Engaging stakeholders

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NHMRC Standards

The following Standards apply to the Engaging stakeholders module:

1. To be relevant and useful for decision making guidelines will:
   1.1 Address a health issue of importance.
   1.2 Clearly state the purpose of the guideline and the context in which it will be applied.
   1.3 Be informed by public consultation.
   1.4 Be feasible to implement.

5. To be focused on health and related outcomes guidelines will:
   5.1. Be developed around explicitly defined clinical or public health questions.
   5.2. Address outcomes that are relevant to the guideline’s expected end users.
   5.3 Clearly define the outcomes considered to be important to the person/s who will be affected by the decision, and prioritise these outcomes.

Overview

Engaging stakeholders early and often can be the difference between developing a guideline that sits on the shelf and one that makes a significant impact.

Guidelines have the potential to affect a wide range of people and organisations by influencing behaviour, changing practice, and having an impact on policy, legal or funding frameworks.
Guideline stakeholders are those individuals or groups who are affected by or who can influence a guideline’s development and implementation, including government agencies, professional societies, people affected by the condition (as individuals and consumer organisations), healthcare and academic centres, quality improvement organisations, and relevant commercial companies (Institute of Medicine 2011).

Stakeholders include a guideline’s ‘expected users’: those who the developers expect or intend to apply, implement, or be otherwise directly affected by a guideline’s recommendations. For the purpose of this module, stakeholders are defined as anyone with a legitimate interest in a guideline or anyone affected by its recommendations (see Table 1. for examples). While stakeholders, including consumers, should be involved in guideline development as members of the development group (if non-conflicted) and through a public consultation process, this advice is discussed in other modules. The purpose of this module is instead to focus on additional methods of stakeholder engagement throughout guideline development.

**Table 1. Types of stakeholders in guideline development**

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Expected users</td>
<td>People intended or expected to apply, implement or be directly affected by the guideline recommendations (for example, health care providers, policy makers or the public who may use the guideline recommendations to assist in decision making).</td>
</tr>
<tr>
<td>Government agencies</td>
<td>Government agencies involved in the funding or administration of health care and policy activities, such as the Department of Health, state and territory health departments, the Department of Veterans’ Affairs, the Australian Commission for Safety and Quality in Health Care and NHMRC.</td>
</tr>
<tr>
<td>Professional bodies</td>
<td>Professional and industrial bodies, such as medical and nursing colleges, specialty societies, industrial groups and public health groups.</td>
</tr>
<tr>
<td>Insurers</td>
<td>Private and public insurance companies such as the National Disability Insurance Agency, and other payment and reimbursement agencies.</td>
</tr>
<tr>
<td>Industry</td>
<td>Industry groups and commercial companies involved in manufacturing, supply or service delivery in health and other relevant sectors.</td>
</tr>
<tr>
<td>Condition groups</td>
<td>Groups that focus on a specific disease or health issue that support research, represent relevant professionals or advocate for patients or other populations of interest (see also Involving Consumers).</td>
</tr>
<tr>
<td>Researchers</td>
<td>Health and medical researchers, institutes and research collaborations.</td>
</tr>
<tr>
<td>Service providers</td>
<td>Hospitals, healthcare centres and other relevant service providers including professionals who work within these organisations (e.g. educators).</td>
</tr>
<tr>
<td>Advocacy groups</td>
<td>Groups that attempt to influence or lobby legislators and other decision makers on behalf of a particular cause or interest.</td>
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Stakeholder engagement can enhance the implementation of a guideline (Grol, Dalhuijsen et al. 1998). First, a guideline developed with the involvement of appropriate stakeholders is more likely to be relevant to the needs of its expected users, which improves its implementability. Second, early involvement by bodies overseeing the administration and funding of services that will use a guideline can lead to greater support for its implementation. These benefits are more likely to be realised if stakeholders are engaged early in a guideline’s development, using a consultative approach (Jones 2011).

Guideline developers should engage stakeholders at critical points during the development process, such as when scoping a guideline or prioritising outcomes. While a variety of engagement methods can be used, evidence of their benefits and limitations in guideline development comes from case studies of the experience of developers rather than from formal and comparative evaluations. In addition, as with all aspects of guideline development, the choice of methods and how they are applied should be balanced with available resources and other constraints (Institute of Medicine 2011).

