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## ABSTRACT

In this methodological paper we discuss use of the Nominal Group Technique to facilitate the involvement of people with chronic pain and other stakeholder groups in the design of a community based pain management program. Based on our experiences of using the technique in a study conducted in the south west region of the United Kingdom, we explore conceptual and logistical issues relating to patient involvement in health service development; discuss political issues relating to the articulation and synthesis of different stakeholder perspectives; and provide a description of how the technique can be applied in the above context. We conclude that while the Nominal Group Technique is not a panacea for the difficulties encountered in patient involvement, it does offer advantages over other approaches.

## KEY WORDS

Research design; focus groups; health care, users' experiences; health care, decision making; patient participation; pain, chronic

Enabling patients to participate directly in decision-making about the design, organisation and operation of health services is frequently espoused as a policy objective, (Milewa, 2004, Forster and Gabe, 2008, Florin and Dixon, 2004), but attempts to do so are often criticised for being superficial, tokenistic, or even manipulative (Rowe and Shepherd, 2002, Arnstein, 1969, Baggott, 2005). This dilemma is particularly acute for service users with social, psychological or health problems that may limit their capacity to engage with formal institutional arrangements for community participation. One solution is to treat the articulation of user views as a research question. Social surveys can quantify needs and preferences and measure support for proposed service models, but although such data are valuable, surveys do not enable respondents to engage in the collective reflection and negotiation that are central to the process of service planning.

Qualitative methods, with their open-ended questioning and rich description of responses, offer an approach to user involvement that is closer to direct participation in the planning process, particularly those that generate data from groups rather than from individual informants. However, many of the problems that apply to direct participatory institutions also apply to the use of qualitative methods, for example, the extent to which participants are representative of the wider patient group, the possibility that power inequalities within a group might silence some voices and valorise others, or that individual differences might be masked within a false consensus. Arguably, many of these difficulties can be diminished by careful facilitation of group interaction and by sensitive and nuanced data analysis and writing up. Important though these skills are, they are difficult to specify or guarantee, and it may be more effective to configure the data collection and analytical process in a way that directly addresses these difficulties.

The problem of achieving legitimate participation in health service development cannot be elided by methodological finesse, but the adoption of techniques that are designed to minimise the effects of power inequalities between participants may at least edge us closer to what Habermas optimistically posits as an 'ideal speech situation', (Habermas, 1970, Habermas, 1990, Habermas, 1996). In this article we describe our experiences of using the Nominal Group Technique to elicit the views of people with chronic pain, (and other stakeholder groups) regarding the development of a community based pain management intervention, as a precursor to a randomised controlled trial of the intervention. Our purpose is to assess the methodology as a means of articulating patient voices in which the distorting influences of power are minimised, and to provide a practical guide to using the technique for this purpose.

## PUBLIC AND PATIENT PARTICIPATION IN HEALTH SERVICE DEVELOPMENT

Providers of goods and services usually need to listen to what their customers want. Private companies often invest in market research to make their products more competitive, and have a strong incentive to act on the findings; if they get it right they make a profit, but if they fail to respond to consumer demand they will not usually prosper. Companies must also consider what customers are willing to pay, as even goods that customers want are unlikely to sell if overpriced. The mechanisms of customer demand, willingness to pay, competition between providers and the likelihood of poorly performing providers going bust, provide a powerful incentive to give customers what they want at a price they are willing to pay. However, despite neo-liberal rhetoric about bringing market mechanisms to bear on the provision of health care (Green, 1988), there are compelling arguments against marketization and a broad consensus that

access to healthcare should not be limited by ability to pay (Blank and Burau, 2010). Electorates in the developed world are reluctant to see individuals suffer or die because they cannot afford health care, (Blank and Burau, 2010), leading to the predominance of health care systems that collectivise the risk of falling ill, either through private or social insurance schemes, state regulated systems funded from general taxation, or charitable provision.

When the UK National Health Service (NHS) was introduced in 1948 it was assumed that patients' needs and wants would be optimally satisfied by the provision of professionally dominated services funded from the public purse – doctor knew best and the taxpayer would pick up the tab, (Milewa et al., 1999:447). It quickly became apparent that without some mechanism for eliciting the views of health care users service provision was likely to become unresponsive to patient preferences and that decisions about the allocation of resources would be perceived as illegitimate. This 'democratic deficit' can also be found, to a greater or lesser degree, in health care systems funded by private or social insurance or by charitable donations, (Cooper et al., 1995).

Health care, therefore, poses a dilemma; the consequences of limiting access according to ability to pay are unpalatable, but suspending the market mechanism removes the means by which consumers traditionally signalled their preferences to providers and (assuming their pockets were deep enough) ensured they were met. The various attempts to facilitate public and patient involvement (PPI) in health care decision making, both in the NHS and elsewhere, are responses to this dilemma, (Mold, 2010, Hogg, 2009, Milewa, 2004, Baggott, 2005). However, willingness to act is not always a guarantee of success, and the current proposals, (Department of Health, 2011), like the ones before them, are likely to encounter tensions or contradictions that make genuine involvement difficult to deliver. Below we discuss three of the key tensions.

