



***National Institute for  
Clinical Excellence***

***Patient Involvement Unit***

**A report on a study to evaluate patient/carer  
membership of the first NICE Guideline Development  
Groups**

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## Introduction

The National Institute for Clinical Excellence (NICE) makes recommendations on treatments and care using the best available evidence. The Institute commissions seven National Collaborating Centres (NCCs) to develop clinical guidelines. The Institute is committed to involving patients and carers in the development of its guidance.

This paper describes a study carried out by the Patient Involvement Unit at NICE (PIU) to explore the experiences of patient/carer members (PCMs) and chairs of Guideline Development Groups, to report on their experiences of patient/carer involvement on the groups, identify good practice, highlight problems, and to improve the process for future GDGs.

This report is set out as follows:

- Background and aims of the study
- Study findings
  1. Patient/carer member views on their involvement
  2. Chairs views on patient/carer involvement
- Discussion and recommendations
- Appendices: copies of the interview schedules

Overall both patient/carer members and GDG chairs were positive about patient/carer membership of guideline development groups. However they also identified problems around

- Information, training and support provision
- Lack of involvement in defining the scope and dissatisfaction with the scope
- Organisation and conduct of GDG meetings
- Patient/carer member research skills
- Access to information on other patient views

The PIU has made a number of recommendations which we feel may help to address some of the issues raised. We look forward to talking with the NICE guidelines team and National Collaborating Centres (NCCs) to agree and prioritise actions to refine the process to facilitate the effective involvement and contributions of patients and carers in the guideline development process.

## Key to abbreviations

- GDG** Guideline Development Group  
**NCC** National Collaborating Centre (*commissioned by NICE to develop guidelines*)  
**PCM** Patient/ Carer Member (*of Guideline Development Group*)  
**PIU** Patient Involvement Unit (*based at NICE to support opportunities for patient and carer involvement*)
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## Summary of recommendations

### Induction, training and support

- Recruitment of PCMs should follow the formal PIU/NCC process
- Ensure systematic availability and provision of NCC and PIU training to all PCMs
- Add information on the training and support that is available to PCMs to the information provided on their appointment to the GDG
- Where possible, PIU to offer training to GDG members before they attend the first GDG meeting
- NCCs to do more to ensure attendance by all GDG members at their induction meeting
- PCMs joining GDGs late, to receive relevant and timely information and training (this may involve better communication between NCCs and PIU about late appointments and change in membership)

### GDG meetings

- Select chairs on the basis of their chairing skills as well as other skills and expertise e.g. clinical expertise
- Ensure everyone recruited to the Guideline Development Group is fully aware of the scope of the guideline and agrees to work within it
- A dedicated item on the agenda of each GDG meeting to discuss patient/carer issues
- More help (for all GDG members, not just PCMs) in understanding complex scientific/technical issues (for example the evidence framework)

### Drawing on other patient views

- Clarification of the acceptability to NCCs of PCMs using their parent organisation as a source of information to inform their contributions
- Continued access to funding for dedicated initiatives to gather patient views, where the GDG considers this to be important
- Clarity around the aims of dedicated work to gather patient views (these might serve different purposes e.g. to identify issues that should be included in a guideline scope, to help refine patient issues within the context of an agreed scope; to provide information on the views or experiences of specific patient subgroups; to comment on draft recommendations etc)
- Avoidance of carrying out additional dedicated work where there is an existing evidence base
- Consideration of the use of adequately resourced external patient reference groups as a further option for patient input

## **Guideline methodology and process**

- Better induction for GDGs in understanding the stages of the guideline development process and tasks of the GDG
- Better training for systematic reviewers in the use of qualitative research data
- A more systematic policy across GDGs on making consensus recommendations
- Improved communication between NICE and the GDG where there is controversy about the guideline content
- Consistency in adhering to the NICE guideline development process

## Background and aims

The National Institute for Clinical Excellence (NICE) makes recommendations on treatments and care using the best available evidence. NICE is committed to involving patients and carers in the development of its guidance. Opportunities for patient/carer input to the NICE clinical guideline programme exist at different levels<sup>1</sup>:

- *Stakeholder involvement*: national organisations representing patients and carers can register a stakeholder interest which provides opportunities to comment on draft scopes, nominate patient/carer members to the Guideline Development Group, submit evidence to the Guideline Development Group and comment on final drafts of the guideline
- *Guideline Development Group (GDG) membership*: all NICE GDGs are expected to include at least two patient/carer members. PCMs may be direct recipients of services, carers or employees of organisations representing patients, carers and service users
- *Information for the Public (IFP)*: the recommendations in NICE guidelines are explained in a version written for patients, carers and the public.

NICE has a dedicated team - the Patient Involvement Unit (PIU) - to develop and support opportunities for patient involvement.<sup>2</sup> At the end of 2003, the PIU began a study to evaluate patient/carer membership on the clinical Guideline Development Groups (GDGs).

The Patient Involvement Unit would like to thank all the participants for their time and enthusiasm in helping us with this work.

## AIMS

The aim for the interviews was to explore the experiences of patient/carer guideline development group members and chairs in order to report on their experiences of patient/carer involvement on the groups, identify good practice, highlight problems, and to improve the process for future GDGs. Final versions of the interview schedules are included in Appendix A (schedule for use with patient/carer members) and Appendix B (schedule for use with chairs).

## PARTICIPANTS AND METHODS

### Participants

For the purpose of this report we have data from 36 PCMs and 19 chairs (20 GDGs in total; 18 GDGs where we have responses from both the Chair and at least one PCM). For one GDG where the Chair agreed to be interviewed, two of the PCMs produced a written report on behalf of the four patient members.

All the PCMs had been nominated by patient organisations or active patient groups to be members of the GDGs (although their role on the GDG was to provide an individual contribution and not to represent these organisations).

- 22 had a personal experience of the condition or topic under review
- 5 were carers
- 20 were employees of patient/carer organisations
- 1 was a staff member from the Patient Involvement Unit

*(NB: figures add up to more than the total as some people fell into more than one category)*

### The interviews

The PCMs and chairs were approached by the PIU and invited to take part in a telephone interview or an interview carried out at NICE or at a location of their choice. Travel expenses were reimbursed for face to face interviews.

The first eight interviews (5 with PCMs and 3 with chairs) were carried out by a member of the PIU. The remaining 47 interviews were conducted by a freelance researcher.

The interview schedule was adapted slightly as the pilot progressed but all participants were asked to respond to a set of core questions in their own words. After the first 6 interviews a scoring scheme was added, so that interviewees replied to questions in their own words and were then asked to summarise their views on related sets of questions by using a five point rating scale.

