

# 'Working the system'. Achieving change through partnership working: an evaluation of cancer partnership groups

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## Abstract

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**Aims and objectives** To investigate the characteristics and achievements of cancer partnership groups – collaborative service improvement groups formed of NHS staff and service users – in the 34 cancer networks in England, and in particular to explore the influence that such groups had on local cancer services.

**Design** A qualitative approach employing a structured telephone survey, face-to-face interviews and documentary analysis.

**Participants and setting** Thirty cancer networks in England with an active Partnership Group completed the telephone survey. From these 30 networks, six networks were subsequently selected from which service users and NHS professionals involved in partnership groups and NHS professionals who were non-members were recruited to take part in face-to-face interviews.

**Results and conclusions** Partnership groups were established in the majority of cancer networks. Typically, these groups were at network level, been established for less than a year, met once every 2 months, and were populated with both service users and health-care professionals. Five common activities and achievements were identified: establishment of the group itself; acting as a 'reference' group for consultation; networking and representation on other groups; patient information and communication and proactive influencing. Activities progressed in scale and complexity as groups evolved. Groups had learnt the basics of change management and some identified a more sophisticated understanding of change processes in the NHS as essential for the group's motivation and survival. When gauging the impact of involvement strategies it would seem important to subscribe to broad indicators of success that include both process and outcome measures.

## Introduction

Patient and public involvement (PPI) is a major theme in the current reformation of the UK National Health Service (NHS), its advancement marked by a succession of policy and legislative milestones including *The NHS Plan*,<sup>1</sup> Section 11 of the Health and Social Care Act 2001,<sup>2</sup> and the NHS Reform and Health Care Professions Act 2002.<sup>3</sup> In the acute sector, the theme of involvement arguably has been most evident in cancer policy. The 1995 Calman-Hine report<sup>4</sup> emphasized not only the need for NHS cancer services to be patient-centred but also the requirement for NHS decision makers at all levels to take account of patients' views and preferences. This direction was reinforced through the NHS Cancer Plan (2000),<sup>5</sup> which set a target that by 2001 'cancer networks will be expected to take account of the views of patients and carers when planning services.'

However, this policy drive lacked a cancer-specific evidence base to inform policy makers as to the structures and processes best suited to the engagement of service users in the planning and monitoring of services. A study published in the same year as the NHS Cancer Plan<sup>6</sup> reported that, generally, cancer service users and staff viewed user involvement as important, but that considerable disagreement existed on the appropriate scope of involvement or on the people who should be involved. The study also found 'mutual suspicion between users and providers' and a 'legacy of mutual hostility between some healthcare professionals and some user groups,' which along with other barriers contributed to a sober view on the short-term outlook for 'involvement'.

In pursuance of the NHS Cancer Plan target, in 2001 a report to the National Cancer Taskforce<sup>7</sup> proposed that a structure of cancer partnership groups be set up in the 34 cancer networks in England. Subsequently, in 2002 the Department of Health and the charity Macmillan Cancer Relief jointly initiated a 3-year programme to support the establishment of local partnership groups, comprising users of cancer services, health professionals and managers, to

work with cancer networks to facilitate user involvement in the planning and delivery of local cancer services: this programme was referred to as the 'Cancer Partnership Project' (CPP). In 2004, the CPP fund commissioned an independent evaluation of the CPP that looked at the structures, activities and outcomes of the 'Partnership Groups' operating in cancer networks. This paper reports the evaluation's findings regarding the activities of groups and their influence upon local NHS decision making. Interested readers are encouraged to refer to the commissioned report for a full description of the study and results.<sup>8</sup>

## Methods

Our research aims and objectives were exploratory and it was decided that qualitative methods would be the best way to elicit views from key informants.

Data collection consisted of two different activities, with a total of four 'sets' of participants approached to provide data. The first activity was a 'mapping exercise' to collect factual information on Partnership Group activity from each of the 34 cancer networks in England. This included information on the composition and structure of groups, activities and achievements and barriers and challenges (Box 1). This information was collected during the course of a telephone interview (carried out by either PC or JS) with a representative of each partnership group. We were able to conduct 29 interviews (27 patients or carers, one health professional, one group facilitator). Twenty-five of these were chairmen, and four were 'ordinary' group members with delegated authority. The interview data were supplemented with documentary evidence, such as annual reports.

