NHS
National Institute for
Health and Clinical Excellence

Patient and Public Involvement Programme

Community membership of NICE groups producing public health guidance - Report of an evaluation study

Ioana Ursu and Jane Cowl

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Introduction

The National Institute for Health and Clinical Excellence (NICE) makes recommendations on promoting good health and preventing and treating ill health using the best available evidence. It also has other related responsibilities, such as developing quality standards for the National Health Service (NHS). NICE is committed to involving patients and the public in the development of its guidance and in all other aspects of its work.

This paper describes a study carried out by the Patient and Public Involvement Programme at NICE to evaluate the involvement of lay people ('community members') in the development of public health guidance. The study aimed to explore the experiences of community members and chairs of Programme Development Groups, to report on their experiences of community involvement on the groups, identify good practice, highlight problems, and make recommendations with a view to strengthening and improving the process for future groups.

The Patient and Public Involvement Programme would like to thank all participants for their time and enthusiasm in helping with this evaluation project.

Glossary of terms

Community members = People who contribute to NICE public health guidance from a public or community perspective. This includes people with direct experience of public health activities (such as those who have used a service to help them quit smoking), as well as individuals involved in health-related community or voluntary action (paid or unpaid).

CPHE = Centre for Public Health Excellence at NICE

PDG = Programme Development Group

PPIP = Patient and Public Involvement Programme at NICE

Summary of key findings

Both community members and chairs were generally very positive about community membership of the Programme Development Groups (PDGs). The chairs valued community members' participation and considered that they had a lot of influence on the group's work. Although community members gave a more mixed assessment of their influence, the majority agreed that they had a lot of influence on the PDG's work.

Good chairing contributed to a community member's positive experience, with most commenting favourably on the chair's leadership and support. Community members welcomed the support offered by the Patient and Public Involvement Programme, and the majority found the training valuable.

Although community members and chairs generally gave positive ratings to questions about the methodology for guidance development, there were some recurrent frustrations and criticisms with regard to the research evidence and the balance between academic perspectives and real life experience. Some community members indicated a problem around access to information on the views of people from groups targeted by the guidance.

NICE's Patient and Public Involvement Programme (PPIP) have made a number of recommendations with a view to building on what is working well and to address some of the issues raised.

Recommendations

Information, training and support

- Continue aiming to schedule PPIP training days for new community members before their first PDG meeting (PDG1). Where this is not possible, before PDG2.
- Continue to run PPIP follow-up workshops for community members who are at least 6 months into their work on the PDG – the first of these workshops was successfully piloted in October 2009.
- CPHE / PPIP to work with PDG chairs in reinforcing the importance of avoiding jargon and explaining technical terms and abbreviations.
- PPIP to pilot an exit questionnaire for community members with the aim of systematically obtaining feedback for all PDGs and refining the process as appropriate.

Programme Development Group (PDG) meetings

- Select chairs on the basis of their chairing skills as well as other skills and expertise relevant to the guidance topic. Alternatively, recruit a chair for their chairing skills and a separate person to provide expert leadership on the topic.
- Ensure individual special needs of community members are addressed.
- CPHE to alert PPIP in the event of a delay or other problem with expenses and payment claims.
- As appropriate for each PDG, consider giving time to one or more short presentations from a community and a practitioner perspective (given by members or experts/co-optees).

Drawing on other community views (the target population for the guidance)

- Routinely search for information on the beliefs, attitudes, views and experiences of the target population in reviews of evidence and calls for evidence.
- Routinely consider other potential sources of information on the perspectives of the target population or specific subgroups; for example, invite a community member to give a presentation, recruit a co-optee, seek testimony from an expert, commission small-scale consultation with members of the target population.
- Clarify the aims of any proposal to gather the views of the target population (for example, to identify issues that should be included in the scope of a guidance project; to help refine community issues within the context of an agreed ‘scope’; to provide information on the views and experiences of specific subgroups; to comment on the relevance and acceptability of draft recommendations).
- Avoid carrying out additional work where there is an existing evidence base.
- Consider the use of reference groups as a further option for input from the target group.

Background

The National Institute for Health and Clinical Excellence (NICE) involves patients and the public in all its work programmes. This project concerns public health guidance, for which there are a number of opportunities[1] for public input including:

- *Stakeholder involvement* – national organisations representing public interests and Local Involvement Networks (LINks) can register a stakeholder interest for specific guidance topics. Stakeholders are automatically invited to contribute at key stages; they can comment on the scope of the guidance project, respond to a call for evidence and comment on the final draft guidance.

- *Membership of Programme Development Groups (PDGs)* – each PDG includes three or more community members, who have experience or knowledge of the guidance topic and networks with others who will be affected by the guidance.

Public health guidance contains recommendations on promoting and maintaining good health and reducing the risk of developing a disease or condition. The guidance also aims to reduce inequalities in health between different groups. It is designed to be put into practice in England by those working in the NHS, local authorities and the wider public, private, voluntary and community sectors. The development of NICE public health guidance can be done in two ways - either as interventions or programmes. Interventions will generally be about actions to be taken by a front line practitioner such as giving brief advice on giving up smoking. Programmes tend to be broader, for example, the organisation of smoking cessation services.

For each new public health programme, NICE sets up a group to develop the guidance called a programme development group (PDG). This group is made up of public health specialists and other relevant professionals, researchers and community members. The programme development group meets regularly over a period of about 18 months to consider the evidence and develop recommendations.

The chair and members of the programme development group are selected following an open and transparent recruitment process, and all members have equal status. An important role for community members is to make sure that the views, experiences and interests of people who will be affected by the guidance (the 'target population') are represented at the group's meetings.

NICE has a designated team – the Patient and Public Involvement Programme (PPIP) - to develop and support opportunities for community involvement. In July 2009, PPIP started an evaluation study about the involvement of community members on programme development groups.

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[1] A series of factsheets describes how individuals and organisations can contribute to public health guidance - http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/ContributingToNICEPublicHealthGuidance.jsp

Aims

The main aim of this project was to examine the involvement of community members in the development of NICE public health guidance. In particular, we wished to find out about:

- community members’ experiences of involvement
- chairs’ experiences of community members’ input
- the views of community members and chairs on the methods and processes of guidance development and the final guidance.

In reporting on community members and chairs’ experiences of community involvement on the groups, we aimed to identify good practice, highlight problems, and make recommendations with a view to strengthening and improving the process for future groups.