The interviews with PCMs covered:

- Expectations of being on the GDG
- General experiences of group working and chairing of the group
- Support for patient/carer members
- Methods used to develop the guideline
- Opportunity to make a contribution to the guideline
- Training opportunities
- Views on the final guideline
- Views on the IFP
- Overall rating of the experience

The interviews with GDG chairs covered:

- Motivations for joining and experiences of being on the GDG
- Initial views and final views on patient membership of the GDG
- Contributions made by PCMs to the guideline
- Benefits of and problems with patient/carer membership
- Training needs of and support available to the PCMs
- Reflection of patient views in the guideline
- Views on the IFP
- Overall rating of patient/carer involvement in the guideline development process

## RESULTS

The results are presented in two sections:

**Section 1** - quantitative and qualitative findings from the interviews with patient/carer members

**Section 2** - quantitative and qualitative findings from the interviews with GDG chairs

The results need to be interpreted on the understanding that respondents were asked about their experiences of a process that was itself in development and therefore changed over time. Furthermore, within the project itself, modifications were made to early versions of the interview schedule:

1. The interview schedule was modified over time (main change was the introduction of a summary scoring system)
2. The interviewer changed after the first 8 interviews
3. The participants were recruited from GDGs that carried out their work at different points in time. Participants from GDGs with the earliest start dates are reporting on experiences of GDG membership that preceded:
  - a) some of the methodological developments in the guideline processes used by the National Collaborating Centres (NCCs) that host them
  - b) training and support systems that are now available to GDG members – this includes support from the PIU and from the NCCs



## Section 1: Quantitative and qualitative findings: patient/carer members

Patient/carer GDG members (PCMs) were asked to respond to questions in their own words and then asked to provide summary scores for sets of answers on a 5 point scale:

### Rating scale:

1. Excellent
2. Good
3. Average
4. Poor
5. Very Poor

In the sections below we have tabled the quantitative scores for different sets of answers, followed in each section by qualitative data which provides the context for these scores.

**NB** The scoring system was introduced after the first six interviews so scores are only available for a maximum of 33 of the 36 PCM participants. The number of respondents in some tables is less than 33 because new scores were introduced as the pilot progressed or because not all PCMs who were asked to rate their answers did so. The qualitative data however, is drawn from all 36 responses.

### Expectations

PCMs were asked about their expectations of joining a GDG.

#### Q: What expectations did you have about joining the group?

Rating	1	2	3	4	5
n(31)	3	15	8	4	1

Although people's expectations varied from the extremely positive to extremely negative, PCMs were all pleased to have been asked to participate. In one way or another everyone talked about the need for input from users of services and carers:

*"I had.....problems of my own and I had views about the way my treatment could have been better.....I felt it was a good way of feeding this into the guideline so it could be better for other people."*

*"[I wanted] to put the patient perspective at the heart of the guideline"*

Most were positive and comfortable with the thought of what lay ahead. Some were apprehensive, even if they had previous experience of working on committees or multidisciplinary groups. The concern was usually about not knowing what to expect:

*"I don't think anyone was keeping anyone in the dark, but I didn't know what to expect or how it would work"*

Those who had no experience of working on groups expressed anxiety:

*"I was quite nervous even though I'm not a shy person; I worried that I would speak inappropriately. I felt overawed"*

*"[I] was full of trepidation.....it was quite scary."*

The most extreme example of not knowing what to expect was described by one PCM who initially thought she would be attending as an actual patient, to be examined by the group.

Others wondered about what they could realistically expect to achieve:

*"I had low expectations of what we might achieve because of the high threshold of evidence required. This devalued the kind of contribution users could make [and] I couldn't see how we could overcome this"*

A small number of PCMs were initially concerned about tokenism and whether they would be rubber stamping the guideline. Another was doubtful of a positive outcome because of an earlier bad experience on a NICE technology appraisal group.

### **General experience of the group process**

Participants were asked about the chairing of the group, how well GDG members worked together, and about support from the Chair and other GDG members.

#### **Q: Was the group well chaired?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n(31)</b>	<b>16</b>	<b>9</b>	<b>4</b>	<b>2</b>	<b>0</b>

#### **Q: Did members of the group work well together?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n(31)</b>	<b>11</b>	<b>11</b>	<b>6</b>	<b>3</b>	<b>0</b>

#### **Q: Were you adequately supported by the chair?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (32)</b>	<b>13</b>	<b>12</b>	<b>6</b>	<b>1</b>	<b>0</b>

#### **Q: Were you adequately supported by other members of the group?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (30)</b>	<b>11</b>	<b>13</b>	<b>5</b>	<b>0</b>	<b>1</b>

The majority of PCMs thought the meetings were well chaired throughout or, if not at the beginning, then as meetings progressed. PCMs positively described a good chair as *"inclusive", "skilled", "open", "honest", "able to influence", "[we were] listened to"*.

*"[The chair] did a brilliant job. He was a good facilitator. Very inclusive."*

*"A lot of the way the group worked was due to the skill of the chair"*

If the PCMs talked favourably about a chair's ability to facilitate the meetings, then they also felt well supported. A good chair gave them opportunities to contribute (see below), and was accessible outside meetings.

One or two PCMs used the term “weak” to describe the chair and, if they did, they felt unsupported.

*“[He]...didn’t always let the patient views come through”*

*“I don’t think we were dismissed by the chair, but I don’t think he had any desire to put a patient perspective forward”*

The skill of the Chair also made a difference to the way the PCMs experienced the workings of the group. The following quotes demonstrate the different perceptions of what happened when differences of opinion arose within the group, depending on whether the Chair was viewed as weak or skilled:

*“There were conflicts”*

*“There was some healthy rivalry between different elements.”*

Nearly all the PCMs said they felt welcomed by the group and that, for the most part, the individual group members worked well together.

*“I was very welcomed by the group. It was an inclusive experience”*

*“I was relieved that the group accepted me [and the other PCM] so well.....I felt valued for what I am.”*

*“I felt that everything I was saying was being listened to.....the group made a very big effort to listen to the views of service users and carers.”*

One PCM said that some members of the group were unsupportive, were too focused on specific issues and tried to skew the guideline.

## **Support available to PCMs**

PCMs were asked specifically about the support provided by the PIU but they also discussed the support available from their parent organisations, the other PCM(s) on the GDG and the collaborating centre.

### **Support available from the PIU**

#### **Q: Were you adequately supported by the PIU?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (23)</b>	<b>5</b>	<b>9</b>	<b>8</b>	<b>1</b>	<b>0</b>

The majority of those who had received support from the PIU were very positive about the receptiveness and responsiveness of the unit:

*“I had regular contact and used this support”*

*“They were excellent”*

*“[They] bent over backwards [to get arrangements made]”*

Some PCMs did not call on the PIU for support, but said they knew that support was available if they needed it.

