

**Patient and public involvement in clinical practice  
guidelines: a knowledge synthesis of existing programs**



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Complete List of Authors:	Legare, France; Centre de recherche CHUQ Boivin, Antoine; Radboud University, Scientific Institute for Quality of Healthcare, van der Weijden, Trudy; Maastricht University, School for Public Health and Primary Care Pakenham, Christine; Ministère de la santé et des Services Sociaux de Québec Burgers, Jako; Maastricht University, School for Public Health and Primary Care Légaré, Jean; Canadian Arthritis Alliance St-Jacques, Sylvie; Institut national de santé publique du Québec Gagnon, Susie; Centre de recherche CHUQ
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3 **Title:** Patient and public involvement in clinical practice guidelines: a knowledge  
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6 synthesis of existing programs  
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10 **Running head:** Patient and public involvement in guidelines  
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14  
15 **Authors:** France Légaré, MD, PhD<sup>1,2</sup>, Antoine Boivin, MD, MSc<sup>3</sup>, Trudy van der  
16  
17 Weijden, MD, PhD<sup>4</sup>, Christine Pakenham<sup>5</sup>, Jako Burgers, MD, PhD<sup>3</sup>, Jean Légaré<sup>6</sup>,  
18  
19 Sylvie St-Jacques, PhD<sup>7</sup>, Susie Gagnon, MA<sup>2</sup>  
20  
21  
22  
23

24  
25 <sup>1</sup>Canada Research Chair in Implementation of Shared Decision-Making in Primary Care,  
26  
27 Université Laval, Québec City, Québec, Canada  
28

29 <sup>2</sup>Research Center, Centre Hospitalier Universitaire de Québec  
30

31 <sup>3</sup>Scientific Institute for Quality of Healthcare, Radboud University Nijmegen Medical  
32  
33 Centre, Nijmegen, the Netherlands  
34  
35

36 <sup>4</sup>Department of General Practice, School for Public Health and Primary Care (Caphri),  
37  
38 Maastricht University, Maastricht, the Netherlands  
39

40  
41 <sup>5</sup>Ministère de la santé et des Services Sociaux de Québec, Québec, Québec, Canada  
42

43 <sup>6</sup>Canadian Arthritis Alliance  
44

45  
46 <sup>7</sup>Institut national de santé publique du Québec  
47  
48  
49

50  
51 **Name of the institution where the work was done:** Research Center, Centre Hospitalier  
52  
53 Universitaire de Québec  
54  
55  
56  
57  
58  
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**Corresponding author's contact information:**

Dr. France Légaré

Research Center, Hôpital Saint-François d'Assise, Centre Hospitalier Universitaire de  
Québec, 10, de L'Espinay, Local D6-735

Québec (Québec) G1L 3L5

Phone: 418 525 4437; Fax: 418 525 4194

Email: France.Légaré@mfa.ulaval.ca

**Contact information for the author to receive reprint requests:**

Dr. France Légaré

Research Center, Hôpital Saint-François d'Assise, Centre Hospitalier Universitaire de  
Québec, 10, de L'Espinay, Local D6-735

Québec (Québec) G1L 3L5

Phone: 418 525 4437; Fax: 418 525 4194

Email: France.Légaré@mfa.ulaval.ca

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1  
2  
3 **Abstract (271/275 words)**  
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8 **Background:** The role of patient and public involvement programs (PPIPs) in developing  
9 and implementing clinical practice guidelines (CPGs) has generated great interest.  
10

11 **Purpose:** We sought to identify key components of PPIPs used in developing and  
12 implementing CPGs.  
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15 **Data sources:** We searched bibliographic databases and contacted relevant organizations.  
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18 **Study selection:** We retrieved 2161 articles and reports on PPIPs in the development and  
19 implementation of CPGs. Of these, 71 qualified for inclusion in our review.  
20  
21

22 **Data extraction:** Reviewers independently extracted data on key components of PPIPs  
23 and barriers and facilitators to their operation.  
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25

26 **Data synthesis:** Over half of studies were published after 2002 and over half originated  
27 from the United States, the United Kingdom, Australia and Germany. CPGs that involved  
28 patients and the public addressed a variety of health problems, especially mental health  
29 and cancer. The most frequently cited objective for using PPIPs in developing CPGs was  
30 to incorporate patients' values or perspectives in CPG recommendations. Patients and  
31 their families and caregivers were the parties most often involved. Methods used to  
32 recruit PPIP participants included soliciting through patient/public organizations, sending  
33 invitations, and receiving referrals and recruits from clinicians. Patients and the public  
34 most often participated by taking part in a CPG working group, workshop, meeting,  
35 seminar, literature review, or consultation such as a focus group, individual interview, or  
36 survey. Patients and the public principally helped formulate recommendations and revise  
37 drafts.  
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3 **Limitations:** We did not contact the authors of the studies.  
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5 **Conclusion:** Our literature review provides an extensive knowledge base for making  
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8 PPIPs more effective when developing and implementing CPGs. More research is needed  
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10 to assess the impact of PPIPs and resources they require.  
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For Peer Review