The following principles (adapted from Department of Health, 2015) can be used to plan authentic stakeholder engagement:

1. Plan in advance for when and how to engage stakeholders
2. Involve stakeholders from the start
3. Set clear expectations by explaining what their role is and how their contribution will inform the guideline
4. Make it easy for stakeholders to be involved, particularly those who may find participation more difficult because of language, culture, age, disability, or financial and other barriers
5. Be aware of stakeholders’ objectives, expertise and level of influence
6. Acknowledge and respect stakeholders’ views
7. Treat stakeholders equitably.

**What to do**

1. **Plan for early and repeated stakeholder involvement**

   Stakeholder perspectives can be considered at different steps in a guideline development process, which should be planned in advance.

   Some agencies use topics suggested by stakeholders to conceive of and prioritise new guidelines (NICE 2014; Shin 2014; SIGN 2015) but early involvement might also include commenting on a guideline’s topics, the relative importance of outcomes, and the settings and expected users of a guideline (see also the Guideline development group and Setting the purpose modules). Thereafter, there should be clear opportunities for the involvement of appropriate stakeholders, such as reviewing recommendations and derivative products to ensure clear and actionable messaging, and planning for implementation (Cluzeau, Wedzicha et al. 2012).

   It is crucial that developers of Australian guidelines involve Aboriginal and Torres Strait Islander Peoples as members of the guideline development group if possible, particularly if key outcomes
differ in these populations. If this is not possible then appropriate methods of engagement to seek their views as stakeholders should be considered and documented.

Once a guideline is implemented, stakeholders might provide ongoing feedback about its usability, relevance, and the need for updates when new evidence becomes available, or when changes in practice or policy occur (SIGN 2015).

While involving stakeholders is likely to enhance a guideline’s relevance and use, it can, depending on the methods used, add to the time required to develop a guideline and to the administrative burden on a guideline developer (Cluzeau, Wedzicha et al. 2012). This presents a particular challenge when guidelines are developed by a volunteer workforce or when guidelines need to be completed quickly.

2. **Identify local and international stakeholders**
   When identifying stakeholders, first define the expected users of a guideline by considering who might use or be affected by its recommendations (Canadian Taskforce on Preventive Health Care, 2017). For example, a guideline on the treatment of muscle strains may be developed for physiotherapists, but other expected users might include general practitioners, primary care nurses, and people with muscle strains.

   Importantly, expected users are only a subset of stakeholders and there will likely be other interested parties in guideline development that should also be considered stakeholders, such as funding bodies and industry groups. Understanding this distinction will help when later planning how to involve different stakeholders, for instance when deciding which groups should be involved in decisions about a guideline and which others should simply be informed about its development and progress.

   It is important to identify not only local stakeholders but also international groups that are developing or publishing advice on similar guideline topics. Searching government websites such as Australian Clinical Practice Guidelines, NICE Guidance (UK), and Centers for Disease Control and Prevention (USA), may help identify relevant guidance that is already in development or use. It may be beneficial to contact developers for advice on a guideline’s scope and selection of topics.

   It is best to be non-selective at this step, ensuring stakeholders are identified across a wide range of relevant groups, regardless of their interests (see Table 1 for examples of types of stakeholders).

3. **Consider levels of involvement for different stakeholders**
   Once stakeholders have been identified, record their name, organisation, position, contact details, and where the individual or organisation is based. It is also useful to record their type, for example whether they are from the government or private sector, or represent a condition group or professional society.

   An important step in determining appropriate levels of involvement is to list all possible stakeholders and consider their degree of relevance to the guideline. Relevance in this case refers to how great an impact the guideline may have on them, and also their capacity to affect, positively or negatively, the guideline’s development or implementation. For example, developers of public and environmental health guidelines should establish and maintain communication with relevant
jurisdictions and align with their advice, since they will likely be ultimately responsible for implementing the guideline.

Not all stakeholders identified need to be directly engaged but it is important to consider who might be interested in a guideline, what their views might be, and what influence they might have on different stages of development. While the degree of relevance can be a useful measure when determining levels of involvement, it is also important to consider the interests of each stakeholder and whether these might preclude them from particular engagement activities.