*"I had contact a couple of times. I didn't need support but would have asked if I'd wanted it."*

One PCM is a member of her second GDG and she described a difference in her experience of the PIU this time around. When she joined the first group more than two years ago she could not remember whether she was aware of the PIU:

*"[I] didn't understand the interaction."*

This time her experience has been much better and she has called on the PIU for help:

*"[On this guideline] I had a problem and was able to pick up the phone to..... get it sorted straight away"*

One PCM mentioned the useful brokering role that the unit played when the "Information for the Public" (IFP) version of the guideline was being rewritten.

Some PCMs said they did not fully understand the role of the PIU at first and were not aware that support was available. One PCM thought its function was only to organise the involvement of the PCMs.

Some PCMs suggested that the PIU should be in contact sooner than they had been

*"They contacted me in the middle of it"*

and at least one felt that meeting the PIU at the second GDG meeting was too much to take in as there was such a lot else going on. Another, who took over a colleague's place on the GDG did not find out about the PIU until she saw the information in the paperwork.

### **Support from their parent organisation**

PCMs from patient organisations mentioned having some support from them. Support ranged from a regular opportunity to discuss progress, to a research function which worked closely with the PCM and, in at least one case, the NCC, helping to establish the evidence. One PCM did not take advantage of this means of support because she thought that all the work of the GDG was confidential and should not be discussed outside meetings.

### **Support from the other PCM(s)**

PCMs acknowledged the importance of the support they had from the other PCM(s) on the group:

*"Other members of the group were not confrontational, but I got most support from the other patient rep"*

One PCM was the only lay person on her group which made her feel quite uncomfortable. Two PCMs on one GDG said that the chair recruited a third PCM who was known to him (and was in fact a patient of his, a policy that the PIU would actively discourage). The original PCMs felt that the chair relied on the new PCM's input at the expense of their views. This third PCM was not interviewed as the PIU only learnt of her existence through these interviews!

### Support from the Collaborating Centre

Several PCMs commented on the support they received from their Collaborating Centre both in terms of personal contact but also practically. The help with supplying hard copies of documents if they had no access to printers was mentioned on several occasions, as was the cost of printing documents on home computers. One PCM had a real problem carrying out her work because she had no printer and hard copies were not supplied.

### Guideline methodology

PCMs were asked about the methods used to develop the guideline.

#### Q: What are your views on the methods used by the group to develop the guideline?

Rating	1	2	3	4	5
n (33)	4	12	7	9	1

PCMs were, at first, fairly non-committal about the methods. Immediate responses were about confusion and a lack of understanding of how the guideline would develop:

*“Much of it was crisis management...we learned as we went along”*

*“At the start no-one really knew what they were doing.”*

*“[With] hindsight I can see how the guideline has emerged as this very thorough and sensitive document. At the time I was bemused at how all this work we were doing was going to turn into a guideline.....It was probably blind faith that something would happen.”*

Further discussion revealed some negative feelings about the process. Problems included workload, the guideline scope, the evidence framework and understanding technical papers, and the involvement of NICE.

### Workload

PCMs frequently raised the workload involved and specifically the amount of reading they were required to do between meetings. Some people felt that they had not been adequately forewarned about the extent of the commitment for which they had signed up.

*“I was told it was light reading between meetings and to turn up to meetings. It’s much more than that. There is masses of reading and a lot of work if you do the job properly”.*

The workload sometimes prevented those who wanted to, giving and getting feedback from their patient group or organisation. One PCM suggested that this could be avoided with a time lag of two meetings between documents being received and discussed. This would mean a slight delay at the beginning of the process but would be ironed out as soon as regular meetings were underway.

### Scope of the guideline

Six PCMs (five GDGs) were frustrated by the fact that the scope of the guideline was determined before the group was set up. The groups worked within the agreed scope (one discussed changing it with the DH) but some PCMs felt the patient focus was undermined, and the guideline was being developed around artificial boundaries. Defining the scope was seen to be an integral part of the process which should include the views of those developing the guideline.

On one group, the clinical questions had also been agreed before the PCMs joined. This was unusual but caused similar problems that had to be ironed out before the group could continue its work effectively, with input from the PCMs.

### **The evidence framework and understanding scientific/technical material**

One PCM talked specifically of her desire to be involved in a process resulting in recommendations drawn from an evidence-base. She and others felt qualified to do the job because they were familiar with research methods.

PCMs without some research knowledge however, reported difficulties grasping the concept of the evidence framework and the statistics surrounding it. Some PCMs who found the documents and reading too technical or scientific said they were helped by the Chair who took time to explain but some decided that they had no contribution to make on these issues and felt excluded.

Working within the evidence framework was a problem on some groups either because available evidence was low grade, or because PCMs lacked confidence about the status of the evidence of patient experience:

*"[I am] unhappy about RCT evidence overwhelming anything else that was out there. If you've got a small RCT and big cohort studies, then the RCT walks all over it, which is probably not right. That is a concern."*

*"The methods ..... are not user friendly. The need for high grade evidence is a real problem. People's experience should be given equal weight as the scientific evidence."*

*"It was quite frustrating to have nothing in the guideline unless it was evidence-based."*

PCMs were positive about opportunities to access patient input from other sources over and above patient membership of the GDG. These included:

- focus groups with patients and carers which PCMs felt they could draw on to inform their own contributions to the GDG
- a permanent patient reference group set up by one GDG, which the PCM felt changed the experience of developing the guideline from a negative to a positive one. She also specifically mentioned the role of the reference group in helping to get the language and tone right in the IFP
- one PCM talked of access to a multi-professional reference group which was also viewed as a valuable resource.

### **NICE involvement**

On some groups, PCMs were unhappy because they felt that some GDG decisions or requests were overturned or denied by NICE. One was a request for an executive summary of the final version of the guideline and another to have quotes and photographs in the "Information for the Public" version of the guideline. A GDG decision to keep costs out of a published algorithm had been ignored when the final version appeared.

### **Making a contribution**

PCMs were asked if they had the *opportunity* to contribute to the guideline, if they felt *able* to make an effective contribution, and if the inclusion of PCMs *made a difference* to the final products. No-one rated any of these items below average.