### *Public versus patient involvement*

Public and patient involvement (PPI) are often linked or used interchangeably in policy statements, even though there is a potential antagonism between the two. Both parties have an interest in the development of high quality cost-effective services, but 'the public' has an interest in seeing the most cost-effective deployment of resources across the full gamut of health services, whereas 'the patient' has an interest in optimising the particular services he uses irrespective of the opportunity costs. This antagonism might suggest that patients should be disqualified from the debate about service planning on the grounds that they are a vested interest:

"We use public involvement to refer to the involvement of members of the public in strategic decisions about health services and policy at local or national level – for instance, about the configuration of services or setting priorities. Public involvement is different from patient involvement, which refers to the involvement of individual patients, together with health professionals, in making decisions about their own health care." (Florin and Dixon, 2004).

This assumption, that planning of health care is a 'public' issue and that patients should only be involved in decisions about their own treatment, is problematic. First, because it assumes that other participants in service planning, (members of the public, clinicians, managers, etc.), are impartial and disinterested. If this assumption cannot be sustained, and it seems to be at least questionable, then why should patients be excluded from service planning when other vested interests are not? Secondly, as the Expert Patient Programme recognised (EPP Evaluation Team, 2005), patients may have an understanding of their needs and how they should be managed that might not be apparent to non-sufferers, which suggests that their role should

extend beyond making individualised treatment choices and submitting complaints about existing services, to include a more proactive engagement with the development of new services.

If we accept that patients may have a privileged insight into the nature of their illness and how it should be addressed, then the question is not whether patients should be involved in service development, but rather what the nature of that involvement should be. A key question is whether patient involvement should extend beyond the articulation of needs and preferences to encompass the delegation of decision-making power.

### *Listening versus delegated power*

Many of the PPI initiatives introduced by successive UK governments have emphasised the need for health care providers to listen, but have not obliged them to act on what they hear, with the result that decision making power ultimately resides with the provider. The reluctance to delegate decision making power stems from the moral hazard of collective provision. In a free market, consumers make a trade-off between the cost and the quality/quantity of services, i.e. their demands are tempered by their willingness to pay. However, patients in a collective health care system utilise resources from a shared pot and the only trade-off they make is between their sense of entitlement and the guilt of using resources that others might need. Game theory suggests that pooled payment mechanisms tend to inflate individual resource consumption, for example, diners who agree to split their restaurant bill equally, tend to consume more than those who pay according to the amount they have consumed (Gneezy et al., 2004). Thus, on the grounds of cost-containment few would argue that patients should be given carte blanche to design the services they want, without considering the competing demands of different patient groups.

One solution to this variation on ‘the tragedy of the commons’ would be to co-opt patients into the planning process in a way that makes them conscious of competing demands and resource constraints. However, obliging patients to adopt the role of public representative, could defeat the purpose of including them qua patient. A better solution might be to separate the articulation of needs and preferences from strategic decisions about service provision, but with PPI built into both. This would entail listening to patients’ needs and preferences, but leaving decisions about service provision and resource allocation to a separate commissioning function that also has public involvement. What is required is a mechanism that encourages the commissioners of health care to act upon the preferences of patients without compromising broader imperatives of cost-effectiveness, quality and equity. Finding such a mechanism is a complex challenge, and patient involvement initiatives are likely to provide little more than a democratic gloss for bureaucratic decision-making until it is met. As well as reconciling patient preferences with competing demands on resources, commissioners must also balance them against expert opinion. This leads into another tension, between science and democracy.

### *Science versus democracy*

Many of the achievements of modern medicine stem from the application of scientific methods, (Le Fanu, 1999, Porter, 1997) and the movement for Evidence Based Medicine/Practice has reinforced the view that the content and configuration of services should be determined largely by empirical evidence of efficacy, (Gray, 1997). However, critics have argued that bio-medical discourse is inevitably bound up with the exercise of professional power, i.e. that the clinical

gaze is a means of surveillance, regulation and the disciplining of bodies, (Foucault, 1963, Foucault, 1980). Should patients, therefore, be given what they want, or what experts think they need? This tension has traditionally been addressed through notions of informed consent, but the principle usually applies to individual treatment decisions and only extends to the right to decline treatment or choose between different treatment options. Involving patients in the design of a service raises the question of which aspects of the service are open to negotiation by patients and which are the exclusive preserve of clinical or other expert decision-making. Decisions that directly influence the effectiveness of treatment might (arguably) be deemed non-negotiable, while other aspects of service provision, such as the location and timing of clinics and the provision of patient information, might be considered appropriate for patient preferences to be considered.