## Introduction

Clinical practice guidelines (CPGs) are systematically developed statements designed to help practitioners and patients decide on health care for specific clinical circumstances.<sup>1</sup> The implementation of CPGs in clinical practice is expected to improve patient outcomes by promoting interventions of proven benefits and discouraging ineffective one.<sup>2</sup> Also, CPGs accompanied by consumers' versions may empower patients to make more informed healthcare choices.<sup>2</sup> Productive interactions—such as shared decision making—between active and informed patients and their healthcare providers have been shown to be a key component of good care.<sup>3</sup> Involving patients in decisions also produces a better decision-making process, more personal comfort with the decision,<sup>4</sup> a reduction in the overuse of options that are not beneficial for the vast majority, an increase in the options known to be beneficial,<sup>5</sup> and better patient quality of life.<sup>6</sup> Nonetheless, implementing CPGs has been a major challenge.<sup>7</sup> CPGs often fail to reconcile patients' preferences and social norms with best evidence<sup>8,9</sup> and do not always account for patients' increased demands to play a more active role in their own care.<sup>10-12</sup>

Involving patients and the public when developing and implementing CPGs is therefore attractive because of its potential to address the gaps between patients preferences and best evidence.<sup>10, 12, 13</sup> Yet there is little guidance as to the design of patient and public involvement programs (PPIPs) in the context of CPGs.<sup>14</sup> Consequently, we reviewed and synthesized the existing knowledge (published and unpublished) to identify and appraise the key components of PPIPs in the development and implementation of CPGs.<sup>15</sup>

## Methods

### *Data sources*

A detailed description of our search methods can be found elsewhere.<sup>15</sup> Briefly, with the help of an information specialist, we searched bibliographic databases and the reference lists of relevant articles for English and French documentation on PPIPs in the development and implementation of CPGs published before January 2009. With help from the Guidelines International Network Public Working Group, we searched for grey literature by writing to the email lists of relevant organizations and by contacting provincial and national institutions involved in the production and implementation of CPGs.

### *Selection criteria*

To be included, the document had to (1) refer to the development or implementation of a CPG; (2) refer to patients (people with a personal experience of the disease, the health intervention, or the service discussed in the CPG, as well as their family members and caregivers) and/or members of the public (members of society interested in healthcare services, whose life could be directly or indirectly affected by the CPG); and (3) refer to a PPIP (at a minimum, refer to a formal method of involving patients and/or the public in the development or implementation of a CPG). Eligible documents included original qualitative, quantitative, or mixed methods studies and reports produced by academics or by national, governmental, for-profit or nonprofit organizations.

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3 Two research assistants screened all the documents thus retrieved to determine which  
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5 were relevant. Any disagreements were resolved in discussions with the co-principal  
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7 investigators (FL and AB).  
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### 10 11 12 *Data extraction*

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15 The data from all relevant documents were independently extracted by pairs of research  
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17 assistants who used a data extraction form employed in previous work in this field.<sup>16-19</sup>  
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20 The data collected consisted of 1) characteristics of the documents; 2) key components of  
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22 the PPIP (who was involved, how and for what purpose were they involved, and at what  
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24 stage of the CPG's development were they involved); and 3) the context in which the  
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26 PPIP was developed and tested: namely, perceived barriers and facilitators and the impact  
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28 of the PPIP on involvement and other outcomes. Pairs of reviewers compared abstracted  
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30 information. Any disagreements were resolved in research team meetings.  
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### 36 37 *Data analysis*

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39 A research assistant entered the abstracted information into a data matrix to facilitate  
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41 comparison of how PPIPs performed on each principal component. Template content  
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43 analysis was used to organize the principal components into a meaningful framework.<sup>20</sup>  
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45 We computed the frequency of mention of each principal component extracted.  
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51 This study was funded by a knowledge synthesis grant from the Canadian Institutes of  
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53 Health Research (CIHR). CIHR had no role in the study.  
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## Results

### *Included documents*

Of the 2104 articles identified in bibliographic databases, 38 were eligible for our review. In addition, we obtained 57 reports from relevant organizations: of these, we included 33 reports in our review. After reviewing the material, we concluded that 7 of the 38 studies were more akin to grey literature reports than to studies. Our review thus consisted of 71 documents: 31 studies from peer-review publications and 40 reports from the grey literature. Figure 1 shows the flow of the data synthesis.