**Q: Did you feel that you had enough opportunity to contribute personally to the development process?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (28)</b>	<b>11</b>	<b>10</b>	<b>6</b>	<b>1</b>	<b>0</b>

**Q: Did you feel able to contribute effectively to the GDG?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (27)</b>	<b>9</b>	<b>13</b>	<b>4</b>	<b>1</b>	<b>0</b>

**Q: Do you feel that the inclusion of patients/carers on the group made a difference to the guideline?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (28)</b>	<b>15</b>	<b>7</b>	<b>4</b>	<b>1</b>	<b>1</b>

### **Ability to contribute**

Those PCMs used to working on multidisciplinary groups and committees said they felt confident about expressing their views at GDG meetings. Only one such PCM described difficulties experienced in making a contribution, despite feeling confident about doing so:

*“You think, I’ve got these particular issues that I think are important, but I’m not sure when this is going to come up so…… you think maybe it’s not relevant [here]. Then you realise you’ve only got a couple of meetings left and you haven’t actually covered the points that are important to you and you have to bring it [them] up at any available opportunity.”*

And one PCM without experience of being part of multidisciplinary groups often felt uncomfortable about making her voice heard:

*“I usually felt like a pest.”*

PCMs who were given a protected opportunity (e.g. a dedicated slot on the agenda of each meeting to address patient issues) to contribute had quite a different experience:

*“There was always a clear agenda item for feedback from patients and carers”*

All PCMs were able to describe the impact they had on the resulting guideline, and very few said that they wanted to, or could have, contributed more:

*“I probably didn’t contribute enough”*

Some PCMs however, were frustrated by what they perceived as a medical bias to GDG discussions:

*“I was frustrated by the dominance of the medics and that other health professionals didn’t contribute as much as they could have …… the issues the doctors wanted to discuss were discussed, not the issues that the therapists and patient representatives wanted to discuss”*

This was avoided when chairs made an effort to include PCMs, even though the subject matter was not their prime interest or focus:

*“It was very health professional/doctor focused. It focused on the health side and talked about medications and treatments I’d never heard of.....They did always try to bring in patients..... A lot of the time the areas that were covered were very technical. I like to think we had some impact. It wasn’t huge.”*

### **Impact on the guideline**

PCMs talked of the general, positive impact they were able to have on the guideline. Some spoke of bringing common sense to bear – in spite of the evidence requirement. Many PCMs felt they had influenced the structure of the guideline and the language used, particularly in the IFP, in some cases re-writing it:

*“The patient booklet.....I think it had been written by somebody who had too much medical knowledge. Some of it was [too] high tech.”*

Five PCMs said they had strengthened the guideline around the issues of communication with patients, and information and support for patients and carers and individual PCMs felt they had influenced individual recommendations on issues ranging from responsibility for care to specific therapeutic interventions.

When asked about what their most important contribution to the guideline was, the PCMs generally spoke about inclusion of topics that they felt might otherwise have been left off. Different PCMs identified the following specific contributions to the guideline:

*“inclusion of support for families and carers”*

*“providing a consistent voice on certain topics, and on the use of language”*

*“The importance of patient education to enable patients to look after themselves better.”*

*“constantly flagging up that children’s issues are distinct from adults”*

*“the inclusion of information for carers and the chapter on the patient’s experience”*

*“being able to express the opinion that medication isn’t always an appropriate treatment”*

*“building in funding for self-help and support groups into the economic review”*

*“bringing a user perspective and a recognition of user views. If users and carers can develop their own skills there’s a lot of things they can cope and deal with and take the pressure off the system.....they can also get a better deal out of the system.”*

*“a holistic approach and psychological support, and the fact that carers need bereavement support.”*

*“I know I’ve made a difference to lots of things throughout it. Pinpointing where is difficult.....Probably the \*\*\*\*\* wording. I think that probably came from me.”*

Some PCMs felt that their presence ensured that issues that might have been overlooked by other GDG members were addressed:



*“Some people were quite dismissive but we were a constant reminder – more attention was paid because we were there”*

*“we felt quite proud that they’d taken it on board and listened to our experience.”*

However, two PCMs specifically reported feeling confident and empowered by the nature of the group.

*“I took it quite seriously. I’d done quite a bit of homework and used to come in with pages and pages of notes.....I don’t think I was wasting anybody’s time because most of the things I brought up appear in the final report. I think I was making a useful contribution.”*

*“I knew the [user experience] literature better than most people.....I was able to tell the group about studies and books [they] could make use of.” “I had direct experience as a carer” “I did a lot of work on the chapter that was about user experience.”*

One GDG was interesting because the two PCMs on the same group had contrasting views on the impact they had had on the guideline. One did not feel that the PCMs made a difference to the guideline:

*“I think we [the PCMs] were there just to say they’d got us there. I don’t think I did a lot really.....Sometimes I had a problem taking part in discussions.....some of it was well above my head.”*

The second PCM however, identified several areas which she felt she had influenced, sometimes in the face of initial opposition from other GDG members:

*“ensuring that user led self-help is given prominence in the guideline; language; the questions for patients to use in a GP consultation.”*

On another GDG, one PCM, while reporting that he had enjoyed the experience, was not sure about his impact, or indeed if he should have had an impact:

*“If we hadn’t have been there the guideline may be identical or not that different. What we did do was to give a point of view that couldn’t be given by anyone else on the group. How much that patient point of view eventually coloured the guideline, I’m not sure.....The group process was better for us being there.” But, “I can’t think of a specific topic that I’ve raised.....[as someone who has experienced the condition] I’m not sure there’s anything there as a result of my contribution”*

Even if PCMs identified specific contributions, some were disappointed that specific issues they considered important were not included. One PCM, for example, was frustrated at the inclusion of “standard” text in the guideline which he felt was not respectful or patient-centred enough. He also felt that it was not made clear enough to the GDG members which sections of the text were not available for editorial discussion. On another group, the PCMs were disappointed that a specific recommendation was not made even though they understood that the Department of Health was due to publish supporting evidence.

## **Training**

PCMs were asked about the training provided by both the GDG and the PIU. The number of respondents to this question is particularly low, and in part reflects the fact that training

provision was not available from the outset but developed over time so that people on the earliest GDGs did not always have access to formal training sessions.

**Q: What are your views on any training provided in the course of GDG meetings?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (16)</b>	<b>0</b>	<b>5</b>	<b>8</b>	<b>3</b>	<b>0</b>

**Q: How helpful was the additional training provided by the PIU?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (16)</b>	<b>2</b>	<b>7</b>	<b>5</b>	<b>2</b>	<b>0</b>

When PCMs did discuss training, the subject brought a wider and less positive range of responses than most other questions. Many felt they had no training needs, others would have liked more, and some, on the earlier groups, said they had no training or were unaware of any training opportunities. Some in the latter group were on GDGs where we know that training was offered at the first GDG meeting!

Those who attended the PIU training day thought it was very good:

*“I would have floundered and felt isolated without the course”*

*“[It] quelled a lot of fears. We were told what to expect.”*

However, if PCMs attended the PIU training day after the first GDG meeting they thought that it was too late in the day. Some suggested that it would be good to hear first hand what to expect and thought a session from an experienced PCM would be useful, as would a video of a group in action. Two PCMs who attended training late in the day described how they were able to pass on their experience:

*“we [had] quite a bit of input into that meeting because we’d been doing it for quite a while and a lot [of those people] seemed to be petrified and we were able to [reassure them].”*

At least three PCMs entered the process late, taking over from a predecessor who had left their organisation. PCMs in this position lacked timely information and access to training.

The most frequently mentioned training need was that of understanding the evidence framework and basic statistics.

