasons. How can the process of promotion and invitation be sustained over time? Will there be regular campaigns at particular times of year? Campaigns for particular groups?

One Stage in the Management Process

- 5.10. Building capacity is just one element in the management process of creating an effective public and patient representative network. It does however offer a number of strong clues as to the characteristics of that management approach. It must be user-centred and adopt administrative procedures that are indeed public and patient centred. The procedures must be tailored to differing circumstances; they must assume little and be ready to learn a lot. Some formality and structure must remain in the structure in the way that records are kept and protected; in the handling of funds and in the way in which opinion is solicited, gathered and transmitted. The system will not be stable, comfortable or easy to manage at all let alone well. We can anticipate great variations in levels of accomplishment. Some forums will fail and disappear, as will

managers. Participation remains a choice for users. How will the official and permanent structures of the Health Service react?

The Permanent Pilot – the Continuous Learning Organism

- 5.11. Experiment, adaptation and evaluation will be abiding features of what may well be an organism in permanent evolution from which we will be able to take new ideas aimed at reviving and revolutionising citizen participation in the national life. In this sense the pilot will be permanent.

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