

G-I-N PUBLIC toolkit introduction

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One question we often get asked at GIN PUBLIC is ‘how can we incorporate the patient’s perspective and what is the best method to involve patients and the public in our guidelines?’ to which we invariably respond, ‘what do you really hope to achieve?’ There are in fact many legitimate reasons why guideline developers want to involve patients and the public, and these reasons can be different from those that would motivate patients and the public to engage in this process. The *best* method is the one that can be used most effectively to achieve those goals, so there is definitely not a one-size-fits-all approach. Furthermore, each method requires time and resources to be implemented successfully, and it is therefore critical to have a clear focus right from the start. Last but not least, although patient and public involvement is widely perceived as a positive component of guideline development, different stakeholders often hold competing and potentially incompatible views over what they consider successful involvement, which may create tensions if these differences are not negotiated early on.¹

The goal of this chapter is to get you started in developing your involvement plan by:

- Introducing the main involvement strategies discussed in the toolkit
- Helping you identify the strategy that best fits your needs.

Three involvement strategies: consultation, participation, and communication

Guideline organisations use a number of different methods to involve patients and the public.^{2,3} It is helpful to distinguish three general involvement strategies, based on the flow of information between your organisation and the public:⁴

- **Consultation** strategies involve the collection of information *from* patients and the public. This can include methods such as surveys, focus groups, individual interviews, online consultation, the use of primary research on patients’ needs and expectations, or the use of a systematic review of studies on patients’ and the public’s perspective.
- **Participation** involves the *exchange* of information between guideline developers and the public. This can be done through participation of patient and public representatives on guideline development groups and other methods.⁵
- **Communication** strategies involve the communication of information *to* patients and the public to support their individual health care decisions and choices. This can include the production of plain language versions of clinical practice guidelines or the development of patient decision aids or education material.

Choosing the right strategy

Each involvement strategy has its specific strengths and weaknesses and may be more appropriate to achieve certain goals:

- **Consultation** strategies are especially useful to gather the views of a large number of individuals regarding their needs, experience, and expectations. Consultation methods are often used in research and add to the evidence base being considered to inform the process of guideline development. Consultation can help assess the public acceptability of draft guideline recommendations and identify topics that appear most important for the public, and are therefore useful in early stages of the guideline development process. A drawback of using consultation strategies only is that it tends to seek out individual viewpoints, presenting an average of ‘the need’ of patients.
- **Participation** methods are useful to foster deliberation and mutual learning between participants with different expertise.⁶ Participation as a member of the guideline development group has the advantage of enabling patients or public members to be present and actively participate in deliberation, which can foster mutual influence between patients and professionals, fostering the development of a collective perspective on guideline development. As such, participation methods are usually put in place to agree on *common group decisions* over guideline content and can be useful to support compromise or consensus between people with different perspectives. When used alone, a drawback of the participation method is that it often allows the involvement of a small number of people and may miss the perspective of vulnerable groups who may feel threatened to participate in meetings with health professionals. As discussed in Chapter 2 of the toolkit a critical issue for successful participation is to support participants’ legitimacy as patient and public members, and their ability to contribute credible knowledge and experience relevant to guideline development.
- **Communication** strategies are most useful in the dissemination and implementation stage of guideline production. For strong ‘black and white’ guideline recommendations—where a single best course of action is clear—communication methods can increase the public’s knowledge and awareness of recommended interventions in order to influence patients’ health behaviours and increase uptake. In cases of ‘grey zone’ decisions—when more than one alternative is acceptable—patient decision aids can help expand the range of options available to patients and assist them in weighing the pros and cons of different choices.^{7, 8}

Finally, it is common to combine different involvement strategies to build more comprehensive patient and public involvement interventions. For example, combining direct patient participation can be complemented with wider patient consultation through focus groups or surveys, which can allow patients to broaden their perspective and experience base, and increase their credibility and legitimacy as guideline development group members.⁹ Furthermore, combining communication methods (e.g. development of patient information material) with participation methods (e.g. participation of patient representatives in the development of this information material) can help ensure the relevance and accuracy of the information produced.¹⁰ [Box 1](#) provides an example of a structured patient involvement intervention combining consultation, participation and communication strategies used for health care improvement.

Box 1: Example of a mixed patient involvement intervention in guideline implementation

The effect of a mixed patient involvement intervention combining consultation, participation, and communication components has been tested in a cluster randomised trial and was found to be effective in increasing agreement between patients' and professionals' priorities for clinical care improvement, based on a list of measurable quality indicators derived from clinical practice guidelines.

Recruitment: Chronic disease patients were recruited through local patient organisations and professionals, using structured 'job descriptions'. A list of potential candidates was reviewed by the team, and a group of 15 patients were selected based on pre-defined criteria to ensure a balanced representation in terms of age, gender, disease status, and socioeconomic status.