Participants

Participants were drawn from the community members and chairs of the first seven programme development groups that produced public health guidance, published between October 2007 and March 2009. Of this total pool of 7 chairs and 21 community members, 4 chairs and 16 community members took part in this survey, giving an overall response rate of 71%, which breaks down as 57% for chairs and 76% for community members.

Community members

Of the 16 community members who participated in this survey:

- 3 respondents were parents or carers of someone who would be affected by the guidance (the target population)
- 7 were members of the public involved in voluntary/community action
- 6 were employees of a voluntary or community organisation or charity representing the target population
- 6 were unpaid members of a voluntary or community organisation or charity representing the target population
- 2 respondents were service users
- 1 did not complete this part of the demographic questionnaire.

For some respondents, more than one of the above categories applied, hence the total number exceeds 16.

- The majority of community members in this survey had tertiary level education with 9 of the 16 holding a postgraduate qualification.
- 3 of the 16 community members described themselves as having a disability.
- 13 out of 15 respondents were aged between 36 and 65, and two respondents were under 35.
- There were twice as many women as men.
- The majority of community members described themselves as White British, of Christian faith, and heterosexual, although a small minority did not respond. (There were three non-responses for ethnicity and sexual orientation and four non-responses for religion or faith.)

Chairs

Of the chairs who responded, all four were from academia, with two of them also practising in the public health field and in the voluntary sector. Due to the small number of chairs in this survey, we are not reporting on equality monitoring data in order to preserve respondents’ anonymity.

Methods

This study was conducted using a written questionnaire (postal/electronic) with mostly open-ended questions and, where appropriate, a rating scale to determine the strength of participants’ responses. Following a small pilot, community members and chairs of seven programme development groups that had finished their work were invited to participate. The seven PDGs were: Behaviour Change, Community Engagement, Maternal and Child Nutrition, Physical Activity and the Environment, Smoking Cessation Services, Promoting Physical Activity for Children and Young People, Management of Long Term Sickness and Incapacity for Work.

28 questionnaires were sent to 7 chairs and 21 community members, together with information about the study, a consent form and an equality monitoring form. These potential participants were invited to respond either electronically or they could request a hard copy of the questionnaire to complete by hand. A follow-up reminder was also sent. We received completed questionnaires from 4 chairs and 16 community members.

The questionnaire for community members explores:

- community members’ experiences of the group process
- their views on the guidance development methodology used and the final guidance
- their views on the support and training offered to them
- their ability to make a meaningful contribution to the group.

The questionnaire for chairs covers many of the same questions, but also examines their views and attitudes towards involving community members in this work.

Results

The results are presented in two sections:

Section 1 - quantitative and qualitative findings from the questionnaires completed by community members

Section 2 - quantitative and qualitative findings from the questionnaires completed by chairs.

The results need to be interpreted on the understanding that respondents were asked about their personal perspective and experiences as part of a process that was itself in development and therefore changed over time. A related limitation concerns the fact that respondents were reflecting on an experience that for some had come to an end relatively recently, whereas for others their PDG experience ended some time ago (the first PDGs finished their work in 2007). Participants' answers may reflect the overall process or a particular moment which the respondent considered to be representative or important.

Community members and chairs were asked to respond to questions by providing scores on a rating scale followed by answers in their own words. Unless otherwise stated, the rating scale was as follows:

1. Very good 2. Good 3. Adequate 4. Poor 5. Very poor

Please note: Respondents did not always give rating scores and/or explanations for their rating. Thus, the number of total respondents may differ from one question to another. Quotes from respondents have been selected from all available qualitative responses for each question to illustrate the type or range of points made.

Section 1: Quantitative and qualitative findings: community members

JOINING THE GROUP

Q1: Please describe the main reasons for wanting to join the PDG

The reasons for wanting to join the PDG varied among respondents, though in general they shared a common desire to shape the future NICE public health recommendations. Individual reasons included:

> "Wanted to make sure the issues [for the target group] were addressed"
>
> to influence "public health policy so that it is relevant to ordinary people"
>
> "making a difference from the inside of the health system after many years doing just that outside of the health care system"
>
> the "opportunity to meet people working in this area, opportunity to work alongside and network with people who work in this area"

GROUP WORKING

Q2: The Chair of the group

How well was the group chaired?

Rating	Very well (1)	Well (2)	Adequately (3)	Poorly (4)	Very poorly (5)
n(16)	12	3	1		

Please comment on how the group was chaired

Most community members were very positive about how the group was chaired, with 12 of the 16 respondents giving the top rating. In almost all cases, they acknowledged the chair's inclusive attitude towards all the members of the group and also the support given to community members to ensure their participation:

> "He was a very inclusive chair. He treated everyone in the group with respect, but also made sure we moved forward with the work at a good pace."

> “The chair was excellent. He ensured that everyone was able to contribute and to share their particular expertise […] It was also obvious that he really knew the subject well and this gave the group confidence in him.”
>
> “I found the chair extremely competent and always sought out and led an inclusive conversation and was really listening to all views. I felt the chair assimilated and got the best out of conversations and the people attending.”
>
> [the chair] “had good control over the group and did extremely well at making all feel welcome and valued and keeping meetings to time.”

Just one response emphasised the need for more appreciation of lay people’s participation:

> “Although committee time was well managed it did not always seem appreciated that the lay people had made a specific effort to be able to meet the agenda times and it was somewhat a surprise for discussions to close earlier in an afternoon than expected - this was only on one occasion.”

Q3: The group members

How well did the group work together?

Rating	Very well (1)	Well (2)	Adequately (3)	Poorly (4)	Very poorly (5)
n(16)	3	10	3		

Please comment on how the group worked together

The majority of the community members were generally pleased with the way the group worked together.

> “Every member, regardless of background, was accorded equal status. Consequently, I felt that I was able to make a significant contribution to the discussions and to the eventual outcome.”

However six members noticed a tension in group dynamics mainly related to communication between academics and other members of the group.

> “There was some inevitable tensions between researchers and practitioners but this added to the debate and in the end did not detract from the working of the group.”

In some groups, respondents observed that group dynamics had improved over time achieving greater balance.

> "Over time, as the group got to be more comfortable with the task and understanding of individual perspectives developed, I felt the group functioned as a team rather than as a group of individuals. Meetings became more productive and quality of discussion and decision making increased."

Two community members from different groups found some personalities or the academic perspective too dominant on occasions.