**Views on the final versions of the guideline**

PCMs were asked about their overall views on the final version of the guideline, the extent to which patient and carer views were reflected and their views on the Information for the Public version.

**Q: What are your overall views on the final version of the guideline?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (27)</b>	<b>9</b>	<b>14</b>	<b>4</b>	<b>0</b>	<b>0</b>

**Q: Do you feel that patient/carer views are adequately reflected in the final guideline report?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (31)</b>	<b>9</b>	<b>14</b>	<b>6</b>	<b>2</b>	<b>0</b>

**Q: What are your views on the ‘patient version’ of the guideline?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (29)</b>	<b>11</b>	<b>11</b>	<b>5</b>	<b>2</b>	<b>0</b>

Most PCMs were pleased with the outcomes of the process and pleased about the extent to which patient/carer views were reflected:

*“We managed to incorporate a lot of things from the patient perspective .....*”

Although some were sceptical about the worth of the recommendations without a plan for dissemination and implementation, this did not detract from their feeling that the guideline was good in its own right:

*“I’m pleased. It’s good and evidence-based where it can be and can potentially make a big difference to care.”*

Of those who believed that patient views were reflected in the guideline some however, would have liked to go further in strengthening the patient perspective.

*“.....[we] would have liked to put more in the public version”*

One PCM went as far as saying that the focus was wrong:

*“It focuses on what researchers have researched and [the patient’s] perspective is lost.”*

and one was completely dissatisfied:

*“[the process] was so chaotic.....a complete shambles.....and the guideline has lost out. I feel no ownership of it. It is not user informed.”*

Most PCMs were pleased with the IFP version of the guideline although getting there was a problem for some. In at least two cases (two GDGs), the original draft was unacceptable and needed extensive re-writing, often with significant PCM input. Two PCMs were unhappy with the form of the IFP and wanted to include pictorial illustrations and/or quotes.

## **Overall Experience**

At the end of the interviews, PCMs were asked to rate the overall experience of being a member of a GDG.

**Q: What is your overall rating of the experience?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n (33)</b>	<b>12</b>	<b>18</b>	<b>1</b>	<b>1</b>	<b>1</b>

All but three of the participants who scored the overall question, rated the experience as 'excellent' or 'good'. When using their own words to describe the experience, participants used terms including "good", "enriching" and "brilliant". However, of the two PCMs scoring the overall experience 4 or 5, one had nothing positive to say about the experience.

Everyone had a story to tell about their membership of the GDG. It was not always a smooth journey, but, for all but two PCMs, even when part of the experience was unsatisfactory, the rest worked well.

**Section 2: Quantitative and qualitative findings: GDG chairs**

Nineteen GDG chairs were interviewed and 15 scored questions on the same rating scale as the PCMs.

**Chairs' motivations and expectations**

The chairs were asked about their motivations for wanting to join the GDG.

**Q: What were your motivations for wanting to join this GDG? (not rated)**

The chairs had all been nominated to the job and either wanted the position because of a professional interest or because they felt that they would be able to do a good job. Several had been involved in guideline development before, but the expectations of some were along the same lines as the PCMs in that they didn't know what to expect or they were apprehensive:

*"I didn't have any [expectations]"*  
*"I was asked [and] felt a little bit of heart-sink. It might be a poisoned chalice"*

**Chairs' initial feelings about involving patients and carers**

Chairs were asked about their initial feelings about patient/carer membership of the GDG.

**Q: What were your initial feelings about having patient and carer members as members of the GDG?**

Rating	1	2	3	4	5
n(13)	7	6			

All who rated this question did so as 'excellent' or 'very good'. The qualitative discussions yielded a very positive response to involving patients and carers, even from those who do not have a lot of experience of working in this way:

*"It would have been unthinkable not to have them. In my work we involve consumers all the time in all our projects from conception to completion..... The consumers at all times bring you back to the experiences of individual women. Consumers are not an add-on part. They're an essential part of the process."*  
*"I would have been dismayed if they **hadn't** been part of the process"*

*“It’s important that the guideline should reflect all parties including patients.”*

Some were concerned about the ability of the PCMs to operate as full members of the group because they wouldn’t understand the technical detail of the work or because they wouldn’t be able to contribute:

*“[I had a slight concern] perhaps, as to whether it would be possible for them to contribute much.”*

*“[Before the group started] I was concerned about the patients because it can be difficult for them to find a voice.”*

and some wondered if the PCMs would come with “*their own agenda or axe to grind*” although one who did so said this could apply to any member of the group.

### **Chairs’ views on guideline methodology and products**

The chairs were asked about the methods used by the group and about the final products.

**Q: What were your views on the methods used by the groups to develop the guidelines?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n(14)</b>	<b>3</b>	<b>10</b>	<b>1</b>		

**Q: What are your views on the final version of the guideline?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n(13)</b>	<b>9</b>	<b>3</b>			<b>1</b>

**Q: What are your views on the patient version of the guideline?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n(12)</b>	<b>7</b>	<b>4</b>	<b>1</b>		

The 13 of the 14 chairs who rated the guideline methodology, considered it to be ‘excellent’ or ‘good’. For the most part the chairs felt that the methods were sound and they appreciated and valued the NCC support. However, some found the consultation periods problematic, reporting tight timescales and a cumbersome process.

*“It was stressful from time to time, especially the consultation period”*

A small number were critical of a process which demands high levels of evidence, often known to be unavailable:

*“The decision had been taken that priority had to be given to clinical questions for which there was research evidence.....we spent 90% of our effort confirming what we know – that the research evidence base was very poor for this guideline and 10% doing the work.....writing a guideline that was largely consensus based because there was no research.”*

*“.....qualitative research doesn’t figure in the hierarchy of evidence.”*

The chairs were generally very happy with the resulting guideline. Twelve out of 13 chairs who rated the final product considered the guideline to be 'excellent' or 'very good'. One rated it 'very poor' but it was not clear why, as when interviewed she was fairly positive about it. In general, the chairs were pleased with the IFP:

*"It identified the research gaps"*

*"Patient views are particularly represented in the public version"*

*"If the recommendations are implemented it will make a huge difference..."*

and commented favourably on the language used. Some had not seen the document and one thought it too long and wondered if patients would read it. One, although pleased with the patient version, rather pointedly commented:

*"We haven't bowed to what lay people would have wanted"*

One chair recognised that the things that PCMs considered important were left out of the IFP because, he felt, of restrictions imposed by NICE.

### **Chairs' views on the support and training for PCMs**

Chairs were asked individual questions about training and support for PCMs and asked to provide ratings for both.