The second activity comprised face-to-face interviews (carried out by either PC or JS), with patients and NHS professionals in six cancer networks. The research team selected the six case sites on the basis of a number of factors. We wanted to access groups in a variety of areas across England with the intention of gaining accounts from an array of differing

**Box 1** Activity 1 (telephone survey) topic list

Configuration of group  
 Chairman  
 Facilitator  
 Establishment of the group  
 Frequency, timing and location of meetings  
 Documentary evidence: terms of reference, minutes, annual reports, etc.  
 Membership: composition, diversity, attendance  
 Inclusion: challenges and strategies  
 Role of NHS members  
 Group's strategy/work plan/objectives  
 Communication  
 Use and management of CPP funding and other financial support  
 Training  
 Other explicit or implicit support  
 Activities  
 Cross-membership and networking  
 Future plans, and barriers and strategies to overcome them

locations that reflected the diverse nature of the country. We were not attempting to gain a 'representative' sample of groups, as in reality no two groups were alike, but rather as wide a variety of groups as possible. With this in mind, we selected groups on the basis of: urban vs. rural location (three primarily urban networks, three primarily rural); areas with more vs. less ethnic diversity (based upon data from the government's 2001 Census Ethnic Group estimates, the proportion of non-White British residents ranged from 3.1% to 32.8% across the six networks); geographical location (one each in north-west, north-east, south-east and south-west England, and East Anglia and the midlands); 'age' of group (range of ages: 6 months, 8 months, 2½ years, 3 years, 5 years, 6 years); more vs. less active groups, judged by responses in the mapping exercise described above; and groups that operated only within one geographical area of a cancer network – 'local groups' vs. those that operated across the whole network (two local, four network). Our intention was to recruit from each network two to three service users and two to three NHS professionals who were members of the group along with two to three other NHS professionals, such as managers and commissioners

who were not members of the group but worked in the NHS organizations covered by the partnership group. In the event we recruited 23 group members consisting of 12 service users and 11 NHS staff, and a further six NHS staff who were not group members; this last group was included to get an 'external', local NHS perspective on the groups. Recruitment was achieved through distribution of a sealed invitation pack to each group member via the group's facilitator and to non-members (external NHS staff) via the Network Lead Cancer Nurse; the lead nurses were asked to distribute the packs to senior NHS staff with a decision-making role in local cancer services. We relied on these 'gatekeepers' – the group facilitators and the lead nurses – to distribute as many packs as possible and we provided selection instructions intended to minimize bias (e.g. packs to be distributed to all group members, and not just the most active or supportive).

Interviews were conducted in each respondent's home or workplace, were audiotaped and followed a semi-structured schedule. Issues explored included participants involvement in partnership groups and views on the group, particularly with regard to its effectiveness and its influence on NHS services (Box 2).

As data were collected from NHS staff and patients across England, approval was sought and subsequently gained from an NHS Multi

**Box 2** Activity 2 (case sites) topic list

Interviewee personal characteristics and professional/service user background  
 Opinion on patient and public involvement in NHS  
 Involvement in similar initiatives:  
 e.g. patients' organizations, voluntary work  
 Impetus/motivation for joining the group  
 Attendance, commitment, particular interests  
 Communication within and organization of the group  
 Group leaders: chairman and facilitator  
 'Performance' of the group  
 'Performance' of the group: challenges and strategies  
 Partnership working  
 Recruitment and membership  
 Personal challenges and rewards of involvement (practical, economic, physical, emotional)  
 Influence of the group on local NHS

Centre Research Ethics Committee. Subsequent to this local NHS research ethics committees were informed of the study and local NHS research and development approvals sought where possible.