Drawing a distinction between issues in the development of health services that are legitimately the exclusive domain of experts and those on which the patient or lay perspective might be brought to bear, is difficult. Who should decide where the line is to be drawn? If patients lack the expertise to make certain decisions, then it might be argued that they necessarily lack the capacity to decide which issues lie beyond their competence, but leaving the experts to decide which decisions the laity can participate in may lead to the boundaries of technocratic power being drawn very wide. Theory is little help here. Translating evidence into practice is rarely a purely technical affair, nor are all technical issues beyond the grasp of the non-expert, so there is no principle that can easily be applied to differentiate between the domains of expert and lay decision-making. The best that can be achieved is a process of negotiation in which lay concerns are articulated and technical/scientific issues are explained and discussed, but this does not answer the question of who should have the final say.

The three key tensions briefly described above go some way to explaining the limitations of previous PPI initiatives in the UK NHS and other health care systems, and provide the backdrop against which all participatory initiatives must be played. These tensions and the issues arising from previous NHS PPI initiatives can be condensed down to two fundamental questions that should be asked of any participatory initiative. To what extent does the initiative capture the patient voice in a form that is legitimate, valid and reliable? And secondly, what weight is given to that patient voice in the decision-making process?

The first question is largely a methodological one concerning sampling, data collection techniques and the minimisation of bias. The second question is essentially political, because it concerns decision-making about the utilization of resources. Our focus in this paper is mainly on the first question, but the second question remains important because our assumptions about the factors that lie behind it, including the tensions between science and democracy and between the public and patient interests, shaped the way in which we elicited data from patients. For example, the service we were designing was based upon Contextual Cognitive Behavioural Therapy (CCBT) (McCracken, 2005), an intervention grounded in clinical psychology and for which there is a scientific evidence base, so it was our assumption that the key components of the intervention were non-negotiable and, therefore, not open to challenge by patients. However, issues relating to who should provide the intervention, where, when and for how long were open to discussion. In short, our intention was not to give patients *carte blanche* in the design of a new service, but to synthesise their preferences within a pre-existing framework of scientific expertise and structural constraints relating to what we felt the NHS would be willing or able to commission.

## PARTICIPATION FOR PATIENTS WITH CHRONIC CONDITIONS: PAIN AS AN EXEMPLAR

It cannot be assumed that a methodology for eliciting the patient voice will be equally effective among different patient groups. It is, therefore important to describe our exemplar patient group and assess whether their experiences of participating in the NGT exercise are transferable to other patient groups.

The first thing to note about patients with chronic pain is the chronicity of their condition. For our study we followed the definition of chronic pain recommended by the *International Association for the Study of Pain* (1986), and the *Merck Manual* threshold of pain symptoms that had persisted for at least three months (Porter, 2011), but most of our informants had experienced on-going symptoms for much longer than this. Having lived with their illness, often for several years, patients with chronic pain are likely to have accumulated a substantial amount of lay expertise regarding their illness and its management. Many have had multiple contacts with health services, which have often failed to ameliorate their symptoms, leading to dissatisfaction, (McCracken, 2005).

Chronic pain is a symptom of many different illnesses, rather than a precise diagnostic category in its own right. We excluded patients with cancer related pain, because the planned intervention was not aimed at or appropriate for this group, whose symptoms are usually managed by specialist palliative care services in the UK. Up to three-quarters of chronic pain cases presenting in general practice are medically unexplained, or cannot be demonstrably linked with physical pathology (Waddell and Aylward, 2005, Haug et al., 2004, Kroenke and Mangelsdorff, 1989), making it difficult for health care professionals to respond effectively, (Melzack and Wall, 1988).

The contestable nature of chronic pain can generate tensions in the doctor-patient relationship, and patients may feel that their problems have not been understood properly, or that they have been inappropriately treated by health care providers, (Reid et al., 1991). This degree of sensitization to the nuances of medical knowledge and power, frequently coupled with a degree of dissatisfaction with previous interventions, can make someone with chronic pain an ideal candidate for patient involvement in service design – at least they frequently have much to get off their chest. However, these concerns are often highly individualised, relating to personal experiences, so it is important to use a methodology that encourages participants to move beyond their own illness narratives and link their experiences to the broader project of service development.

In short, the characteristics of patients with chronic pain include: the chronicity of their condition; liminality in terms of the bio-psycho-social continua of aetiology and treatment; multiple (and possibly unsatisfactory) contacts with health services; and a high degree of lay expertise regarding their illness and its management, and in some instances a heightened sensitivity to the nuances of medical power, stigma and delegitimation. These characteristics are also found among other patients with chronic conditions, particularly those whose symptoms are medically unexplained, (Wessely et al., 1999). Our conclusions regarding the efficacy of using the NGT technique for involving patients in service design might, therefore, be transferable to similar groups of patients.