**Q: Do you think the patient members were adequately supported by you in your role as chair?**

Rating	1	2	3	4	5
<i>n(13)</i>	3	5	4	1	

**Q: Do you think the patient members were adequately supported by the other members of the GDG?**

Rating	1	2	3	4	5
<i>n(13)</i>	3	5	3	2	

**Q: Do you think the patient members were adequately supported by the PIU?**

Rating	1	2	3	4	5
<i>n(5)</i>		2	2	1	

Most chairs felt that they themselves supported the PCMs, mainly by giving them (and other GDG members) time to say what they wanted, time for explanation of complex data and time to listen. One talked about encouraging the PCMs to challenge the group so that they would bring reality to the guideline that would otherwise be medically dominated. He met patient groups beforehand to reassure them about contributing. He also talked about giving feedback to one of the PCMs to:

*"reassure her that she wasn't going over the top"*

and another said:

*"I did consciously try to ensure that at the end of a technical discussion that they understood."*

**Q: Were the training needs of patient members met by any training provided in the course of GDG meetings?**

Rating	1	2	3	4	5
n(11)		3	5	3	

**Q: How helpful was the additional training provided by the PIU?**

Rating	1	2	3	4	5
n(3)		1	2		

Chairs who rated the overall training available to PCMs (n=8) or PIU training specifically (n=3) felt it was 'good' or 'average'. Several chairs said that the PCMs needed training on the evidence framework and critical appraisal. At least two thought other GDG members would also have benefited from this. The number of chairs rating PIU training was low, reflecting in part the fact that PIU training was not available to early PCMs but also some chairs' lack of awareness of the training offered by the PIU. One who was aware noted a change in the PCMs after the PIU one-day session:

*"they came back armed!"*

One chair suggested that clinicians should link into the PIU to learn more about patient involvement. Another suggested that an experienced PCM should be involved in the training of GDGs.

### **Chairs' views on the contributions of the PCMs**

Chairs were asked about the contributions PCMs made to the group.

**Q: What contributions, if any, did the patient members make to the group?**

Nearly all chairs talked highly of the PCMs' contributions to the guideline, saying:

*"there is no doubt about them making a difference to the guideline."*

*"Some of the best contributions to what we've ended up with [came from the PCMs]"*

*"without having a patient representative we wouldn't have got such richness [in the guideline]"*

However, the latter chair agreed with two others that PCMs sometimes had a less than adequate understanding of 'the science'.

*"I felt on occasion that she wasn't totally keeping pace"*

Generally chairs thought that the PCMs were able to contribute effectively to the process and were instrumental in bringing discussions back to the patient experience.

*"It created increased respect from the health professionals and a continued focus on the service user issues"*

One chair expressed positively the contribution that he felt the PCMs had made to the guideline:

*"A very mature contribution. They provided a necessary 'reality check' and a focus on the emotional involvement in specific cases. They gave a focus on the humanity of the topic and the need for services to be patient-orientated."*

However, there were some reservations. Three chairs commented on the problem of the scope being unacceptable to the PCMs and the time taken up going over the same ground on different occasions to confirm the scope.

**Q: What do you think the patient members' most important contributions were?**

When asked about the impact PCMs had on the guideline, many of the chairs could not be specific and talked generally about:

*"reminding us to talk in patient-centred terms"*

*"it was helpful to have them there to test recommendations against"*

The question that asked about the PCMs' *most important contribution* brought the fullest responses, although even then, some chairs could still not cite specific examples:

*"it's hard to say.....I have a sense she made us remember that the condition can make you pretty miserable."*

Chairs who could remember specific contributions tended to focus on non-medical examples:

*"When looked at medically, symptoms at night are not considered important, but they are for patients and this point was made and listened to."*

*"It was very useful having a patient perspective at the beginning.....what outcomes did we want to look at? Having patients there, we did have a much less medical focus. There were things like partner satisfaction, breast-feeding, interventions such as aromatherapy .....things which are not traditional medical models."*

*"the major influence is in the chapter on creating services that are acceptable to service users."*

*"[They] made contributions particularly in discussions on primary care and also on the recommendations about what the NHS should provide."*

*".....about support and advocacy and information and support for patients.....In the chapters on information and psychological support and on practical care and the roles and contributions that patients make in the models described."*

*".....about how local services should be involved"*

*"There's an extensive section on users' perspective of treatment which is particularly important in this field."*



Three chairs felt that PCMs made important contributions citing, for example, lifestyle issues and communication and *“the importance of the role of relatives”*. One chair said the professionals on his group thought this was bland and wanted to concentrate on medical issues.

There were some ‘negative’ views of the PCMs’ impact on the guideline. The chair of one GDG was concerned about the way things developed on the group and was disenchanted with the whole experience of which, the PCM element was a part. He felt that in the end, too much weight was given to the patient view but he also reported that a specific issue raised by the PCMs was perhaps one of the most important parts of the guideline.

Two chairs said simply:

*“She didn’t make a difference.”*

*“[contributed] nothing that made a difference to the weight of the guideline”*

When asked specifically if PCMs complemented, contradicted or agreed with other members of the group, in general the chairs wouldn’t distinguish the PCMs from other members of the group. Responses were along the lines of:

*“there was no great disagreement within the group and the patient representatives either agreed or complemented the discussion depending on the topic”*

One chair said the PCMs were *“fairly unobtrusive”* but meant this in the sense that their contributions didn’t stand out from other members because he also said

*“there’s a balance between them giving users’ views and trying to participate as equal members reviewing technical stuff.....they managed to do both in our case. They were highly educated.”*

One did say that one of the PCMs

*“was not really able to take as big a role as one would have liked.....[the PCM] found it difficult to disagree with the doctors”;*

but about what the chair couldn’t say. One chair, although supportive overall of PCM membership and contributions to the GDG, felt there were sometimes *‘prickly tensions’* which arose from a PCM’s support for their organisation’s agenda.

### **Q: Was there anything the patient members could have contributed to the process that they did not?**

No chair answered ‘yes’ to this question but some said they didn’t know or that it was hard to tell.

One chair commented on the setting up of a patient reference group part way through the development process. The chair felt that this improved the working of the whole group and provide a resource that the PCMs could draw on to enhance their input.

### **Chairs’ overall rating of the experience of involving patients and carers**

Chairs were asked to provide an overall view of patient/carer membership of the GDG.

**Q: What is your overall view now on patient involvement in the GDG?**

<b>Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>n(14)</b>	<b>7</b>	<b>6</b>	<b>1</b>		

Chairs rated the overall experience of involving patients and carers as 'excellent' (7 chairs) 'good' (6) or 'average' (1). Most chairs' qualitative responses were generally supportive of patient involvement as a whole, although they identified individual issues that could have worked better. There was one exception to this pattern of responses. For one of the earliest guidelines, both the chair and the PCMs felt patient involvement had been unsatisfactory, with the PCMs reporting too little opportunity for any input and the Chair feeling that too much weight was given to patient views.