> "It took a few meetings for the academics to get together and there were some large egos in the room on occasions but we came together as a team by the end."
>
> [There were] "diverse views and backgrounds which was useful in forming different perspectives and rounding the debates. There was strong academic knowledge which reflected the needs for the NHS model but sometimes overpowered experience and sense."
>
> One respondent noted that "dynamics changed every meeting as new people came and others were not able to attend, so I do not feel that we always had continuity as a group."

METHODS USED BY THE GROUP

Q4: Your views on the methods used to develop the guidance

4a. Did the group have access to the relevant range of evidence to inform its work?

rating	yes	no
n(15)	10	5

10 of the 15 respondents indicated there was no problem in the group having access to the information relevant to their topic. However several community members considered there was an issue regarding the quality and the type of evidence used.

> "The system was very formulaic and not entirely relevant for our subject area but I think we were one of the first programme development groups and so things were still being developed. The other issue which I think other groups also had problems with is the lack of robust evidence to base recommendations on."
>
> "There was too little evidence based research on which to base the guideline. The evidence available was from different countries with different policies and definitions […]"

> “There was a HUGE amount of documentary evidence considered, not all of it seeming very relevant.”
>
> “Although this was public health guidance, the evidence considered was very clinical.”
>
> “Some of us felt that too much time was spent on reviewing evidence that did not serve to assist in formulating a successful outcome. I do not think that the model used by NICE in this PDG was suitable for a wide-ranging multi-factorial set of questions […] I do not think that there was sufficient understanding of what factors would need to be addressed by the people setting the subject/questions and therefore getting the right people with the right knowledge as members of the group.”

Sometimes, even defining the evidence became an issue in itself:

> “I felt academic vs practice was a poor line and evidence was narrow due to constraints of what evidence is.”

4b. ***Please rate your views on the way the group considered the evidence***

Rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(16)	2	10	4		

One respondent commented on the ability of community members and practitioners to bridge the gap between academic knowledge and real practice by providing their personal experiences:

> “I felt NICE were very open to perspectives of the PDG […] The group were able to offer experience as evidence which valued practice equally – this was I felt an evolution for NICE and one that worked brilliantly to support the production of useful guidance.”

However, in other groups the value of practical experience had less impact:

> “Might be useful if considered more space to expand on ‘real life experiences of issues’ – more balance between academic and issue in context of everyday life. Community members presenting their experiences of issues to group?”

And another respondent suggested it:

> “would have been good to have more evidence from practice earlier in the life of the PDG”

The type of evidence available to the group seemed to lead to a degree of disatisfaction with the work :

> “There was some frustration around the strict criteria for allowing or not allowing certain types of evidence. To some extent, the guidance focussed on areas which we weren't particularly interested in […] but where there was lots of written evidence. Other more important issues were not addressed because of the scarcity of evidence.”
>
> “Sometimes, members dominated the research with opinion, which was hard, and there was little practical evidence apart from anecdotal experience.”

Two respondents commented on the value of small group work:

> “this helped to manage time” and allowed “more focus”

4c. ***Please rate your views on the methods used to develop the recommendations***

Rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(16)	1	8	7		

Although many respondents rated the methods ‘good’ or ‘very good’ and none below average, the qualitative answers suggest a common problem with adapting the methodology requirements to the topic.

> “I feel that we were trying to apply methods more commonly used in drafting clinical guidance to public health guidance. There didn't seem to be any room to draw on the group’s experience or plain common sense. This however was highlighted reasonably earlier on in the process and was I believe dealt with.”
>
> “Promising UK and international interventions were excluded if they did not meet the strict evidential criteria of the review team; therefore the final guidance did not reflect the breadth of public health knowledge in this field.”
>
> “the nature of the project […] made it difficult to develop methods for looking at ‘grey areas of evidence’ ; questioning established ‘gold standards’; and seeking to further develop social science methods in public health.”
>
> One respondent commented that: “Decisions are made by those ‘who turn up’”, while another expressed satisfaction with the whole process: “All documentary evidence was considered and experts were used in trawling the field and producing this for the group’s consideration. A great deal of time was devoted to this task. As a result, the final outcome had authority which was enhanced by experiences of group members.”

Q5: ***Taking into account the views and experiences of people whose health should benefit from the guidance***

5a. *Did the PDG have* ***access to evidence*** *on the views and experiences of people whose health should benefit from the guidance?*

Rating	yes	no
n(15)	9	6

5b. *How well did the PDG* ***take into account*** *the views and experiences of people whose health should benefit from the guidance, when developing the recommendations?*

rating	Very well (1)	Well (2)	Adequately (3)	Poorly (4)	Very poorly (5)
n(16)	2	5	5	4	

Please describe your views on how well the PDG took into account the views and experiences of people whose health should benefit from the guidance

The majority of the respondents rated their answers average or above. However, the qualitative responses reflect a different perspective. Most considered there was little input from the ‘target group’ due to a lack of their involvement:

> “To my knowledge there was little input from individuals from our ‘target’ group.”
>
> “group members tried to take a diversity of views and experiences into account but this was not done as well as it might have been if a broader range of organisations had been represented”
>
> “There was almost no inclusion of people or their views, who actually came from the group under review.”

Some respondents gave reasons for a lack of involvement of the target group:

> “I am not sure the group was constructed to do this”; “the subject was so broad”; “very difficult to consult with young people” and two people suggested time or financial contraints.
>
> One respondent commented: “those whose health should benefit had representatives on the group” while another expressed the view that: “It needs more than just relying on community members to bring this.”

> Another respondent felt that the comments of “patient reps” were taken on board but raised a particular issue about difficulties accommodating the access requirements of a person with complex needs from the target group.

SUPPORT

Q6. ***Were you aware of the Patient and Public Involvement Programme (PPIP) at NICE during your time on the group?***

rating	yes	no
n (15)	14	1

Q7: ***Support from the PPIP***

Please rate the support provided by the PPIP

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)	Not applicable
n(16)	8	6				2

Please describe the support you were offered by the PPIP

Most respondents welcomed the support given through training and personal contact via phone and email.

> “They were very good. An excellent induction programme, very thorough documentation and information resources. Personal contact and support.”
>
> “I was given a sound introduction to the process and support was available when required.”
>
> “One to one support was appreciated and helpful - as well the extra training and contact.”
>
> “Ample documentation. A training course was also given which proved invaluable.”