## APPLYING THE NGT METHOD

### *The NGT method*

The Nominal Group Technique is a 10-step process that generates both qualitative and quantitative data, (Van de Ven and Delbecq, 1972, Gallagher et al., 1993) . The steps involve: i) an introductory statement, ii) initial generation of important issues individually, iii) a round-robin listing of ideas, iv) clarification of the issues, v) generation of individual top ten lists, vi) rating issues according to importance, vii) time out and ice-breaker, viii) group top ten and discussion of issues, ix) re-ranking of the issues, x) conclude and close. The process takes around two hours and generates individual and group rankings of key issues as well as rich qualitative data exploring and describing the issues that are raised.

Seven of these groups were held, three with General Practitioners and nurses, three with chronic pain patients, and one with health care commissioners. Results of the study will be published elsewhere, here we provide a detailed guide to using the method, describing the strengths and weaknesses of using this technique with different stakeholder groups and particularly with informants with chronic health conditions, and focusing on issues raised in the earlier discussion of patient participation in service development.

### *Sampling and recruitment*

When designing the study we reflected on which stakeholder groups we should include and whether they should be grouped together for the purposes of data collection. Our main interest lay in capturing the views of chronic pain patients and staff responsible for managing their problems in primary care, (general practitioners and nurses), but we were also interested in the views of health care commissioners, (then based in Primary Care Trusts), as they would ultimately take the decisions about whether and in what form a chronic pain management programme based on CCBT might be commissioned.

All three stakeholder groups were likely to have different perspectives and agendas for service development and at some level these perspectives would have to be synthesised into a single plan for how the service would ultimately be delivered, even if only for the purposes of the RCT in the first instance, (we did not want to trial a service that would be unacceptable to any of these groups). We considered bringing the stakeholders together in ‘mixed’ groups. This would have had the advantage of enabling them to exchange views, contest assumptions and directly negotiate a consensus view. The NGT method is designed to avoid one individual or viewpoint dominating the discussion, but even so, we were concerned that the professional and commissioner viewpoints might dominate and foreclose the expression of patient preferences. We were also concerned that the views of the above stakeholders also needed to be synthesised with those of the service providers, (represented by the principal investigator on our study). We concluded that it would be preferable to conduct single stakeholder groups and for the research team to develop a service delivery model which synthesised competing stakeholder priorities with other considerations that were necessary to preserve the integrity of the intervention. This decision has important implications regarding the nature of the participatory exercise that will be explored in the discussion. Of course, the separation of stakeholder groups is not an essential component of the NGT, and the composition of groups can and should vary according to what is considered most appropriate for a particular study.

Similarly, the selection and recruitment strategy may also vary depending on the requirements of a particular study. Given the small size of the groups, random sampling is not appropriate, but there are many qualitative approaches to sampling that might be used, (Patton,

1990). In our study, we adopted a broadly purposive sampling strategy, selecting patients registered in one of three practices located in South West England, who had suffered chronic pain for at least three months. As a condition of the ethical approval for the study, we were not allowed direct access to medical records, (which were held by the practices), and had to rely on practice staff to select and approach potential participants. We provided staff with our inclusion/exclusion criteria and briefed them to avoid selecting on the basis of who they thought might make 'a good interviewee', but to try to maximise variation in terms of age, gender and social class. We have no way of assessing how rigorously this advice was followed, and not all of the patients who were approached agreed to participate, which may have introduced a degree of self-selection bias. As the recruitment was done for us by the practices we decided not to ask them to record the characteristics of those who declined participation.

We recorded the demographic characteristics of our participants, and found the group to be mixed in terms of age, gender and class, but as the numbers were small it would have been inappropriate to statistically assess how representative it was of the broader chronic pain population. The limitations of qualitative sampling strategies always raise the issue of representativeness and generalizability, (Mays and Pope, 2000). The problem becomes particularly vexed in a participatory initiative, where issues of representation are not just methodological, but also democratic, i.e. it is not just a matter of generating potentially biased data, but also of using those data to make decisions about service design which may favour one type of patient (the type that participates in studies), over another type (the type that declines to participate). This issue will be revisited in the discussion.

### *Timing and setting*

All of the NGT sessions were conducted during the daytime and in accommodation provided at the participating GP surgeries, (except for the commissioner group which was conducted at the Primary Care Trust offices). Holding the sessions during the working day might have excluded patients who were in paid employment, however, the timing of the sessions was determined after recruitment and we were not informed of any difficulties with attendance. This might well have been a problem for a different patient group, so future studies will need to be sensitive to this issue.

Patients with chronic pain have particular needs regarding the quality of accommodation, so we ensured that hard and soft seating was available and that the accommodation had room for participants to get up and walk around during the session if they needed to do so to alleviate their symptoms. Unfortunately, the only suitable room at one of the surgeries was at the top of a flight of stairs. This did not exclude any participants, but some did struggle with the stairs and complained about them. Siting the groups in a clinical setting, might also have influenced participants' responses, particularly as we were interested in where the proposed service should be located. We considered alternative neutral sites, such as community halls, but found that the GP surgeries were better in terms of access and accommodation.