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## Discussion

In this section we draw together themes from the PCM and chair interviews, describe initiatives that the PIU and NCCs have already started to implement to try to address some issues raised, and suggest ways of making further improvements to the role of PCMs on GDGs.

**NB:** While we make some suggested recommendations, we are not suggesting that all the recommendations can or should be acted on at this stage.

### PCM and Chair views on patient membership of GDGs

When asked to rate their *overall* experience, 30 PCMs rated it as good or excellent, one average and two poor or very poor. When asked to rate individual elements of the GDG experience, PCMs gave lowest scores to the questions about expectations, methods and training. All the chairs thought the PCMs had made contributions to the guideline and 13 of the 14 chairs, who rated the overall experience of involving PCMs, rated it as 'excellent' or 'good'. One chair (who wasn't asked to rate his answers) was more ambivalent than others about patient involvement.

The agenda for most of the PCMs was to make sure the patient voice was heard and reflected in the guideline. The importance of this role was supported by the GDG chairs. In the interviews, participants (both PCMs and Chairs) felt that this had been achieved. With the exception of one of the earliest guidelines, the overall experience of PCM involvement was very positive. However, both PCMs and Chairs identified specific areas for improving the experience of PCMs and/or the effectiveness of their contributions.

One of the difficulties in responding to issues raised by participants in this project is that we are not evaluating a static process. Changes to the guideline development process have taken place since the earliest guidelines were commissioned from the NCCs by NICE. These changes have been paralleled by developments in the support provided to all GDG members by the NCCs, and by new initiatives developed by the PIU to support PCMs specifically. We hope that initiatives already implemented are already going some way to address some of the issues raised, although the interviewees have identified areas where further improvements could be made.

The overall experience of most chairs and PCMs who took part in the evaluation project has been positive. However, it should be noted that missing feedback from six PCMs on GDGs included in this study would have presented a less positive picture than that presented here:

- Four PCMs from one of the earliest guideline were not interviewed because they had already submitted detailed written comments to NICE about negative aspects of their involvement (see p4).
- Two PCMs from a later guideline were so dissatisfied with the process that they resigned from the group (although the carer member on this group found the experience "*stimulating*" and "*rewarding*".) The PCMs who resigned were not interviewed as their views on the process were publicly documented in a press release. Reasons for their resignation included what they considered to be resistance by the GDG to user research, disparity of esteem between user and professional members, and doubts about the structure of and processes used by the group<sup>3</sup>.

### Information, training and support

When PCMs first volunteered to become members of GDGs, some were less clear than others about what their participation would involve. This may in part reflect the varying skills and experiences of different people but may also reflect the information that PCMs received

when they put themselves forward. Many had no idea what to expect, and some were anxious and nervous about what lay ahead. Even those with experience of multidisciplinary working and committees expressed reservations. People on early GDGs felt they would have benefited from training and those on later GDGs who received training, felt it contributed to the effectiveness of their role.

Since the start of the earliest guidelines, several initiatives have been put in place, supported by the interview responses:

- PIU job descriptions for all patient/carer nominees, including an explanation of the guideline development process and role of the patient/carer members
- PIU information packs for successful applicants
- PIU contact with nominated members before they attend a GDG meeting
- Appointment of at least two PCMs to each GDG
- NCC information packs for GDG members
- Support for PCMs from NCC project managers and GDG chairs
- NCC training for all GDG members
- PIU training offered to all PCMs
- Presentations given by a PCM who has already been through the process at PIU training sessions (from June 2004)
- PCMs offered payment to attend PIU training to encourage attendance (from 2004)

Problems arise where people miss out on the training (for example, because PCMs miss the GDG induction meeting; PCMs miss or elect not to attend the PIU training workshop; PCMs join a GDG group late (e.g. because they replace an existing member) or PCMs are recruited without reference to the agreed PIU process. There is also an issue about the timing of training. For this reason **we recommend the following**:

- Recruitment of PCMs to follow the formal PIU/NCC process
- Ensure systematic availability and provision of items in the bulleted list above to all PCMs
- Add information on the training and support that is available to PCMs to the information provided on their appointment to the GDG
- Where possible, PIU to offer training to GDG members before they attend the first GDG meeting
- NCCs to do more to ensure attendance by all GDG members at their induction meeting
- PCMs joining GDGs late, to receive relevant and timely information and training (this may involve better communication between NCCs and PIU about late appointments and change in membership)

Some PCMs expressed frustrations with having to work within the context of a predetermined scope. Some chairs were frustrated by the revisiting at different meetings of issues outside the scope. (The PIU has observed that it is not always or necessarily the PCMs who do this!). Some PCMs would have liked to have been involved in decisions about the guideline scope.

However, it is important to note that some patient stakeholders are not engaged with the process until the stakeholder meeting and then need to find people to nominate to be on the GDG. So there is a definite tension between identifying PCMs before the full range of patient stakeholders who may wish to nominate PCMs have engaged with the process.

### **GDG meetings**

Generally, PCMs were positive about GDG meetings and the opportunities they had to make contributions to the development of the guidelines. However, there were individual instances of either PCMs or chairs feeling that more significant contributions could have been made. Opportunities to contribute were influenced by different factors including the support provided by the Chair and/ or other GDG members, the confidence or skills of the PCM, and the ways in which the NCCs ran the GDG. **We recommend more systematic provision across NCCs of the following:**

- Select chairs on the basis of their chairing skills as well as other skills and expertise e.g. clinical expertise
- Ensure everyone recruited to the Guideline Development Group is fully aware of the scope of the guideline and agrees to work within it
- A dedicated item on the agenda of each GDG meeting to discuss patient/carer issues
- More help from NCC staff (for all GDG members, not just PCMs) in understanding complex scientific/technical issues (for example, the evidence framework)

### **Guideline methodology and process**

Several PCMs voiced concerns about both the processes and methods used by GDGs, including what some perceived as:

- Confusion, on the part of many or all GDG members, about what processes they would use to develop the guideline
- Dismissal by some GDGs of patient views and experiences
- Undervaluing of qualitative research evidence (sometimes a refusal to consider it at all)
- Reluctance of some GDGs to make consensus recommendations
- Interference from NICE which meant that GDG decisions were sometimes overturned

### **We recommend:**

- Better induction for GDGs in understanding the stages of the guideline development process and tasks of the GDG
- Better training for systematic reviewers in the use of qualitative research data
- A more systematic policy across GDGs on making consensus recommendations
- A more systematic approach across NCCs to the use of qualitative research
- Improved communication between NICE and the GDG where there is controversy about the guideline content
- Consistency in adhering to the NICE guideline development process

## PCM research skills

The variability of PCMs in understanding complex scientific issues was raised by both some PCMs and some Chairs. The PIU is not sure what to recommend here. We aim, through the job descriptions provided to people who want to put themselves forward for GDG membership, to identify the minimum skill set needed to participate in a GDG. This ranges from knowledge and experience of the condition to the ability to understand scientific articles. We also provide some rudimentary training to PCMs in appraising research papers, as do the NCCs when they provide training to all GDG members. We also provide an extensive glossary of terms as part of the initial information packs. The PIU does not think that PCMs are alone in not understanding some of the most complex data.