Q8: ***Support from the Chair***

Please rate the support you received from the Chair

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(16)	10	4	1	1	

Please comment on support from the Chair

Most respondents were pleased with the support received from the chair with ten community members giving the top rating:

> “The chair included me fully in discussions. I didn't feel any different from the professional panel members in the treatment I received or the degree to which my views were listened to.”
>
> “Approachable; ensured that individuals were able to make their points; always appeared interested in what we had to say; ability to summarise meandering comments and tactfully help us to keep on track.”
>
> “Friendly and welcoming, very approachable”
>
> “The chair did his very best but we were far from an easy group to bring together and, on reflection, trying to make the group productive was a major concern.”
>
> [The chair] “made good use of the time and ensured that progress was made and targets achieved. The summing up at the end of each session was clear and those given tasks left each session with a clear view of what was expected.”

Two chairs were praised for their proactive attitude in ensuring the participation of community members and their inclusive approach:

> [The chair] “took time to speak to us prior to the meetings to check we were happy with what we had looked at and if we had any queries that we wanted clarification on she was happy to help.”
>
> “The Chairperson controlled the group well. It was a disparate group and some members were more vocal than the others, but the Chair ensured that everyone was given opportunity to contribute and she ensured that the views of lay members were seriously considered.”

However two members from different groups commented on a lack of response from their chairs outside of the meetings:

> “At the beginning of the process I tried repeatedly to communicate some concerns, in writing, to the Chair. Although I was told my communication had been passed to him, he never contacted me directly.”
>
> “In my own case I was surprised not to receive acknowledgement of my email to her, giving my comments on evidence when I was unable to attend a meeting.”

Q9: ***What, if anything did NICE, PPIP or members of the PDG do well to support community members?***

The training and support (by phone, email and in meetings) were considered helpful and welcomed by the respondents. Also, some expressed appreciation of NICE’s attitude regarding the status of lay people and recognition of equal importance with the professional and academic members of the group.

> “The induction training was excellent and was very beneficial. I also appreciated the telephone calls throughout the process to check that all was okay.”
>
> “I think NICE and PPIP worked hard on this as did some of the members.”
>
> [NICE] “did not aknowledge a difference in status. Acted respectfully and with equity at all times – I was surprised to learn the difference in status at the end of the PDG.”
>
> “The Development Group leader was in constant communication and at each meeting went out of his way to meet and welcome each member as a personal ‘friend’. He was always available to help with any queries or misunderstandings. I had great confidence in the support given and also in the relaxed approach which he adopted.”
>
> “Phone calls and e-mails to ensure we knew support was available, made me feel welcome - little daunting especially with so many academics.”
>
> “Staff, particularly those who attended our meetings, were always available when needed to support or hear concerns.”

One community member raised an issue about the apparent difficulty NICE had to meet a request for a footrest in all meetings.

Q10: ***What, if anything, do you think should be done differently to support community members on PDGs in the future?***

Three respondents recommended that the training day be available for all community members <u>before</u> they start their work on the PDG.

> “The one day course should be offered to all new community members before they start on a PDG.”

Further suggestions included:

> “try to avoid PDG meetings during school holidays”
>
> “Depending on available resources I think that it could be useful if there were opportunities for community members to get together to identify any real pressing issues they each have and how they can work together to address them – e.g. supporting one another in meetings.”
>
> “Maintain true equity and perhaps in pre-PDG training do a mock debate and prepare lay members for an academic procedure. Remind everyone that language is best simple.”
>
> “There needs to be a clear line of action if/when PDG community members respond with concerns. I am not sure this exists or, if it does, how it works.”
>
> “Meeting someone who had already been a community member was very helpful and this should continue.”
>
> “do surveys like this after each PDG – otherwise it is too long a period after the person leaving the PDG”

CONTRIBUTIONS FROM YOU AND OTHER COMMUNITY MEMBERS

Q11: *Influencing the PDG’s work*

What influence did the community members have on the work of the group?

rating	A lot	Little	None
n(15)	9	6	

Please describe the influence of community members on the work of the group

9 respondents felt that community members had a lot of influence on the work of the group through contributing their experiences, knowledge and/or perspectives; while 6 considered they had just a little influence.

> “Community members were able to enlighten the group on how peer support […] works in practice and some of the challenges around adequacy of training for health professionals […] We suggested speakers and experts who should be heard, and evidence was sought from these people. Some community members

> were able to bring to the PDG some research which had not been considered by the academic partners. Community members spoke a lot about the work of their organisations and about the experiences of [the target group]. We were listened to and our views included."
>
> "The discussion about [a specific target group] was greatly enhanced and given much higher priority thanks to the contribution of the other two community members."
>
> "I believe the community members brought life and energy to the PDG and real life experience."
>
> "Equity and diversity – is now included"
>
> "Offered different perspectives – often common sense and real experiences that challenged academic views."
>
> "I felt that community members brought a broad range of knowledge and experience of effective services. [They] were able to inform theory with practical reality."

Q12: ***Opportunities to contribute***

12a. ***Please rate the opportunities you personally had to contribute to the work of the group***

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(16)	8	6	2		

12b*. Please rate how effective you feel your contribution to the PDG's work was*

rating	Very effective (1)	Effective (2)	Adequate (3)	Ineffective (4)	Very ineffective (5)
n(16)	2	9	4	1	

Q13: ***Please describe what you think were your most important contributions?***

Some respondents gave practical examples of their contributions:

> "A presentation to the PDG on my work, various telephone conference calls between the PDG meetings."

> “I was individually responsible for a full recommendation that appears in the final guidance. I offered real experience/perspective which informed a fuller debate and was at times more realistic than ‘evidence’.”

> [I had] “the ability to cite examples from direct experience relating to some of the problems connected with […] Consequently to assist in ensuring that the final document would be relevant to those about to embark on community projects. Was also able to produce evidence of successful community ventures and was able to respond to some of the evidence before the group and to make comment in draft documentation as the work of the group progressed.”

Others gave a more general perspective of their contribution to the PDG’s work:

> “The ability to relate things to the real world”

> “being able to speak (from personal experience and my area of work) of the practical difficulties facing people with […]”

> “Perspective from inner city and from someone actively involved in a school as a parent.”

> “Helping the group to focus on inequality issues.”

> “Keeping the focus grounded for how the actual people who will use the guidance can put it into practice.”

The qualitative responses suggest that community members felt comfortable in sharing their experiences and practical knowledge, and recognised the value of their perspective.

Q14: ***Were there any things you wanted to contribute but did not have an opportunity to do so? If so, please describe***

All but one respondent indicated that they had contributed what they wanted to.

> “No, I don’t have any anxieties about wishing we had done more than we did.”

However, one community member would have welcomed more representation from the target population, while another participant commented on the time limitations.