### *Running the groups*

The sessions were digitally recorded and transcribed verbatim. The ten stages of the NGT method were implemented as follows:

*Stage 1 - Introductory statement.* As well as introducing the researchers and the methodology, we also used this session to frame the question that we wanted participants to engage with. The NGT approach usually comprises just one question that is clear and easily intelligible, (Gallagher et al., 1993, Dewar et al., 2003), which participants then respond to as they wish. In this study we wanted to provide more information about what was and was not being asked for, as this had been a problem in a pilot group we conducted beforehand. As discussed above, we wanted participants to describe their preferences regarding the organization and delivery of the service, but not re-design the core elements of the intervention, because we already had evidence of its clinical effectiveness in the tertiary setting and wanted to see if this could be transferred to the community setting. We decided to make this explicit in the introductory statement and to provide examples of the types of issues that might be raised. It is unusual in qualitative research to be so prescriptive. Usually qualitative researchers are reluctant to give strong prompts, preferring participants to raise issues that are salient to them, rather than responding to the researcher's agenda, (Patton, 1990). In this instance, we felt that a more prescriptive approach was required, but we did emphasise that participants could raise new issues that they saw as important and ignore the prompts if they were not felt to be germane. This raises questions about the appropriateness of agenda-setting in participatory initiatives that we will come back to in the discussion.

*Stages 2-4 – Silent generation of ideas: listing ideas on flip-chart; and clarifying the issues.* One of the strengths of the NGT approach, particularly for participatory initiatives of this kind, is that it begins with the individual generation of ideas by each member of the group, without any discussion. This reduces the possibility of inequalities in power, status and articulacy between group members, leading to individuals dominating the discussion and excluding the concerns of others. Although, we prompted participants in stage 1 by giving examples of the type of issues we were interested in, at no point did we attempt to exclude issues that were spontaneously raised by the participants. Once the individual lists of ideas had been generated, participants were asked to articulate one issue at a time in rotation around the group, until all issues had been aired and written onto flip-chart paper. The group was then asked to consider each item on the list to clarify its meaning and ensure that all participants understood what was being referred to. It was made clear that at this stage the discussion should focus on clarification of meaning rather than the importance of issues or detailed discussion of their content.

*Stages 5 and 6 – Choosing and prioritising individual top ten lists.* Having seen all of the issues raised by the group, participants were asked to individually select and prioritize the ten issues that they felt were most important and record them on a worksheet, again without discussion. The worksheets were collected and the issues and rankings were entered into a spreadsheet. The individual rankings for each issue were then summed to give a total score for each issue. The list was then sorted by the total column to give a prioritized list of issues for the group as a whole. The top ten issues were then put onto a flip-chart for presentation to the group.

*Stage 7 – Time out and ice-breaker.* The process up to this point takes about an hour, so particularly for patients with chronic pain, it is important to provide the opportunity for a comfort break and refreshments. This also fills the time taken by one of the researchers to enter the rankings into the spreadsheet and produce the group top ten. Up to this point very little interaction or discussion has occurred. Indeed it is discouraged, in order to capture individual concerns and priorities without the influence of other group members. For this reason, we did

not get participants to introduce themselves at the beginning of the session. However, the later stages of the process do entail discussion of the issues raised, so it was important to prepare participants for this engagement by encouraging them to interact with each other. We originally planned an ‘ice-breaker’ activity that would be conducted during the break, but participants preferred to chat to each other more informally, about their symptoms, previous treatments, local health services etc. We encouraged this, not least because it enabled participants to vent sometimes quite lengthy personal illness narratives that we tried to discourage in the other stages. However, these data were not included in our analysis.

*Stage 8 – Discussion of group top ten issues.* Following the break, participants were presented with the group top ten issues that had emerged from the spreadsheet analysis. We asked the group to discuss the ranking and say if they agreed or disagreed with it, if they were surprised by any omissions and, if so, why. This stage was the closest to an ordinary focus group. The facilitator took a back seat, only intervening to: steer the group back to the main topic; draw in participants who were struggling to interject; curtail lengthy monologues; etc. Some participants were quite forceful about asserting their own preferences, but at least the methodology obliged them to consider other participants’ views. Whatever the dynamics of these exchanges, they are closer to those that public or patient participants in health service planning/commissioning fora are likely to encounter, and we felt that it was important that as well as capturing individual preferences, we were also able to explore the emergence of views that had been mediated by group discussion.

*Stage 9 – Re-ranking and rating group top ten ideas.* Following the group discussion we asked participants to individually re-rank the ten issues identified by the group as a whole, again without discussing their rankings with others, and record their ranking on a worksheet. When all participants had individually re-ranked the list, we asked them to assign a weighting to each item, with the most important issue receiving a weighting of 100 and the least important a weighting of 1. The eight remaining issues were to be given a weighting between 1 and 100 depending how important they were felt to be relative to the issues above and beneath them, for example, if the second item on the list was felt to be almost as important as the first item then it might be assigned a score of 99, but if it was substantially less important, the score would be lower, say 75. These data were later entered into a spreadsheet and the individual weightings were summed and divided by the number of participants to produce a mean weighting for each issue, (see data analysis section).