Chairs suggested that more training might be needed. However the PIU is not clear what training we could offer to turn PCMs overnight into competent researchers. Nor are we convinced that this is a necessary requirement. The PIU has consistently argued that a specific role of the PCMs is to provide the patient perspective – ranging from considering whether the research evidence measures outcomes that patients consider important, to raising issues about patient acceptability and preferences for interventions that may be recommended by the GDG. The issue perhaps therefore is how best to select people with the confidence and ability to raise these issues within the context of a scientific process. Interview responses suggest that so far we have been successful sometimes, but not always, in selecting people or equipping them with the skills to do this.

## Drawing on other patient views

In an ideal world, GDGs would be able to draw on published research evidence of patients' views and experiences to inform the development of the guideline. Usually (though not always) this information is lacking. PCMs commented on how useful additional information on patient views was to inform their responses. PCMs on different GDGs had access to different sources of patient views ranging from

- consultation with their parent organisation (if they had access to one)
- dedicated work carried out by the NCC (e.g. focus groups or workshops to gather patient views)
- the use by one GDG of an external patient/carer reference group

### We recommend:

- Clarification of the acceptability to NCCs of PCMs using their parent organisation as a source of information to inform their contributions
- Continued access to funding for dedicated initiatives to gather patient views, where the GDG considers this to be important
- Clarity around the aims of dedicated work to gather patient views (these might serve different purposes e.g. to identify issues that should be included in a guideline scope, to help refine patient issues within the context of an agreed scope; to provide information on the views or experiences of specific patient subgroups; to comment on draft recommendations etc)
- Avoidance of carrying out additional dedicated work where there is an existing evidence base
- Consideration of the use of adequately resourced external patient reference groups as a further option for patient input

## **Conclusion**

Previous attempts to include patient and carer members on GDGs have criticised their contributions.<sup>4</sup> However, responses from both PCMs and chairs of NICE GDGs suggest that it is possible to engage patients and carers as effective members of GDGs. Responses from this study suggest that effective contributions depend on a number of supporting factors, ranging from providing information to help identify people with the skills needed to participate in the activities undertaken by a GDG to supporting PCMs once they have joined an initiative. Some initiatives that have been developed over time both by the PIU and NCCs go some way to addressing early problems with patient/carer involvement. However, the interviews have also suggested ways in which existing initiatives can be refined or enhanced.

## **APPENDIX A - Interview Schedule for the Patient/Carer Members of GDGs**

1. What were your main reasons for wanting to join this Group?
2. What were your general experiences of being part of this multidisciplinary group?
3. What expectations did you have about joining the Group?
4. Was the Group well chaired?
5. Were you adequately supported by the Chair?
6. Did the members of the group work well together?
7. Were you adequately supported by the other members of the group?
8. Were you aware of the Patient Involvement Unit (PIU)?
9. Were you adequately supported by the PIU?
10. What are your views on the methods used by the Group to develop the guideline/guidance?
11. Do you feel that the inclusion of patients and carers on the Group made a difference to the guideline/guidance?
12. Did you feel that you had enough opportunity to contribute personally to the development process?
13. Did you feel able to contribute effectively to the Group?
14. What do you think your most important contribution was?
15. Was there anything you wanted to contribute but did not have an opportunity to do so?
16. Did you have any training needs?
17. What are your views on any training provided in the course of Group meetings?
18. How helpful was the additional training provided by the PIU?
19. What, if anything, was done well to support patient members on the Group?
20. What are your overall views on the final version of the guideline/guidance?
21. Do you feel that patients'/carers' views are adequately reflected in the final guideline/guidance report?
22. What are your views on the 'patient version' of the guideline/guidance?
23. What, if anything, do you feel should be done differently to support patient members on these groups in the future?
24. Do you have any general comments that you would like to share?
25. What is your overall rating of the experience?
26. Did you get anything out of the process yourself?



## **APPENDIX B - Interview Schedule for the GDG Chairs**

1. What were your motivations for wanting to join this Guideline Development Group (GDG)?
2. What are your general overall experiences of having been part of this multidisciplinary Group?
3. What were your initial feelings about having patient and carer members on the GDG?
4. What is your overall view now on patient involvement in the GDG?
5. What were your views on the methods used by the Group to develop the guidelines?
6. What contributions, if any, did the patient members make to the Group?
7. What do you think the patient members' most important contributions were?
8. Was there anything you felt the patient members could have contributed to the process that they did not?
9. Were there any benefits in having patient members on the Group?
10. Were there any problems in having patient members on the Group?
11. Do you feel that the inclusion of patients and carers on the Group has made a difference to the resulting guideline?
12. Do you think that the patient members were adequately supported by you in your role as Chair?
13. What do you think the other GDG members felt about having patient members on the Group?
14. Do you think the patient members were adequately supported by the other members of the GDG?
15. Were you aware of the support role available from the PIU?
16. Do you think the patient members were adequately supported by the PIU?
17. Do you think that the patient members had any training needs?
18. Were these needs met by any training provided in the course of the GDG meetings?
19. How helpful was the additional training provided by the PIU?
20. What are your overall views on the final version of the guideline?
21. Do you feel that patients and carers views are adequately reflected in the final guideline report?
22. What are your views on the patient version of the guideline?
23. What, if anything, was done well to support patient members on the GDG?
24. What, if anything, do you feel should be done differently to support patient members on GDGs in the future?
25. Do you have any general comments you would like to share?
26. What is your overall rating of the experience of involving patients and carers in the development process?

## References

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- <sup>1</sup> Kelson M (2001) *Patient Involvement in Clinical Guideline Development – where are we now?* Journal of Clinical Governance; **9** 169-174
- <sup>2</sup> Kelson M (2002) *The National Guidelines and Audit Patient Involvement Unit.* Journal of Clinical Excellence; **4** 194-5
- <sup>3</sup> James A *A Disparity of Esteem* Open MIND Jan /Feb 2003 119
- <sup>4</sup> Van Wersch A and Eccles M (2001) *Involvement of consumers in the development of evidence-based clinical guidelines: practical experiences from the North of England Evidence-Based Guideline Development Project.* Quality in Health Care **10** 10-16

## Key to abbreviations used in this report

- GDG** Guideline Development Group  
**NCC** National Collaborating Centre (*commissioned by NICE to develop guidelines*)  
**PCM** Patient/ Carer Member (*of Guideline Development Group*)  
**PIU** Patient Involvement Unit (*based at NICE to support opportunities for patient and carer involvement*)