Preparation: These patients were invited to a one-day preparation meeting to discuss their personal experiences in relation with chronic disease services, which helped broaden their perspective and understanding of patients from their community.

Consultation: At the end of this preparation meeting, all patients voted on their priorities for clinical care improvement for their community.

Participation: Four patients who participated in the preparation meeting agreed to participate in a 2-day deliberation meeting together with health professionals from their community. This meeting allowed patients and professionals to deliberate among themselves and agree on common priorities for improvement. All participants also received feedback about the consultation done with the broader group of 15 patients.

Communication: The quality indicators selected as priorities for health care improvement were implemented locally and its results were communicated to all patients who participated in the prioritisation, as well as to lay board members of the local health authority.

Although this patient involvement strategy was used locally for guideline implementation, its format could easily be applied to guideline development at a larger scale. Details of the intervention have been published elsewhere.¹¹

In summary

Guideline organisations have experimented with a vast number of different methods to involve patients and the public. As summarised in [Table 1](#), these involvement methods can usefully be grouped in three basic strategies: *consultation* from the public to inform the guideline development process, *participation* of patients and the public in deliberation with other guidelines developers, and *communication* of guideline content and other health information to patients and the public. Each strategy has its strengths and limitations and their use must be tailored to specific contexts and goals. Effective involvement starts with finding the *right method*, but is also about *doing it right*. Following chapters of the toolkit therefore provide best practice advice on how to implement these methods successfully within your organisation.

Table 1: Methods available to involve patients and the public in guidelines

Involvement strategy	Goals and strengths	Example of methods used by guideline organisations	Toolkit chapters
Consultation (information is collected <i>from</i> patients and the public)	<ul style="list-style-type: none"> • Collect information from a large group of people • Possible to collect data from a variety of perspectives and from groups that are harder to involve in participation methods 	<ul style="list-style-type: none"> • Open (online) consultation on guideline scope and topic • Comments on draft guideline • Focus groups, individual interviews, or surveys of patients' experience of care • Literature review of existing qualitative and quantitative research on patients' needs and expectations 	Chapter 1
Participation (information is exchanged <i>between</i> the public and other guideline developers)	<ul style="list-style-type: none"> • Foster <i>mutual learning</i> and agreement between the public and other experts • Facilitate compromise and consensus on collective decisions about guideline recommendations, content, and process 	<ul style="list-style-type: none"> • Patient or public participation in guideline development group to foster deliberation with other guideline developers 	Chapters 2, 3
Communication (information is communicated <i>to</i> patients and the public)	<ul style="list-style-type: none"> • Inform patients and the public about professional standards • Support individual health care decisions and choices among different health options 	<ul style="list-style-type: none"> • Publish patient version of guideline and patient education material • Production of patient decision aids 	Chapters 4, 5, 6

References

- ¹ Boivin A, Green J, van der Meulen J, Légaré F, Nolte E. Why consider patients' preferences? A discourse analysis of clinical practice guideline developers. *Medical Care*. 2009;47:908-15.

- ² Boivin A, Currie K, Fervers B, Gracia J, James M, Marshall C, et al. Patient and public involvement in clinical guidelines: international experiences and future perspectives. *Qual Saf Health Care*. 2010;19:e22.
- ³ Legare F, Boivin A, van der Weijden T, Pakenham C, Burgers J, Legare J, et al. Patient and Public Involvement in Clinical Practice Guidelines: A Knowledge Synthesis of Existing Programs. *Med Decis Making*. 2011;31:E45-74.
- ⁴ Rowe G, Frewer LJ. A Typology of Public Engagement Mechanisms. *Science, Technology & Human Values*. 2005;30:251.
- ⁵ Slokum N. Participatory methods toolkit: A practitioner's manual: King Baudouin Foundation. 2003. p.
- ⁶ Abelson J, Forest PG, Eyles J, Smith P, Martin E, Gauvin FP. Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Soc Sci Med*. 2003;57:239-51.
- ⁷ van der Weijden T, Boivin A, Burgers J, Schunemann HJ, Elwyn G. Clinical practice guidelines and patient decision aids. An inevitable relationship. *J Clin Epidemiol*. 2012;In Press.
- ⁸ O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2009:CD001431.
- ⁹ Diaz Del Campo P, Gracia J, Blasco JA, Andradas E. A strategy for patient involvement in clinical practice guidelines: methodological approaches. *BMJ quality & safety*. [Research Support, Non-U.S. Gov't]. 2011;20:779-84.
- ¹⁰ Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. *BMJ*. 2002;325:1263-.
- ¹¹ Boivin A, Lehoux P, Lacombe R, Lacasse A, Burgers J, Grol R. Target for Improvement: A cluster randomized trial of public involvement in quality Indicator prioritization (intervention development and study protocol). *Implement Sci*. 2011;6:45.