> “Bringing real people from those affected to contribute their experience and knowledge.”

> “Could have done with a bit more time to read through the mass of documentration. Felt that the process had to be hurried through in order to meet the deadline – on the other hand it meant that the group was very focused at

> each meeting. On the whole I think we did the best we could in the time available."

One member commented on a barrier to contributing:

> "Sometimes it took a little longer for me to understand some language used and then it was too late to make a point."

TRAINING

Q15: *Training workshop from the Patient and Public Involvement Programme (PPIP)*

15a. ***Did you attend the training workshop offered by the PPIP?***

rating	yes	no
n(16)	15	1

15b. ***If yes, please rate how helpful the workshop from the PPIP was***

rating	Very helpful (1)	Helpful (2)	Adequate (3)	Not very helpful (4)	Not at all helpful (5)
n(15)	10	3		1	1

Q16: *Please comment on the training provided to PDG community members*

Of the respondents, just one community member did not participate in the PPIP training. Of the 15 members who did, two responses were below average. In both cases, the community members suggested the training was not relevant for their work on the PDG.

The rest of the respondents however, welcomed the training and considered it appropriate and inclusive, responding to different needs as the members had different backgrounds:

> "it was much needed and very good"

> "Useful, not daunting; inclusive and appropriate for a wide range of experiences/backgrounds."

> "Really helpful as little unsure before of what to expect - however many of the other PDG members felt they too would have benefited from the training and this meeting to create guidance was new to many."

One respondent found the training helpful but commented:

> "I don't think it prepared me for the academic intensity of the need to base our recommendations on proven evidence and this is more so on my second PDG."

As in question 10 above, two community members made a clear recommendation for ensuring access to the training before the beginning of the PDG's work.

> "very good, but could have done with going on it before I started the PDG"

> "It should be offered before work starts and it should be offered to all members – not just the lay members, because I felt that some of the professionals would have benefited and it may have saved precious time."

FINAL GUIDANCE

Q17: *Please rate your overall views of the final guidance recommendations*

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(16)	5	7	3	1	

Please describe your views of the final recommendations

Twelve community members rated their answers above average and were pleased with the results:

> "Clear and helpful. I am very conscious of them being put into practice and I feel proud to have been part of the process of developing them."

> "It was tough to come up with final recommendations, but I felt that the end version were clear and to the point."

> "Brilliant. Proud that the NHS/NICE have been foresighted to influence responsibility for health outside of NHS."

> "Got the message across clearly and concisely."

One member considered the final recommendation below average:

> "Due to the lack of relevant evidence on which to base the guidance, and the current […] I don't think this guidance will be very useful."

The same lack of evidence was highlighted by a few other members who considered the final recommendations to be weak or broad due to the evidence gap:

> "Would like to have gone further in some aspects, it felt a bit conservative in places. Once again the lack of evidence influenced this."
>
> "Given the nature of the project, and the evidence available, the final recommendations were very broad."
>
> "Given the lack of robust evidence, the final recommendations were all we could make, hopefully the research recommendations will be picked up and in future more direct recommendations will be made."

One respondent who gave an average rating expressed disappointment:

> "Disappointingly technical - I felt it was a missed opportunity to give professionals real practical guidance."

Q18: ***Reflecting the views of people whose health should benefit from the guidance***

Please rate how well you feel the views and experiences of people whose health should benefit from the guidance are reflected in the final guidance

rating	Very well (1)	Well (2)	Adequately (3)	Poorly (4)	Very poorly (5)
n(16)	1	4	8	3	

Please describe your views

The majority gave an average rating in response to the question about how well the final recommendations reflect the views and experiences of the target population. Only five respondents rated this 'very well' or 'well', while three ranked this as 'poor'. One response sums up most of the comments of the average rankings:

> "There wasn't enough time to do a huge amount of field work, and there was little evidence available, so I can't be sure if the guidance takes into account [users'] views sufficiently."

One respondent also noted the difficulty when a topic is very broad:

> "As already mentioned our subject area was so broad there is not just one group of people likely to benefit."

One participant emphasised that:

> “many of the points representing the user perspective were removed before the final draft”

Q19: *Community member influence on final recommendations*

Please rate the influence that community members had on the final recommendations

rating	A lot (1)	Some (2)	Adequate (3)	Little (4)	Very little (5)
n(16)	6	4	4	2	

Please describe any influence you think the community members had

Most respondents felt that community members had either a lot or some influence on the final recommendations, with only two respondents considering they had little influence. The influence of community members on the final guidance also seemed to vary from one group to another reflecting the different dynamics:

> “I think we brought balance to the proceedings and helped the chair and the NICE team develop sensible recommendations from the evidence.”
>
> “We had as much influence as the academics but the lack of robust evidence made it difficult to make very direct recommendations.”
>
> “As much influence as any other member of the group.”

One community member raised the issue of the extended timeline and a lack of motivation by this endpoint:

> “To be honest, I had lost motivation by this point. The process was very long and we went over our initial timetable. I was given the opportunity to contribute to the wording of recommendations. I did to a small extent, but didn't have the energy to make a big contribution by this point.”

OVERALL EXPERIENCE AND GENERAL COMMENTS

Q20: *Your overall experiences of having been part of the PDG*

Please rate your overall evaluation of the experience of being on the PDG

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(15)	10	4		1	

Please describe your overall evaluation of the experience

The overall experience was a very positive one for the majority of members who rated their participation in the PDG as ‘good’ or ‘very good’, completed by qualitative descriptions like:

> “brilliant”, “felt well supported, informed and included”, “it was a joy working with [...]”, “fascinating, stimulating hard work”, “very positive and constructive. One I would (and have) recommended to others active in the community.”

Just one respondent gave a ‘poor’ rating but no additional explanation was given for it.

Q21: Please describe if you got anything out of the process in terms of your own personal development

In terms of personal development, four respondents indicated an increase in their confidence and self-esteem as they had the opportunity to put their experience to wider use.

> “Confidence; valuable experience; transportable skills/knowledge; opportunity to put experience and knowledge to wider use.”

> “Being part of a large conference type meeting, speaking and presenting within this type of meeting, awareness of how guidance is formed - now I have more respect for the guidance available as understand the processes behind it.”

The interdisciplinary approach was positively appraised by other members:

> “It was also really useful to see professionals from many diverse disciplines working together towards a guidance.”

> “A wonderful opportunity to be part of a multi-disciplinary group, and a fascinating insight into how a process that intends to be systematic can be rather ad hoc and heavily influenced by who is there.”