In order to achieve effective engagement with NHS cancer service users in the design, execution, data interpretation and dissemination a study reference group was convened. In addition to five service users it included representatives from commissioners and experts in the field. The processes of data analysis and interpretation were iterative, and via the reference group were inclusive of service users' perspectives and insights. Thematic analysis involved the responses to both the telephone and face-to-face interviews. This required the careful reading and re-reading of data with the aim of noting recurring patterns or themes that pull together many separate pieces of data. It was conducted by two members of the team, with input from three other researchers not involved in the project as a means to ensure the concepts being investigated were shared and whether multiple coders could reliably apply the same codes. This 'collective' approach to analysis proved to be both effective and relatively rapid.

## Results

Information on the characteristics of groups, how they were set up and how they function will be presented before proceeding to the findings on activities and influence.

### Characteristics of partnership groups

Groups had been established in 30 (88%) of 34 networks. A network-level partnership group existed in 25 networks (83% of networks with groups); local (in fact NHS trust-based) groups operated in the other five networks. In 27 networks (90%), the group had direct representation on the network Board or equivalent high-level committee, typically via two service user representatives. Groups had been established for a median of 21 months (range: 6 months to

8 years). Twenty-five (83%) groups had been active for less than 3 years, and nine (30%) for 1 year or less. The other five (17%) groups pre-dated the CPP initiative, i.e. had been independently established and resourced by cancer networks or trusts.

Without exception, the interviewees indicated that the group's establishment had been led by an NHS organization (trust, health authority or cancer network). A number of interviewees perceived that the NHS organization had acted in response to a national directive or initiative, citing the Calman-Hine Report or NHS Cancer Plan. For network-level groups, the network lead nurse often was cited as the 'driving force' behind the establishment of the group.

The process of setting up a group typically involved an advertising campaign to attract service users to a 'development day' at which a forward plan could be discussed and agreed. Officers from Macmillan Cancer Relief typically provided support and advice for the NHS staff leading the initiative, assisted with 'development days', and provided training for service users via Macmillan's Cancer Voices programme.

Twenty-five (83%) groups met at least once every 2 months. Groups typically had a 'core' membership of 20 people who attended meetings regularly and were active between meetings, and had a larger 'mailing list' membership of up to 100 people. On average, two-thirds of core members were service users and one-third NHS staff. Of the 'service users' in a group, characteristically 75% were cancer patients and 25% carers. Service users often made a significant commitment to the group in terms of time and energy: they carried out activities for the group in between meetings, they worked within sub-groups or 'working parties' to take forward specific projects, and they read and considered documents – some respondents mentioned 3 or 4 h of reading per week. NHS staff generally reported less 'commitment': with some exceptions, NHS staff participated in the group as (a small) part of their job and their involvement was limited by competing demands.

### Cancer Partnership Project funding

The CPP provided funding to each cancer network of £15 000 per year for 3 years to support the advancement of partnership groups. Each network set its own budget and spending plan. Twenty-five (83%) groups used the funding to meet the salary costs of a paid facilitator, typically a network employee for whom service user involvement was their core role. Funding also was used to meet meeting expenses, including members' expenses and training costs.

### Aims of partnership groups

The groups' aims were typically framed around influencing local cancer policy and services for the benefit of patients, and ensuring that the service user perspective was integral to service development. While no two groups' aims were exactly the same, it was possible to draw out some core elements that underpinned the aims of the groups: (i) providing a 'voice' for service users; (ii) working in partnership with other parties; (iii) ensuring service users were involved in decision-making; (iv) influencing policy and services; (v) improving patient care.

### Activities and achievements

We found five categories of common activities and achievements.

#### Establishment of the group itself

Bearing in mind that over 80% of groups had been active for less than 3 years in December 2003, some groups could point only to 'set up' work – recruiting for and establishing the group, recruiting a Chairman, recruiting a facilitator, drawing up terms of reference, reaching a consensus on initial plans, and producing promotional material. Some respondents were rather apologetic for this 'slow progress', while others saw this as a very necessary, if somewhat dull and frustrating, stage of group development. Respondents from both new and older groups noted that simply maintaining the group –

organizing meetings, meeting paperwork and communications, arranging speakers, arranging training, managing expenses – in itself provided a substantial workload.