*Stage 10 – Conclusion.* We thanked the participants for their help and closed the session. Participants were not given feedback at the time, but were later sent a brief summary of the findings.

### *Data analysis and writing up*

The NGT process yields quantitative and qualitative data. The quantitative data comprise both individual and aggregated rankings and weightings of issues from two points in the data collection process. First, from the stages prior to the group discussion, participants produce individual rankings that are then aggregated to produce a group top ten, and then following the group discussion participants re-rank the top ten individually, weight them relative to the other issues, and these weightings are then averaged to produce another weighted group top ten. All of these data are entered into a spreadsheet. As the sample is small and not randomly selected, inferential statistics are not appropriate, but simple descriptive analysis is appropriate and useful.

The complete list of issues, (beyond the top ten) is worth considering, even though they are not high priority, because they may include preferences that are easy and inexpensive to implement and about which there is a broad consensus. The two sets of group top ten rankings may also be worth comparing, to see how priorities change as a result of discussion. This comparison can be enhanced by using some of the qualitative data to shed light on how and why these changes occur. Capturing this process of mediation may be of value when communicating the results of the participatory initiative to external stakeholder groups, because it provides information on what their initial preferences might be and on arguments that are likely to change these preferences. In our study, we conducted single stakeholder sessions, with separate ones for patients, practitioners and commissioners. Where mixed sessions are used, there may be value in aggregating the data by sub-group, to pick up on inter-group variations.

Perhaps the most valuable quantitative output is a table relating to the final stages of the process in which individuals re-rank and give weightings to the top ten issues. These weightings are then averaged and the list is sorted according to the mean score for each issue. It is important to recognize that the mean scores do not represent a consensus in the sense of a collective agreement based on discussion and negotiation. Indeed, one of the strengths of the approach is that the individual scores behind the mean can still be seen, revealing variations from the collective view.

The qualitative data generated by the NGT process relate to stage 4 – clarification of ideas, and stage 8 – discussion of group top ten issues. These discussions were recorded and transcribed verbatim. There are, of course, many different approaches to qualitative data analysis, often relating to different methodologies, for example, Grounded Theory (Corbin and Strauss, 2008), or Interpretive Phenomenological Analysis, (Smith et al., 2009). However, our purposes were pragmatic and descriptive, rather than relating to the development of theory, or mapping the ways in which phenomena are represented in consciousness. Our aims were to clarify the meaning ascribed to the necessarily short labels applied to the issues used in the rankings, and to describe why these issues were considered to be important, to map disagreements between the participants, and broadly to add depth and understanding to the priorities and preferences that emerged from the sessions. For example, one issue that emerged was the time of day that the intervention should be delivered, particularly whether sessions should be provided inside or outside working hours. One concern was that patients in full-time employment might not be able to attend during working hours, but during the discussion the view was expressed and widely supported that most patients with chronic pain would be willing and able to take time off work for an effective medical intervention. The nuances of this issue could not have been inferred from the label ‘opening times’ that appeared in the rankings.

In our study we conducted 7 sessions, 3 with patients, 3 with practitioners, and 1 with commissioners, raising the issue of how data from different sessions should be combined. As the qualitative data provide a thick description of the issues that arise in the rankings, it might be possible to aggregate the data from different sessions and produce a single ranking of issues for all of the sessions. However, as the data were generated in discreet group discussions we felt that this would be inappropriate and possibly misleading, so we treated each session as the primary unit of analysis. When we wrote up the findings in a report for the project management group (PMG) to consider, we presented the findings for each session separately, but identified overarching themes and variations between groups and produced a synthesis of important issues that the group should consider when discussing the design of the intervention. This degree of synthesis was felt to be important to render the findings manageable and useable. However, it is

important to emphasize that the PMG was able to see how this synthesis was arrived at and had detailed data relating to each session and indeed to individual participants. Thus, the report for the PMG contained tables describing the individual and aggregated rankings for each session, qualitative accounts, (including verbatim quotations), of the key issues, as well as a broad overview of what had emerged from the study.

### *Using the findings from the NGT Sessions to design a service specification*

It is perhaps unusual to include reference to the use of research findings alongside an account of the methods used to produce them. However, in this instance our purpose was not just to identify stakeholder preferences, but to incorporate them into the design of a service, so it seems appropriate to briefly describe the process by which this was achieved.

Findings from all of the NGT sessions were written up into a report for the PMG. The report had the following structure: a summary of the key points; a synthesis of findings from all seven sessions, detailed findings from each of the sessions including the ranking tables, and qualitative analysis of the discussions which clarified the meanings of the issues raised and described how and why they were considered important.