These are important decisions, since the content and implementation of guidelines may change as a result of perspectives considered and whether they are convergent or contrasting (Green and Aarons 2011).

**Table 2. Examples of different levels of stakeholder involvement** (adapted from Department of Health, DoH 2015).

<table>
<thead>
<tr>
<th>Level of involvement</th>
<th>Nature of involvement</th>
<th>Example</th>
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<tbody>
<tr>
<td>Collaborate</td>
<td>Partner with stakeholders for the development of mutually agreed solutions and a joint plan of action (two-way or multi-way communication where learning, negotiation and decision making occur on both sides).</td>
<td>This is an option for stakeholders who will be affected by and could influence the guideline’s development and implementation (e.g. organisations that should be involved in implementing the guideline).</td>
</tr>
<tr>
<td>Involve</td>
<td>Work directly with stakeholders throughout the process to ensure that issues and concerns are understood and considered (two-way or multi-way communication where learning takes place on both sides).</td>
<td>This is an option for stakeholders who will be affected by the guideline but would not otherwise affect its development (e.g. people who should be targeted to assist in prioritising outcomes).</td>
</tr>
<tr>
<td>Consult</td>
<td>Gain information and feedback from stakeholders to inform decisions made internally (limited two-way communication whereby developers ask questions and the stakeholder can provide answers).</td>
<td>This is an option for stakeholders who are unlikely to be affected by the guideline but whose activities may influence its development or implementation (e.g. other guideline developers who could assist in providing evidence tables on related topics).</td>
</tr>
<tr>
<td>Inform</td>
<td>Inform or educate stakeholders in one-way communication (there is no invitation to respond).</td>
<td>This is an option for stakeholders who are unlikely to be affected by the guideline or influence its development or implementation (e.g. people who should be sent an email to inform them when public consultation will occur).</td>
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</table>
4. Decide how and when to engage stakeholders

When deciding the timing and methods for involving stakeholders, consider at which stages of development it will be most important to consider their views and plan for distinct engagement activities. Ensuring an appropriate level of engagement (see step 3), let the focus and desired outcome of the engagement inform its method, and avoid tokenistic involvement (Cottrell, Whitlock et al. 2014).

Develop a communications plan which specifies the aim, method and logistics of each engagement activity (see Table 3 for examples of methods).

For all methods, it is important that the scope of the engagement is well defined and it is made clear which parts of the guideline will be the focus. Prospective participants should be informed of how the information they provide will be disseminated and used; for example, if it will be published in the guideline or made available to other stakeholders on request.

Contact a range of stakeholders by widely advertising opportunities for them to contribute. For example, consider print and online newspapers and magazines, email (including asking relevant organisations to use existing email lists), social media (e.g. Facebook, Twitter, LinkedIn), advertising through conferences and using the websites of organisations involved in the guideline’s funding and development. In addition, it may be worth setting up a system such as an electronic mailing list or online portal whereby individuals and organisations can register their interest in being involved.

It is crucial that efforts are made to contact all relevant stakeholder groups, including those that may be difficult to reach. Furthermore, not all stakeholders will have the same opportunity to provide feedback, so consider working differently with some stakeholders to help them contribute, or offer alternative ways of engagement to ensure their views are treated equitably. For example, if a stakeholder has limited resources (time, people and money) to engage, greater flexibility in the timing and method of involvement may be necessary (Department of Prime Minister and Cabinet, 2013). Methods to ensure all relevant stakeholders have an equal opportunity to be involved are discussed further in the Equity module.