Other respondents pointed to the existence of the group being in itself an achievement and cause for celebration. Their judgment was that, typically for the first time, a formal and accessible channel of regular, business-like communication was open between service users and senior local NHS staff. Moreover, service users were becoming involved, albeit it gradually, in NHS decision-making processes; service users were 'at the table', and the large majority felt their voices were being heard and perceived as having value.

#### Acting as a 'reference group' for consultation

A prime activity of most groups was to act as a 'reference group' for consultation, providing an organized resource, clearly valued by NHS staff and others, to access service users' views. At one end of the scale this might involve a health professional asking for feedback on the wording and distribution of a local patient survey questionnaire; at the other, it might involve service users working alongside NHS staff on a service redesign or development project.

One group, for example, had been substantially involved in the planning of a new cancer centre. An NHS member of the group said of the service users:

They've taken a very active role in designing the building, turning up to all the meetings and saying 'This will work, this won't work, you should do it this way, you should do it that way'. They're on all levels of that process, from the very high-level project group to the working parties, and they have made a big difference to the way that building is being designed. I think it's an excellent group. It's been a great privilege to work with them. (Interview 41: group member: consultant clinical oncologist)

Another group provided a good example relating to cancer research:

At the behest of the network Research Group, we've been looking at how to recruit more patients into trials. We discussed why there were problems

recruiting people, from the patients' point of view, and advised that perhaps information be given out earlier on in the process, rather than just being asked – full stop – when you are about to go into the trial. They've taken that on board, and somebody has produced a piece of paper now which can be given to all patients on diagnosis... which explains that they might be asked at a later stage to join a trial, and explains what trials are, and how your treatment isn't any worse if you don't join them, etcetera, to get people in the frame of mind, if you like, so it isn't such a stark choice when the time comes. (Interview 19: group chairman, patient)

### Networking and representation on other groups

While most service users were involved in partnership groups in an 'independent' capacity, rather than as formal representatives of another group, almost without exception, partnership groups provided the nucleus for an incredibly wide network of user involvement in other groups and committees. With one or two exceptions, groups were represented upon the cancer network Board or equivalent committee, and had cross-membership with a wide array of other network and non-network, cancer-related and non-cancer-related, local, regional and national groups. This list from one group serves as an example: Cancer Network Management Group, Service Improvement Partnership, Patient Information Group, Palliative Care Steering Group, Research Network Steering Group, three Tumour Site-Specific Groups, the Cancer Action groups in three acute trusts, plus various trust-based project groups, the Cancer Clinical Lead group in 10 primary care trusts, the national Macmillan Listening Study Steering Group, and a national research group in palliative care.

### Patient information and communication

Many groups reported that their activities included projects concerned with patient information and communication. Partnership groups had developed booklets, leaflets and template letters for a wide array of purposes, some had

established subgroups dedicated to patient information, and at least one group had compiled an information directory to enable patients to access existing resources more easily.

Another topic, which arose from several groups, was that of 'breaking bad news'. At least one group had a 'breaking bad news' working party, another had been involved in training for NHS staff, and others had worked on drawing up and ensuring the implementation of 'breaking bad news' policies and standards. This quote from a group chairperson shows the steps taken in such a process:

We have successfully drawn up, and now implemented Breaking Bad News standards. It came up in an initial brainstorming session the group had, and it was a manageable chunk of work that we could do. I felt, as Chair, it was very important to have an initiative that we could start and see a finish to, to really encourage people to carry on and do something a bit bigger.

We looked at how we would want to have bad news given to us. We had a whole list of things on a flip chart and then from that we drafted up our guidelines. They were taken to the network Policy Board for endorsement, endorsed and introduced as a standard across the network. A subgroup – with the support of the audit department – have developed audit of the standards ... Patients now will be given bad news in a respectful and dignified manner. They shouldn't be told in open ward, it should be done in a sensitive manner, and they have the choice of having carer or relative with them. (Interview 22: group chairman, patient)

### Proactive influencing

Last, but by no means least, 'proactive influencing' was seen by groups as a vital element of their role. The tactics used to influence the shaping of cancer services were many and varied and included getting people onto decision-making groups, talking to influential actors such as NHS Chief Executives, Clinical Directors and Lead Cancer Nurses, press and publicity, road shows, conference talks and involvement in strategic service planning.