The PMG comprised the principal investigator, the researchers, experts in chronic pain, methodological experts and a general practitioner with experience of commissioning services. The PMG did not include patient representatives, although arguably it should. We consulted the British Pain Society patient group on the design of the study but did not include a patient representative in the PMG, partly because we felt that the objective of the NGT groups was to facilitate patient involvement in service design as an *alternative* to the rather tokenistic inclusion of a patient representative, however, with hindsight this did mean that decisions about which patient views to act upon were taken exclusively by professionals.

The task of the PMG was to receive and discuss the findings from the NGT sessions and advise the principal investigator on the development of a service design/treatment plan in the light of the findings. This was achieved by circulating the NGT report to the PMG; holding a series of meetings to discuss the findings, followed by the principal investigator producing a draft service design; which was then circulated and discussed in meetings; before a final version was agreed.

The principle guiding this process was to achieve a balanced synthesis of the preferences expressed by the different stakeholders without compromising fidelity to the core CCBT approach, the demands of the Randomised Controlled Trial that was to follow; and within the constraints imposed by the NHS commissioning and governance process.

## DISCUSSION

The first and most important question is whether use of the NGT method enabled patients and other stakeholders to meaningfully participate in the process of service design. The full findings from the study will be published elsewhere and will contain a detailed account of the issues raised in the NGT sessions and the extent to which they influenced the service design specification, from which readers may arrive at their own answer. The view of the PMG was a qualified yes. The NGT sessions raised many issues that the PMG had not considered beforehand, for example, patients expressed a preference for out-of-hours support between treatment sessions, and on-going follow-up and support after the intervention sessions had been

completed. This request was partially met, with arrangements put in place for telephone and email support and a fixed term follow-up period, but open-ended and on-going support was rejected on clinical grounds, (because it was felt that this would contradict the aim of the intervention which was to enable patients to manage their pain independently, rather than create lasting dependence on professional support), and on commissioning grounds, (because it was felt that the NHS would be reluctant to commission a treatment that did not include an exit strategy for patients). Other findings contradicted the expectations of the PMG, for example, the literature on chronic pain suggests that patients can feel delegitimized by psychological (as opposed to bio-medical) interpretations of their illness which led us to expect that patients might prefer the intervention to be delivered by a doctor rather than a psychologist, but this was not the case. Patients did not object to the intervention being delivered by a psychologist, so long as they were sensitive, understanding and knowledgeable. The PMG accepted this view and the intervention was provided by a psychologist, although the additional suggestion from the patient groups, that an 'expert patient' should work alongside the psychologist was not accepted.

The above examples are typical of the way in which issues raised in the NGT sessions were addressed by the PMG. It is immediately apparent that this process did not comprise the delegation of decision-making power to patients – design of the service specification ultimately rested with the principal investigator, supported by the PMG, and patient preferences were only addressed if they did not contradict expert opinion regarding clinical efficacy and the constraints of the commissioning process. Critics might argue that this amounts to little more than applying a participatory gloss to a process that remained professionally dominated and which only served to channel patient preferences into existing organizational structures, rather than challenging the assumptions on which those organizational structures are based. This may be a valid criticism, but in defense, our objective was not to build political opposition to clinical expertise or to existing health care institutions, but rather to make the existing model of health care delivery more responsive to the preferences of its users. Even so, future studies or participatory initiatives may wish to directly involve patients in their PMG or equivalent decision-making forum.

### *Strengths and weaknesses of the NGT method*

It is important to draw a distinction between the capacity of health service providers and planners to act on the expressed preferences of patients, and the strengths and weaknesses of the NGT method in articulating those preferences. Many studies explicitly limit their aims to the articulation of preferences and do not concern themselves with the extent to which these preferences are acted upon, for example, Dewar et al (2003) limited their study to identifying the perceived challenges and needs of chronic pain patients, and did not describe the extent to which these perceptions influenced service design. In our study we framed the extent of patient participation in a limited way to ensure that the clinical integrity of the original intervention was preserved and that the service design was one which met the requirements of the commissioning agency. However, this approach is not integral to the NGT method which could be deployed in participatory initiatives that adopt a different approach to the delegation of decision-making power. In this section we focus in on the strengths and weaknesses of the NGT method as a means of eliciting the patient voice.

We begin by considering the 'who' question. We have already noted that the selection of participants is governed by qualitative sampling strategies, (of which there are several varieties),