Trust in NICE recommendations increased for several respondents:

> “It was a good insight into the workings of a NICE committee. I understand more clearly the different ways in which we can rank, rate and assess the value of evidence. I feel a sense of ownership of the […] guidance which helps me when I am teaching health professionals - I understand where the recommendations came from, so I trust them.”

Q22: Do you have any other comments you would like to share? Please feel free to make any additional observations here

Some respondents reiterated their positive experiences of work on the PDG, with only one community member indicating a less positive experience overall. Several people raised additional points or made suggestions.

> “Just to emphasise that the long, paper-heavy process is hard work for any human.”

One member raised issues about the payment of expenses:

> “NICE only pay a 6p a mile for cycle travel when CTC Ireland revenue agreed is 20p a mile. […] The speed of repayment of claims is slow. But the honorarium is a good idea. And it assists in keeping up the momentum.”

Another respondent recommended a smaller number of experts on the PDG in order to have a faster decision making process:

> “I'm not sure that a round table of 25 experts makes for effective or efficient decision-making. Some members of our panel said very little in any meeting and I wonder what the value of their ongoing membership was.”

Finally, one member suggested the need for an extra meeting at the end of the work:

> “The sudden end to a concentrated series of meetings left me a bit in a limbo. It would have been useful to have had a further less pressured post-final meeting just to wind down and contemplate the end of a process.”

Section 2: Quantitative and qualitative findings: chairs

PRIOR TO PROGRAMME DEVELOPMENT GROUP (PDG) MEETINGS

Q1: Please describe your main reasons for wanting to chair the PDG

The chairs explained their motivation for taking on this role by emphasising their interest and experience in the field or because they considered it an “interesting experiment” and an opportunity to bring research into practice:

> “Longstanding academic interest in this area.”
>
> “I was excited to see social sciences included in the NICE purview and felt that such guidance was badly needed by health promoters, health boards, policy makers and providers and practitioners in the NHS.”
>
> “one of my main drivers was making research evidence accessible to practitioners”

GROUP WORKING

Q2: How well did the group work together?

rating	Very well (1)	Well (2)	Adequately (3)	Poorly (4)	Very poorly (5)
n(4)	2	2			

Q3: How well did the community members work with the group?

rating	Very well (1)	Well (2)	Adequately (3)	Poorly (4)	Very poorly (5)
n(4)	2	2			

Please comment on how the group worked together

One chair was extremely pleased with the way the group worked together:

> "in long experience of chairing a range of groups, I have never known any more commited to effective teamwork to which the NICE staff made a crucial contribution"

Two chairs commented on the challenges for group working given the range of members' different experiences and backgrounds:

> "It was occasionally difficult to get agreement between such a broad range of professionals, let alone the community members […] There was also quite lot of background reading and members appeared to vary in their ability to assimilate this."

> "it is difficult to find an approach common to all the disciplines represented including sociology, psychology, economics, politics and others"

A fourth chair highlighted the importance of the selection process and group working methods:

> "We were careful in group selection and we also worked in small groups"

METHODS USED BY THE GROUP

Q4: *Your views on the methods used to develop the guidance*

4a. Did the group have access to the relevant range of evidence to inform its work?

rating	yes	no
n(4)	3	1

4b. Please rate your views on the way the group considered the evidence

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(4)		1	3		

4c. Please rate your views on the methods used to develop the recommendations

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(4)	1	2	1		

Please describe your views on the methods used to develop the guidance in relation to 4 a), b) and c) above

The comments regarding access to evidence (4a) suggested it was considered positive by 3 of the 4 respondents. One chair responding 'no' explained that the topic was very broad and the initial material given as a basis for evaluation was more clinical than public health oriented.

The problem of defining what is ‘relevant evidence’ and the challenges presented by the established or developing methodology were highlighted by the chairs as well as by the community members (see previous section):

> “There were difficulties about the definition of the relevant range of evidence and problems about considering qualitative research and dealing with issues in policy and politics. However, a set of generic principles was eventually produced and was agreed by the whole committee.”
>
> “The group were provided with good evidence although the rapid nature of the reviews and inclusion criteria for papers sometimes meant that useful evidence was rejected.”

The way the group considered the evidence was considered above average by all the chairs. They also commented on the challenges and limitations.

> “The involvement of community members was very helpful as they brought complementary skills and had all acted in expert roles for NGOs […] It was on the other hand necessary to persuade some senior professional members that there were forms of evidence other than randomised trials, and that both contextual / colloquial sources had importance.”
>
> “limited by pressure of time”
>
> “The group had been anxious to try, subsequently, to use this experience to contribute more formally – from various different perspectives – to the debate about the methodology of appraisal of evidence in complex arenas and this might have been useful if it had been possible.”

Q5: ***Taking into account the views and the experiences of people whose health should benefit from the guidance***

5a. Did the PDG have access to evidence on the views and experiences of people whose health should benefit from the guidance?

rating	yes	no
n(3)	2	1

5b. How well did the PDG take into account the views and experiences of people whose health should benefit from the guidance, when developing the recommendations?

rating	Very well (1)	Well (2)	Adequately (3)	Poorly (4)	Very poorly (5)
n(3)		2	1		

Please describe your views on how well the PDG took into account the views and experiences of people whose health should benefit from the guidance

The extent to which this perspective was taken into account by the PDG was given an average or above average ranking by the 3 respondents.

On analysing the access of the PDG to the views and experiences of people whose health should benefit from the guidance, two chairs responded in the affirmative while one replied in the negative and another one did not provide a rating. However the chair who responded in the negative also explained that there was no clear-cut definition of such a group for their particular guidance topic:

> “This section is not easy to answer since ‘people whose health benefit from the guidance’ were never really defined; in effect, the whole population of the nation. The guidance was directed at those involved in health promotion at local and national levels, including statutory and voluntary bodies. The views and experiences of these, treated as ‘stakeholders’, were taken into account.”

Two chairs commented that the experience of group members was drawn on. One suggested that in retrospect:

> “it might have been educative to have interviewed [the client group] before finalising the recommendations”

CONTRIBUTIONS FROM COMMUNITY MEMBERS

Q6: Influencing the PDG’s work

What influence did the community members have on the work of the group?

rating	A lot (1)	Little (2)	None (3)
n(4)	4		

Please describe the influence of community members on the work of the group

All the chairs considered the community members to have had a lot of influence on the work of the group.

> “the community members had unique expert roles”
>
> “They contributed from their professional and personal experience […] The other group members encouraged and appreciated their contributions.”