Groups sought to influence not only the NHS but also other bodies whose systems or working

practices affected the lives of local cancer patients. Access to services was one common focus for this influencing, with groups actively working to bring about positive changes to car parking arrangements and public transport provision by lobbying car park management companies, bus companies, a bridge management company and local councils.

#### *Influence of partnership groups*

Well-established, active groups provided evidence for a plurality of achievements, points of influence, activities and projects. These activities typically were closely aimed at improving the patients' experience and, it was generally agreed, were unlikely to have been conducted had the group not been in existence. However, group members did not overstate the 'impact' of their activities upon patient care: when asked about the 'influence' of the group, many respondents prefaced their comments by acknowledging that service user involvement is a huge and complex challenge, which, if taken to a literal conclusion, would require substantial shifts in NHS culture, funding, and systems. The size of the endeavour was important: even the most meaningful of achievement seemed but a small step forward.

Bearing this in mind, respondents overall felt very positively that the groups were 'making a difference' to local NHS cancer services. A small minority were of the opinion that the groups were making no 'real' difference. However, respondents who responded negatively or were undecided related almost exclusively to groups that were at a fledgling stage of development or had other operational difficulties: it was not that a vibrant, well-organized group was making no difference, it was that the group was not yet working 'properly'. The point was stressed repeatedly that 'things take time' – groups take time to form, work takes time to do, change takes time to happen – and that user-influenced change is a long-term project:

I think it's starting to. I can't say for definite if it's really making a difference – come back in twelve months time! (Interview 52: group member, Cancer Information Officer)

More than one service user referred to the sense of being a 'pioneer', and others made other comments on a similar theme:

It's a very exciting time within the NHS, isn't it? It's just the time to be influencing. (Interview 35: group member, carer)

Respondents often referred to the enormity of the task of changing NHS culture:

The NHS is like a huge oil tanker, it takes a long time to turn around. The culture needs to change, people have got to learn to do things differently. (Interview 16: group chairman, patient)

Given the size and complexity of the undertaking, it was noted as critical that groups have a 'realistic' understanding of the 'workings' of the local NHS, and adopt effective strategies to work with it. This NHS member gives an example of what other interviewees referred to as the 'chipping away' or 'drip, drip, drip' approach to influence and change:

I know the size of the mountain they have got to push. They may feel frustrated [but] soon learn that it is not enough to say their views once, they need to echo things and wait for the right opportunities and sometimes they are told there is no chance of changing what they want. There's a little air of deceit sometimes; we invite people in because we want to hear them and then we don't do anything with what they tell us. (Interview 43: group member, network lead cancer manager)

Partnership groups expressed a need to 'learn to work the system', to know which 'buttons to push', to know who has influence and who does not:

You have to get to people who can make a difference ... ideally it's the Chief Executive of the acute trust. (Interview 44: group member, patient)

The feedback loop is important. You need to be looped back into key influential figures, like the commissioning managers. The groups need to have local strong links that can actually influence. To me, without that part of the loop they end up being – possibly being – nothing more than a support group to each other. (Interview 55: non-member, specialist cancer nurse)

In addition to slowly 'chipping away', and 'learning to work the system', a third strategy

for influence was to focus on 'small hits': achievements that might not be huge systems change but have a real, positive impact upon patients' lives.

It's about making differences with individuals, I don't think differences with systems, I don't think we make any differences with those. But if you can have some impact with a group of individuals who look at things differently as a result, that's all to the good. (Interview 44: group member, patient)

Yes, influence in little ways, only little ways. You can't do anything [more] because our health authority is part of the big, national NHS, so it's got to do what it's told. (Interview 33: group member, patient)

## Discussion and Conclusions

This was an exploratory, small-scale qualitative study that aimed to describe the type of activities partnership groups are involved in and to gauge their perceived influence to date. Certainly we found evidence of activity: the large majority of groups had developed quite substantial portfolios of projects, with a clear focus being the improvement of local services and the 'patient experience'. It was also evident that these activities progressed in terms of scale and complexity with the growth in a group's knowledge, expertise and confidence. A typical early activity was to act as a 'reference group' for NHS consultations; 'mid-level' activity consisted of relatively self-contained initiatives to improve the current patient experience, such as development of patient information leaflets or changes to hospital signposting; 'high-level' activity, visible only in well-established groups, consisted of 'proactive influencing' and involvement in decision-making about substantial service developments, such as new builds. All three levels may be regarded as legitimate PPI or partnership activities; the 'high-level', however, is the only one that demonstrates significant collaboration in NHS 'corporate' decision making.

