



PS06: Methods of public and patient involvement – a toolkit

Public consultation strategies

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- **The term ‘consultation’:** *process of collecting information from patient and public stakeholders (to inform guideline development and implementation)*
- **Vs ‘participation’:** *exchanging information with other stakeholders, for example as members of a guideline development group.*

Boivin A, et al on behalf of G-I-N PUBLIC (2010) Patient and public involvement in clinical guidelines: international experiences and future perspectives. *BMJ Quality & Safety in Health Care* 19:1-4

- To ensure issues important to patients/families/carers are taken into account - scoping of topics and questions to address
- Add value when important gaps are identified in the evidence related to their views and experiences
- Helping to ensure the CPG is relevant and acceptable to patients and carers, and to specific groups
- Paving the way for patient/carer support for the final CPG - receptivity to its uptake and dissemination

- Enhancing the legitimacy of the development process and the end product from a public perspective
- Requirement: accrediting producers (NHS Evidence-NICE), approval of CPG (NHMRC Australia), standards (IOM USA)
- CPG Programmes: NICE (UK), SIGN (Scotland), GuíaSalud (Spain)

- Open to the public and/or targeted to relevant patient/carer groups and other stakeholders
- Remotely (e.g. online), in meetings or in workshops, or a combination of these
- Research (qualitative) with patients and/or carers (surveys, focus groups and interviews)
- In most processes - such as feedback on draft scoping documents and draft guidelines - can occur simultaneously with professional consultation



Whichever approach - adds time and resource

| | OPEN | TARGETED | OPEN & TARGETED |
|--------------------------------|--|--|--|
| Ways | Public posting of draft documents & questions | By invitation to all relevant stakeholders | Public posting of draft documents /questions & targeted invitations |
| Potential advantages | Transparency and opening up process to all | More effective in generating responses Finding individuals or groups and invite them to contribute Volume of feedback manageable | Combines openness and transparency with reaching all relevant stakeholders |
| Potential disadvantages | High volume of feedback Inadequate feedback | Important viewpoints overlooked or avoided Invited organizations not interested or able to respond timely | High volume of feedback |

Consulting patient/carer organizations - NICE

- Open consultation - draft documents posted on its website at key stages in the CPG development process
- To manage volume - encourages individuals to respond via a relevant stakeholder organisation.
- Organisations receive a response from developers to their comments - both published on NICE website
- Registered stakeholder organisations are invited to contribute at key stages of the development process

Patient and public as expert reviewers

- SIGN : CPG reviewed in draft form by independent experts including at least two patient/public reviewers.
- NICE & GuíaSalud : external review mainly through consultation with stakeholder organizations; but developers may consider additional expert review including patients, during development or at the final consultation stage.
- NICE & SIGN & GuíaSalud: declaration of interests

Consultation at key stages: setting the scope

Before the first meeting of the GDG

- SIGN:
 - form supplied to enable them to structure their feedback and to indicate the source
 - focus groups with patients in different regions
- NICE:
 - participation in a scoping meeting-draft scope
 - 4-week online consultation to comment
- GuíaSalud (Spain): form, focus groups and interviews

Consultation at key stages: the draft guideline

- SIGN: open consultation on the draft with a later period of peer review
 - National open meeting: professionals and patients
 - Draft guideline also posted on the SIGN website
- NICE and GuíaSalud: similar online consultation process, inviting stakeholder organizations to comment on the draft guideline during a set period.

Responding to consultation comments

- Patient and public members presenting the proposed modifications to the broader GDG
- IOM (USA), NHMRC (Australia) : advises developers to keep a written record of the rationale for modifying or not modifying a guideline
- NICE:
 - guideline producers accreditation: reasons explained if patients views not taken into account
 - NICE guidelines: enters all comments into a table, which includes a responses column
- GuíaSalud: consultation comments and responses publicly available

Consulting using research techniques

- To supplement gaps: in the evidence, insufficient feedback from patient organizations, in membership of the GDG
- Methods: focus groups, interviews (in-depth, semi-structured), participant observation and surveys (ex. Palliative Care CPG – UETS)
- Before considering such work : check if the information is already available (grey literature, other data bases)

Díaz del Campo P, Gracia J, et al (2011) A strategy for patient involvement in clinical practice guidelines: methodological approaches. *BMJ Quality & Safety* 20:779-784.

Key messages about consultation

- Involve health professionals & patients/organizations representing their interests
- Effective consultation adds value to the process of guideline development and can help support use
- Requires transparent and inclusive consultation
- Can be conducted at all key stages, with a diversity of methods
- Requires additional time and resources, which need to be factored in from the start

Best practice principles for consultations

& Case Studies & more.... Available at :

<http://www.g-i-n.net/activities/gin-public/toolkit>

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