

***“Community members brought real
life experience”***

***Evaluation of lay people’s contribution
to NICE public health guidance***

Jane Cowl

Programme Manager, Patient and Public Involvement Programme
National Institute for Health and Clinical Excellence

Objectives

To evaluate:

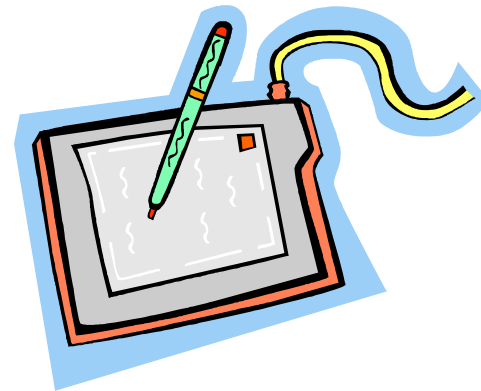
- lay people's experiences as members of NICE groups developing public health guidance
- chairs' experiences of having lay members (known as 'community members') on the group

To explore:

- the views of community members and chairs on the process, methodology and final guidance

Methodology

- Mixed method questionnaire (completed electronically or in hard copy)
- Small pilot followed by main survey
- Qualitative responses and quantitative rating scales
- Information sheet and consent form
- Demographic form



Themes

- Methods of guidance development
- Group working and role of the chair
- Contribution of community members
- Support and training for community members
- Final guidance
- Overall experience



Participants

- First 7 public health guidance groups (guidance published between October 07 and March 09)
- Community members and chairs
- 28 eligible participants – 21 community members, 7 chairs
- Overall response rate of 71% (n = 20)
 - 57% chairs (n = 4)
 - 76% community members (n = 16)

The 7 public health guidance development groups

Behaviour change

Physical activity and the environment

Smoking cessation services

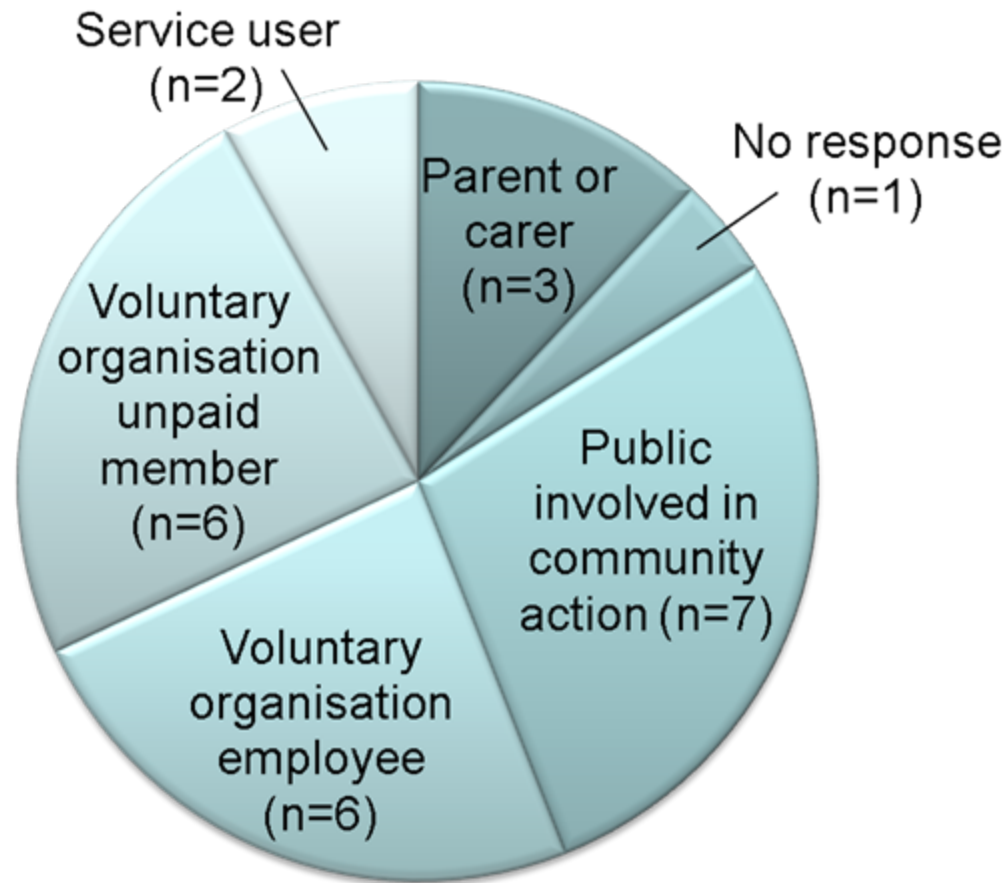
Community engagement

Maternal and child nutrition

Promoting physical activity for children & young people

Management of long-term sickness & incapacity for work

Participants – community members



Some respondents ticked more than one of the above categories

Views on NICE methodology

- Community members and chairs generally positive about the methodology
- Some recurrent frustrations and criticisms
 - limitations of research evidence
 - what counts as evidence
 - balance between academic and real life

Group working and role of chair

- Community members generally positive about group working and the opportunities they had to contribute
- 37% (n=6) community members commented on tension in approach between academics and other group members
- Good chairing contributed to positive experience



Incorporating views of target population

- Community members gave lowest ratings to questions about incorporating the views of the target population

“it needs more than relying on community members to bring this”

“the subject was so broad”

- 1 chair said: *“it might have been educative to have interviewed [the client group] before finalising the recommendations”*

Support and training

- The majority considered the induction, training and support from NICE staff to be helpful

“An excellent induction programme, very thorough documentation and information resources. Personal contact and support.”

“support was available when required”

“A training course was also given which proved invaluable”

- Most community members were positive about support from the chair, valuing an equitable and inclusive approach

Contribution of community members

- All 4 chairs considered community members had ‘a lot’ of influence on the group’s work
“unique expert roles”
- Community members gave mixed responses - ‘a lot of influence’ (n=9); ‘a little influence’ (n=6); non-response (n=1)
“Often different perspectives – often common sense and real life experience”
“Helping the group to focus on inequality issues”
- Some respondents gave practical examples of their contribution, e.g. presentation to the group, identifying research, suggesting experts to give testimony, drafting a recommendation

Views on final guidance

- All 4 chairs and 75% community members rated the final guidance 'good' or 'very good' (1 'poor' rating)

- Community members:

“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.”

“I don't think this guidance will be very useful”

- Several community members and chairs cited lack of evidence limiting the final recommendations

Overall experience (1)

- 10 community members gave top rating 'very good', 4 rated their experience 'good', 1 'poor' & 1 non-response

“fascinating, stimulating hard work”

“very positive and constructive – one I would (and have) recommended to others active in the community”

“felt well supported, informed and included”

- Rated 'very good' or 'good' by all 4 chairs

“challenging-hard work but enjoyable”

Overall experience (2)

- All 4 chairs valued community members' involvement 'very highly' or 'highly'

“their input was invaluable”

“they were, and were seen as, equal contributors. In some ways, their practical experience made them more ‘expert’ than some of the academic members...”

Key recommendations

- Importance of selecting chairs on basis of chairing skills as well as other expertise
- Timing of training for community members
- Possibility of improving search for, and use of, information on the perspectives of the target population
- Exit questionnaire after guidance publication

Final thoughts

- Results validate the benefit of lay participation in the development of public health guidance
- Benefits to the process, outcome and to the individuals involved
- Report by Ioana Ursu and Jane Cowl available at: www.nice.org.uk

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