Only a handful of groups demonstrated the capacity to undertake high-level activity and

these displayed certain characteristics. They had been established for 2 years or more. They were well organized, with systems in place to conduct communications and business in between meetings, sometimes practically on a full-time basis. Sometimes a paid facilitator did this continuous work, sometimes a small group of committee members. High-performing groups also had distinct leadership from the Chairperson, who might be a service user but alternatively might be the facilitator: the key characteristics were that they were committed to the group and that they had actual leadership/chairing skills. Moreover, they contained a highly-committed and active 'core group' of members, a nucleus who got involved in projects, responded to consultations, and acted as conduits (albeit unsystematically) for information and news from numerous other cancer-related groups and networks. Context was also important: successful groups typically were situated in cancer networks where there was tangible support for PPI, be that actual corporate support, evidenced, for example, by positive engagement with the Network Board, or proxy support such as that offered by senior clinicians and other senior staff. In short, successful groups were in receipt of the message, from one or other senior NHS source, that they were wanted and that their work was valuable.

Although this was not a prospective study that tracked groups' development over time, from our retrospective data on a cross-section of groups at different stages of development it was clear that groups were evolving organically over time. This evolutionary process needs to be acknowledged in order to understand the needs of service user group members at different stages in this process and to appreciate the level and type of achievement possible at each phase. It also underlines the importance of subscribing to broad indicators of success that include both process and outcome measures when gauging the impact of involvement strategies. At present there are no agreed criteria by which to judge the success or failure of these groups, these would be important when planning any future evaluation.

A key outcome measure is 'influence' or impact. This is difficult to assess. Certainly the large majority of respondents, both service users and NHS staff, were of the opinion that the groups' activities were 'making a difference' to local NHS services; some groups more than others, some differences more evident than others. Specific instances of positive 'change' were cited. Respondents also believed that the activities would not have been undertaken had the groups not been formed, sometimes citing examples of projects or ideas that had been 'sitting on the shelf' for years previously with no NHS capacity to take them forward. However, it is not possible to substantiate these views with comparative data: no prospective evaluation was commissioned, nor did we find any group that had identified measurement of impact as a strategic objective.

There is no substantial, coherent body of evidence to verify the usefulness of PPI in improving health and health services. This may be because it is difficult to identify the effects of such involvement. Equally, it is not easy in health services research to demonstrate that a decision can reasonably be attributed to a particular source. Crawford's major review on user involvement<sup>9</sup> notes that much of the literature consists of accounts prepared by those directly involved or by those with a vested interest in an initiative's success and may therefore be subject to bias. This charge might be levelled against two recent compendia of case studies of PPI published by the Department of Health.<sup>10,11</sup> Nonetheless, a modicum of evidence that user involvement has led to some changes in service provision was found by Crawford. Such changes pertain primarily to the preparation of patient information or systems to make services more accessible. The authors note that some research also suggests that user involvement has had a wider impact on the organizations involved, altering staff attitudes and general organizational culture. The view that user (and public) involvement has had a limited impact on service provision is reiterated in a recent report.<sup>12</sup> It argues that while the NHS is improving its systems for obtaining feedback from users, it is less active in ensuring that this

information influences decision making. In short, user involvement in service-level change has often been assumed to be an intrinsic good with no substantial evidence as to its impact.<sup>13</sup>