One chair commented on community members’ response to some of the academic arguments, appreciating their ability to maintain their position and make a valuable contribution to the group:

> “They remained, I believe, a little puzzled about some unfortunate interdisciplinary and theoretical arguments among academic members, though always very much engaged and coming down very firmly on the side of common sense. In this way they performed a valuable function for the group.”

Q7: ***Was there anything you felt the community members could have contributed to the process that they did not? If yes, please elaborate***

rating	yes	no
n(3)		3

Q8: Were there any problems in having community members on the PDG?

rating	yes	no
n(4)		4

Q9: What is your view on the value of community member involvement in the PDGs?

Please rate your view on the value of community member involvement in PDGs

rating	Very high (1)	High (2)	Medium (3)	Low (4)	Very low (5)
n(4)	2	2			

Please describe your views

The community members’ contribution was highly valued by all chairs. One chair emphasised community members’ role as representatives of “consumers/patients”; another highlighted their practical community experience and expertise:

> “they were, and were seen as, equal contributors. In some ways, their practical experience made them more ‘expert’ than some of the academic members and to have had a greater proportion would have been advantageous.”
>
> “their input was very valuable”

A fourth chair suggested that the “consumer” perspective might have been lost in the selection process:

> “Ideally one would have wanted less rigorously selected members of the ‘consumer’ groups though to an extent this has to be accomplished by field testing.”

SUPPORT FOR INVOLVING COMMUNITY MEMBERS

Q10: Were you aware of the support role available from the Patient and Public Involvement Programme (PPIP) at NICE?

rating	yes	no
n(4)	4	

Q11: Support from the PPIP

Please rate how well you think the PPIP supported the community members

rating	Very well (1)	Well (2)	Adequate (3)	Poorly (4)	Very poorly (5)	Don't know
n(4)		1				3

Please describe your views on the support from the PPIP

All the responding chairs were aware of the support available from NICE’s Patient and Public Involvement Programme (PPIP). However, only one was able to rate the nature of this support. One chair explained:

> “I don't know the nature of this support, nor the extent to which it took place in the case of my own particular group.”

Q12: Support from you as the Chair – please describe the support you offered to community members (if any)

When asked how they (the chairs) had supported the involvement of community members, all the respondents highlighted their effort to integrate them and incorporate their views in the PDG work:

> “I hope that I supported the members in discussion and that they feel their views were incorporated.”
>
> “ensuring their contributions were valued and taken on board”
>
> “I made a particular point of ensuring that the community members were included.”

Q13: What, if anything did NICE, PPIP or members of the PDG do well to support community members?

One chair emphasised the role of the NICE team:

> “I worked with the NICE team to make sure that they were given space to build confidence and express their views.”

Another chair highlighted the inclusive attitude towards community members:

> “Making them welcome as valuable members of the group but without patronising or condescending them (which would have beeen disastrous given their characters and experience).”

While the third chair noted that:

> “other members of the Group also went out of their way to include the community members in every discussion”

Q14: What, if anything, do you feel should be done differently to support community members on PDGs in the future?

None of the chairs suggested ways to improve support for community members.

FINAL GUIDANCE

Q15: The final version of the guidance

Please rate your overall views of the final guidance recommendations

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(4)	1	3			

Please describe your views of the final recommendations

The final recommendations were evaluated as ‘very good’ or ‘good’ by all four respondents.

> “I think the Recommendations laid appropriate emphasis.”
>
> “In my opinion (reinforced by subsequent discussion with for e.g. people working in the local NHS Trusts) this guidance was very useful in setting up appropriate approaches and supporting workers on the ground. Some important principles were firmly established.”

The qualitative answers indicate the limitations of the final guidance, associated with a lack of evidence, resource limitations on the ground, or the long timeline for guidance to be developed (which can lead to ‘outdated’ recommendations).

> “We resisted the temptation to go beyond conclusions based on evidence, which was a constraint, and we bore in mind the limit imposed by the availability of resources.”
>
> “the problem always lies with the fact that new data merges over the period that the NICE production of guidance also occurs”

One respondent emphasised that the usual format of NICE recommendations is not always the most appropriate for the topic:

> “it was agreed that, rather than the standard set of specific recommendations, all that could be produced at this wide level was a set of generic principles”

Q16: Reflecting the views of people whose health should benefit from the guidance

Please rate how well you feel the views and experiences of people whose health should benefit from the guidance are reflected in the final guidance

rating	Very well (1)	Well (2)	Adequately (3)	Poorly (4)	Very poorly (5)
n(3)		2	1		

The chairs rated the guidance as good or average with regard to reflecting the perspectives of the client group or target population, with one chair not responding.

Please describe your views

One chair commented:

> “The frustrating thing here is that it is difficult to get spontaneous feedback from vulnerable and underprivileged groups, so it's hard to identify their own priorities and one ends up hearing the views of others about these groups.”

Other explanations seemed to reflect different interpretations of the question. Comments included:

> “None of us assumed that ours was the last word on the issue.”
>
> “As a PDG we did not feel it would directly enhance the guidance if we invited [the target group] to PDG meetings. Further views on the guidance and its applicability to [the target group] would be considered after the field work.”

Q17: Please rate the influence that community members had on the final recommendations

rating	A lot (1)	Some (2)	Adequate (3)	Little (4)	Very little (5)
n(4)	2	1	1		

Please describe any influence you think the community members had on the final recommendations

From the chairs’ perspective, community members had either a lot or some influence on the final recommendations, with one chair assessing their influence as ‘adequate’.

The answers ranged from:

> "The community members retained their active interest to the very end and had as much influence on the final guidance as any other member of the Group"

to

> "I seem to recall that by this stage in the proceedings we were not getting so much feedback from community members as we were earlier in the exercise. Perhaps some fatigue due to the duration of the project."

OVERALL EXPERIENCE AND GENERAL COMMENTS

Q18: Your overall experience of having been part of the PDG

Please rate your overall experience of the PDG

rating	Very good (1)	Good (2)	Adequate (3)	Poor (4)	Very poor (5)
n(4)	3	1			

Please describe your overall experiences

Respondents rated their overall experience as very good or good. The initial stages were considered difficult by one chair due to the problems associated with the definition of evidence and the amount of work required. However, the following statements indicate a positive perception of the process overall:

> "challenging - hard work but enjoyable"

> "in the end satisfying to be working with such an excellent group of people"

Additional comments

Two of the chairs noted in particular the support given by the NICE staff:

> "I thought the whole exercise from scope, and Committee recruitment through to issue of Guidance was admirably supported by the secretariat […]"

> "The staff 'team' were outstanding […] they never missed an opportunity to support and softly to guide the process."