Finally, consider the monetary, time and other resource costs of involving stakeholders in different ways (e.g. people, meeting locations, outreach tools, travel) and balance the methods and timing chosen with any funding or existing resources available to the development group (Institute of Medicine 2011) .
<table>
<thead>
<tr>
<th>Method</th>
<th>Description</th>
<th>Examples of use</th>
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<tr>
<td>Stakeholder advisory groups</td>
<td>These structural groups are not involved in developing the recommendations or drafting the guideline but their advice could be sought on a range of issues at any time during development.</td>
<td>These should be formed at the beginning of guideline development with defined terms of reference. For example, the James Lind Alliance Priority Setting Partnerships enable clinicians, patients and carers to work together to set priority questions for review. The Implementability module also discusses the use of advisory groups to consider implementation issues.</td>
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| Surveys:                          | • Written  
  • Telephone  
  • Email  
  • Face-to-face | These can be used to seek specific advice using structured, straightforward questions. Written surveys are relatively inexpensive and can be used to retrieve feedback from a large population or geographical area, but response rates can be low. | These could be used at any stage of guideline development. Using them early may help to identify individuals and groups who should be consulted in more depth later in the process. For example, developers of the NHMRC Guidelines for the Management of Overweight and Obesity surveyed consumers and expected users to identify barriers and facilitators to implementation. |
| In-depth interviews:              | • Telephone  
  • Videoconference  
  • Face-to-face | These can be used to seek detailed information from selected stakeholders, but they can be expensive, difficult to arrange and may require skilled interviewers and analysts. Note also that depending on how these are used, the selection of stakeholders may be divisive if it introduces a hierarchy of importance. | These could be used to seek individual patient preferences or values related to specific treatment options. For example, developers of the Australian Clinical practice guidelines for antenatal care conducted face-to-face meetings with Aboriginal health workers. |
| Focus or discussion groups        | These can be used to explore specific issues, but they require a skilled facilitator and analyst and it can be difficult to retrieve a variety of different views from participants.                                                            | These could be used to explore perceptions within specific groups. For example, conducting a series of discussion groups in different regions may be useful for the development of national guidelines. |
| Public meetings and forums        | These can provide opportunities to share information and invite views on a broad range of issues. There may be a risk that discussion is dominated by particular individuals or groups rather than be representative of the whole population. It requires a skilled facilitator to ensure a range of views are presented and to remain focussed on particular topics. | These could be used to bring different disciplines together to discuss a topic. For example, a national public forum was used to develop definitions and principles of care for NHMRC’s National Guidance on Collaborative Maternity Care. |
| Citizen juries                    | These can be used to explore values and preferences through well informed and structured discussion. They can be useful for sensitive topics where discussion of values and preferences may be divisive.                                                                 | These could be used to prioritise outcomes and explore different values and preferences on sensitive topics. Depending on the topic, this method may require particular expertise (e.g. health economics) to be effective. |
| Workshops                         | These can bring together diverse groups to explore a specific issue or work towards a specific goal. Participants should be carefully recruited depending on the aims of the workshop.                                                                         | These could be used to bring together implementation experts and expected users to discuss implementation strategies and formulate a plan. For example, developers of the Australian Guidelines for the Prevention and Control of Infection used workshops to pilot recommendations using the Guideline Implementability Appraisal (GLIA) tool. |
5. **Consider and respond to stakeholder feedback**

Unlike public consultation, it can be relatively straightforward to predict the volume of feedback received during stakeholder engagement given the developers have shaped the engagement activity and targeted a specific audience.

It is important that all feedback received is documented and the participants acknowledged. Participants should have access to documentation on how their comments were considered and any resulting changes there may have been as a result. This information could be published with the guideline, provided participants have given permission to do so and were informed of how their feedback would be used prior to commencing the engagement activity.

If stakeholders identify new evidence, it should be considered if it meets the inclusion criteria used for the evidence review process. If the evidence was published outside the timeframe of the search parameters, the development group may still wish to consider its potential impact and decide if it should be included in the review or otherwise incorporated into the guideline.
**NHMRC requirements**
Guidelines approved by NHMRC must meet all requirements as outlined in the [Procedures and requirements for meeting the NHMRC standard](#). The following requirements are relevant to involving stakeholders:

- **F.4** The developer has identified and consulted with key professional organisations (such as specialty colleges) and consumer organisations that will be involved in, or affected by, the implementation of the clinical recommendations of the guideline.

**Useful resources**
Existing guidance to assist in identifying other developers:
- Australian Clinical Practice Guidelines
- NICE Guidance (UK)
- Centers for Disease Control and Prevention (USA)

Resources on methods of stakeholder involvement:
- James Lind Alliance Priority Setting Partnerships
- NICE Citizens Council
- Department of Health Stakeholder engagement framework

**References**
PM&C (2013). Cabinet Implementation Toolkit, Australian Government Department of Prime Minister and Cabinet.