Crawford and colleagues<sup>14</sup> identified three key purposes of PPI, one being to improve the effectiveness of services and the patient experience as discussed above. The others are to increase accountability and to promote the interests of service users. The first of these typically is identified with a 'democratic' model of involvement, in which citizens should be involved in service planning as a 'right'. The second is identified with a 'consumerist' model, the foci of which are individual choice and return on investment. Croft & Beresford,<sup>15</sup> among others, see a fundamental conflict between these two, the former being concerned primarily with individual 'satisfaction', the latter with personal and collective empowerment. It might be seen as unfortunate then that government PPI policies attempt to cover both options. One key guidance document, as an example, states: 'Four of the ten core principles underpinning the NHS Plan directly support the PPI agenda. They are that the NHS will: (i) shape its services around the needs and preferences of individual patients ...' [<sup>16</sup> p.vii]. Rhodes and Nocon<sup>17</sup> warned against the forced conflation of consumerism and empowerment, citing evidence that it caused confusion and acted as an impediment to partnership initiatives.

It is noteworthy not one of our 58 interviewees made any indication whatsoever that the partnership groups were set within a consumerist model. The service users we interviewed were adamantly altruistic and the groups were not perceived by professionals as existing to advance patients' interests *per se*. The emphasis was upon the use of direct (patient) experience to inform service development, and collective patient empowerment indicated as a corollary of that. The scepticism of cancer professionals towards user involvement found by Gott *et al.*<sup>6</sup> and more recently by Barley *et al.*<sup>18</sup> was in our study more usually directed towards senior NHS management: that is, professionals were sceptical of the actual commitment of, and suspicious of the motives of, NHS boards and

indeed 'the government' to PPI, rather than being sceptical of PPI itself.

We argue that reasons for this include the emphasis upon 'partnership' in the CPP model, and the working philosophy of pragmatism. 'Complexity' was a dominant theme. Many group members spoke of the complexities of the NHS, cancer services and the culture of health care. Understanding and knowing how to work within the mainstream of the 'system' was an important goal in itself, and learning who to contact and how to influence them were recognized as essential lessons. Influencing change seemed effective when relationships were developed with key people, and groups put effort into nurturing these relationships in a strategy to further their influence. In summary, groups appeared to have learnt the basics of change management and some identified a more sophisticated understanding of change processes in the NHS as essential for the group's motivation and survival.

## Conclusion

Section 11 of the Health and Social Care Act 2001<sup>2</sup> placed a new duty on NHS institutions to make active arrangements to involve and consult patients and the public in (i) planning services, (ii) developing and considering proposals for changes in the way those services are provided, and (iii) decisions that affect how those services operate. PPI forums are the model for user involvement in NHS and Primary Care trusts that has emerged. Although each PPI Forum has some say over its actual work and role, their core roles are to: monitor and review local services, seek patients' views on services, inspect NHS premises, make reports and recommendations to trust management, and refer problems to other authorities.<sup>19</sup> There is an undeniable emphasis upon 'scrutiny' in these core roles. This emphasis is wholly lacking in the CPP model, which in contrast emphasizes involvement in NHS decision-making coupled with smaller-scale, user-led initiatives.

Commission for Health Improvement (CHI),<sup>12</sup> in a recent summary of the progress of

PPI in the NHS, reported that organizations routinely gather feedback from service users, but that very few are doing anything that allows service users directly to influence policy and practice. The CPP model appears to address this need relatively well. Nevertheless, it is difficult to estimate the magnitude of impact of cancer partnership groups, especially because there have been many other influences at work, such as the growth of user involvement generally in the NHS.

Groups were beginning to treat organizations as what Anderson *et al.*<sup>20</sup> term 'a messy political process', where influence can be brought to bear all the time and where learning and change are achieved in both formal and informal (and often unpredictable) ways. Established groups with a strong core membership and a portfolio of projects were beginning to talk about and think about the next step, the third stage of PPI. These respondents felt that, while their groups were achieving much, they remained – to use a phrase from the CHI report – at the 'periphery of corporate decision making'. This third stage is one in which PPI activities are integrated with other efforts to improve services and in which PPI is regarded as a core activity for the NHS organization: that is, PPI becomes part of everyday practice across an organization. It would be valuable to conduct more work, possibly through employing a prospective approach, to further understand the stages of evolution of partnership groups, and in particular to identify strategies for the next stage of their development.

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