and therefore lacks the representativeness that might be achieved with a large random sample. Whichever qualitative sampling strategy is used, it is therefore unlikely that the sample will be a microcosm of the broader population (in this instance of people with chronic pain). The question is whether the sample is large and diverse enough to capture the most common perspectives and preferences of the wider population. Strategies such as maximum variation sampling can help to increase the heterogeneity of the groups and the diversity of views expressed. Nevertheless, self-selection bias is likely to lead to some degree of over or under representation according to age, gender and class. Regrettable though this may be, the bias is likely to be less significant than that found in formal health care participatory fora, for example, Community Health Councils, and lay participation on health care boards, which have often been criticized for being demographically biased. The sequential nature of qualitative data collection also allows for efforts to recruit from sub-groups that have been under represented in early rounds. So even though the composition of NGT sessions may not be formally representative, it is possible to capture a wide range of perspectives and preferences which gives the exercise legitimacy, particularly in comparison with the lay membership of health service committees and boards. It is also possible to use findings from the NGT groups to develop questions for inclusion in a survey questionnaire, which could employ random sampling and have a larger sample size, although there might still be response bias. Van de Ven and Delbeq (1972) have described a process for transforming NGT data into survey questions. It is also important to recognize the extent to which qualitative methods of this kind can give access to patient groups and sensitive topics that other methods might have difficulty accessing at all, for example, Tuffrey-Wijne et al (2007) successfully used the NGT technique to explore the views of people with intellectual disabilities on end-of-life care.

Perhaps a more important issue is the extent to which the NGT method enables the expression of an 'authentic' patient voice. Authenticity is a slippery phrase, because our perceptions and preferences are often influenced by the context in which they are formulated or expressed. However, qualitative methods have traditionally prioritized the aim of achieving an in-depth understanding of participants' attitudes and beliefs while minimizing the influence of the researchers' meanings and definitions, for example by using semi-structured interview schedules and open-ended questioning, (Patton, 1990). In our application of the NGT method we departed from this imperative to a certain degree, by briefing participants at the beginning of the process regarding the type of issues we were interested in, and also by stating that the core elements of the intervention needed to be held constant. Again, this was an element of our study that need not be duplicated elsewhere, although we would argue that participation in health service planning is always likely to take place within constraints of one kind or another. Moreover, despite our briefing, participants did raise issues that were salient to them but which lay outside the brief and we made no attempt to rule these points out of order during data collection or analysis. The structure of the data collection process as it moves from generation of issues, through clarification, ranking, detailed discussion and re-ranking, does provide a means of moving from what might be termed 'blue-skies' thinking, through to a more focused awareness of what might and might not be possible, which occurs as a spontaneous result of the mediation of ideas, rather than by the intervention of the researchers.

The decision to run separate sessions for patients, practitioners and commissioners also enabled the patients to discuss their preferences without the foreclosure of discussion on grounds of impracticality or cost constraints. Miller et al (2000) in their study of diabetes patients and their carers conducted separate NGT groups for both, identifying quite different issues and

priorities that may not have emerged in mixed groups, they also suggest that further differences might have emerged had they separated groups by age, gender and ethnicity. The commissioner group in our study placed such heavy emphasis on cost-containment and the need for new services to generate net savings on the health care budget, that it seems very likely that this would have curtailed the expression of patient preferences had we adopted a mixed group design. Of course, there is a need for patient preferences to be reconciled with available resources at some point in the planning process, but our view was that this synthesis should be done post hoc - we wanted to at least know what patients' preferences were, even if further down the line they were deemed impractical or unaffordable. It is also important to recognize that even if costs are capped, patient preferences can influence how the funding is used, thus, what might appear to be an unnecessary expense to practitioners or commissioners may be considered an essential pre-requisite for uptake of the service in the eyes of potential patients. The rich qualitative data generated by the NGT technique can provide persuasive evidence of why a particular prioritized issue is so important to patients.

The production of a prioritized list of issues may also be questioned by those familiar with more conventional qualitative approaches, particularly given that the method involves focusing in on the top ten issues and setting aside those of lower priority. However, the process has several advantages. First, asking all participants to silently generate their own list of issues, does at least ensure that all participants have the opportunity to present their concerns to the group and in so doing influence the agenda for discussion. Without this check, there is a danger that the more assertive members of the group will dominate the agenda setting function and effectively exclude the views of others. Selecting ten issues may seem arbitrary, but it is important to recognize that those issues that fall outside the top ten are still captured by the data collection process and can still be included in the findings. The process of selection and prioritization does, however, ensure that the issues which are most important to the group as a whole receive a reasonable amount of time for discussion. Without this mechanism there is a danger that the discussion can be hijacked by one or two contentious issues. The rankings themselves can, with caution over the small numbers involved, be used to explore variations in the priorities of sub-groups within the sample. Moreover, the rankings and weightings do encourage the group to focus on which issues are most important and why. It would be difficult to infer such a clear cut account of priorities using the traditional methods of qualitative analysis.

### *Conclusion*

We conclude that where the research aim is to involve patients in service design the NGT approach has advantages over other techniques, partly because it reduces the effects of power differentials between participants, but also because it encourages participants to link their personal experiences to the task of designing a service and reduces the tendency to lapse into personal illness narratives. However, the NGT method is not a panacea for the problems of patient participation. The tensions that have emerged in formal health service participatory mechanisms must still be addressed in applying the NGT method. The mixture of individually identifying/ranking issues and open-ended discussion of them, can provide a very rich and compelling account of patient preferences, but the extent to which these preferences can or should be acted upon remains a political problem that no amount of methodological finesse can resolve.

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