Discussion and recommendations

In reviewing the findings of the study, the following limitations need to be borne in mind:

- Although the overall response rate for this survey was good, the actual number of participants was quite small, especially the PDG chairs.
- Respondents were asked about their personal perspective and experiences as part of a process that was itself in development and therefore changed over time. This is particularly relevant to the evolving methods of public health guidance development.
- The seven PDGs in this study started and finished their work in different time periods and so there is a wide variation in the time lapse between participants finishing their PDG work and completing the questionnaire.

In the rest of this section we bring together themes from the two sets of responses (community members and chairs), and suggest ways of further improving the participation of community members and incorporating community perspectives.

Views on community membership of PDGs

When asked to rate their *overall experience*, 10 community members gave the top rating of ‘very good’, 4 rated it ‘good’ and only 1 ‘poor’. When asked to rate individual elements of the PDG experience, community members gave the lowest scores in response to questions about the extent to which the views of the target population were taken into account when developing recommendations (Q5b) and reflected in the final guidance (Q18). However 14 community members considered that they and other community members on their PDG had had ‘a lot’, ‘some’ or ‘adequate’ influence on the final guidance recommendations.

In terms of their influence on the PDG’s work as a whole, 9 community members responded that they had ‘a lot’ of influence and 6 ‘a little’ influence. By comparison, all four chairs considered that the community members had ‘a lot’ of influence on the PDG’s work and rated the value of community members’ involvement ‘highly’ or ‘very highly’.

Information, training and support

Community members welcomed the support offered by the PPIP in terms of induction, information and ongoing support, and the majority valued the PPIP training. Community members and chairs also expressed appreciation for the support provided by the NICE public health team.

Regarding support from the chair, both categories of respondents highlighted the chairs’ efforts to integrate the community members in PDG work. Generally, community members characterised the chairs' approach as supportive, equitable and inclusive. However, in two examples, issues of lack of communication from the chair were highlighted.

Several community members made suggestions for improving support and some are included in the recommendations below.

We recommend:

- Continue aiming to schedule PPIP training days for new community members before the the first PDG working meeting (PDG1). Where this is not possible, before PDG2.
- Continue to run PPIP follow-up workshops for community members who are at least 6 months into their work on the PDG – the first of these workshops was successfully piloted in October 2009.
- CPHE / PPIP to work with PDG chairs in reinforcing the importance of avoiding jargon and explaining technical terms and abbreviations.
- PPIP to pilot an exit questionnaire for community members with the aim of systematically obtaining feedback for all PDGs and refining the process as appropriate.

PDG meetings

Generally, community members were positive about PDG meetings and the opportunities they had to make contributions to the development of guidance. Overall, both they and the chairs considered that the dynamic within groups was a good one. However, both types of respondents highlighted some tension, mainly related to communication between 'academics' and other members of the group. Good chairing contributed to community members' positive experience, with most community members commenting favourably on the chair's leadership and inclusive approach. However two community members from different PDGs were disappointed by a lack of response from the chair outside of the meeting.

One respondent raised concerns about apparent difficulties in meeting a person's needs arising from their disability, and another expressed concern about delays in reimbursing expenses.

We recommend:

- Select chairs on the basis of their chairing skills as well as other skills and expertise relevant to the guidance topic. Alternatively, recruit a chair for their chairing skills and a separate person to provide expert leadership on the topic.

- Ensure the individual special needs of community members are addressed.

- CPHE to alert PPIP in the event of a delay or other problem with expenses and payment claims.

Guidance methodology and process

10 out of 15 community members (and 3 out of 4 chairs) considered that their PDG had access to the relevant range of evidence. Community members and chairs gave a positive or average rating to the way the evidence was considered and the methods used to develop the recommendations. Some community members and chairs highlighted an issue with defining what relevant evidence is and many expressed frustration with the limitations of the research evidence presented to the group. Several community members considered the information to be too theoretical with not enough evidence from practice or sufficient utilisation of group members' practical experience. A few respondents commented that the initial difficulties were addressed as the work progressed.

We recommend:

- As appropriate for each PDG, consider giving time to one or more short presentations from a community and a practitioner perspective (given by members or experts/co-optees).

Drawing on other community views (the target population for the guidance)

9 out of 15 community members (and 2 out of 3 chairs) who responded, said that their PDG had access to evidence on the views and experiences of people whose health should benefit from the guidance. However, in the context of all the survey questions, community members gave the lowest scores in response to questions about the extent to which the views of the target population were taken into account when developing recommendations and reflected in the final guidance. One group (community members and chair) could not single out a target group as the guidance was aimed at the general population. Most community members considered that the PDG had little input from members of the target population.

For most guidance topics, the NICE public health team commissions a qualitative review of evidence which may pick up relevant research on the views and experiences of the target population (and practitioners) where that evidence exists. For each piece of public health guidance to date, the draft recommendations have also been tested out in fieldwork with practitioners and this includes professionals from the voluntary and community sector. Occasionally, the public health team commissions additional work to consult target groups, such as young people.

We recommend:

- Routinely search for information on the beliefs, attitudes, views and experiences of the target population in reviews of evidence and calls for evidence.
- Routinely consider other potential sources of information on the perspectives of the target population or specific subgroups; for example, invite a community member to give a presentation, recruit a co-optee, seek testimony from an expert, commission small-scale consultation with members of the target population.
- Clarify the aims of any proposal to gather the views of the target population (for example, to identify issues that should be included in the scope of a guidance project; to help refine community issues within the context of an agreed 'scope'; to provide information on the views and experiences of specific subgroups; to comment on the relevance and acceptability of draft recommendations).
- Avoid carrying out additional work where there is an existing evidence base.
- Consider the use of reference groups as a further option for input from the target group.

Conclusion

Previous evaluations of patient and carer involvement in the development of NICE clinical guidelines have shown that it is possible to engage lay people as effective members of guideline development groups. [2] Responses from both community members and chairs in this survey indicate a similar conclusion with respect to developing public health guidance. Responses also suggest ways in which the process can be refined or enhanced.

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[2] National Institute for Clinical Excellence (2004). A report on a study to evaluate patient/carer membership of the first NICE Guideline Development Groups. This evaluation was repeated in 2008. Reports available at: www.nice.org.uk/getinvolved/patientandpublicinvolvement/ppipinvolvementprogramme.jsp