### *Characteristics of the documents*

All documents included in our review (table 1) were produced from 1996 to 2008. More than half (49/71)<sup>21-69</sup> were produced after 2002. Most originated from the United States (23/71),<sup>21, 31, 35, 39, 40, 42, 43, 54, 62, 64, 69-81</sup> the United Kingdom (15/71),<sup>23, 24, 30, 33, 36, 48, 50, 51, 60, 63, 68, 82-85</sup> Australia (8/71)<sup>34, 37, 38, 56, 61, 86-88</sup> and Germany (5/71).<sup>45, 47, 57-59</sup> Most of the published studies were descriptive (22/31)<sup>22, 23, 25, 32, 40, 44-46, 48, 49, 56, 62, 64, 68, 69, 71, 72, 77, 79, 80, 82, 87</sup> and used qualitative methods (22/31).<sup>23, 25, 32, 35, 37, 38, 40, 45, 46, 48, 49, 62, 64, 68-71, 75, 79, 80, 82, 88</sup>

CPGs that had involved a PPIP addressed a variety of health problems. Mental health (13/71)<sup>24, 27, 37, 38, 52, 56, 62-64, 69, 72, 78</sup> and cancer (8/71)<sup>28, 30, 40, 42, 45, 75, 84, 87, 89</sup> were overly represented. The CPGs mainly targeted users: patients (13/71),<sup>22, 26, 28, 41, 45, 48, 54, 60, 70, 71, 75,</sup>

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3 76, 84, 88 physicians (13/71),<sup>25, 35, 40, 45, 54, 60, 69, 71, 75, 87-90</sup> other health professionals (12/71)<sup>26,</sup>  
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5 28, 31, 41, 42, 54, 64, 75, 77, 78, 87 and the public (8/71).<sup>22, 37, 38, 44, 49, 86, 89</sup>  
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### 10 *Patient and public involvement programs in CPGs*

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12 The patient and public involvement programs and interventions discussed in the  
13 documentation are described in table 1. In general, the studies and reports provided a  
14 superficial description of the process of development of the CPG and the components of  
15 the PPIP involved. Only one study, from Australia, assessed the PPIP's impact on  
16 participants.<sup>88</sup> Reports from organizations made more detailed presentations of the  
17 components of the PPIP and the practicalities of involving patients and the public in CPG  
18 development and implementation activities.  
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32 The most frequently cited objective of using PPIPs to develop CPGs was to incorporate  
33 patients' values, preferences, knowledge or perspectives in CPG recommendations  
34 (23/71).<sup>21, 25, 28, 30, 33, 37-39, 41, 47, 50, 51, 54, 57, 60, 61, 64, 67, 77, 81, 83, 85, 87</sup> Other objectives were to  
35 improve the implementation of the CPG (7/71),<sup>26, 39, 50, 55, 59, 65, 66</sup> increase the  
36 comprehensiveness of the CPG (7/38),<sup>49, 58, 72, 76, 85, 86, 89</sup> promote patients' or the public's  
37 influence over the CPG development process (6/71),<sup>22, 25, 43, 82, 85, 88</sup> and adapt CPGs to the  
38 target population (5/71).<sup>32, 46, 70, 79, 80</sup>  
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50 Individual patients (45/71)<sup>24-33, 35-39, 41, 46, 48, 50-53, 55-57, 60, 62, 64-67, 69-73, 76, 77, 80, 82, 83, 85, 87, 91</sup>  
51 and patient representatives (family, caregivers) (32/71)<sup>23, 25, 28, 30, 32-34, 36-41, 43, 50, 51, 53, 54, 59,</sup>  
52 60, 62, 63, 65, 66, 69, 70, 76, 83, 85, 88, 91 were the parties most frequently involved in PPIPs,  
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3 followed by a more diverse group of individuals (e.g., community leaders and individuals  
4 without health problems but who might use the CPG in future) (14/71).<sup>39, 44, 47, 49, 50, 60, 68,</sup>  
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70, 74, 78, 79, 81, 86, 89 Methods used to recruit patients or the public in the CPG development process were rarely described, but recruiting through patient/public organizations (12/71),<sup>28, 30, 33, 37, 38, 41, 49-51, 60, 70, 83</sup> sending invitations (8/71)<sup>33, 45, 50, 82, 84, 85, 87, 90</sup> and receiving referrals and/or recruits by clinicians (6/71)<sup>25, 32, 37, 38, 77, 88</sup> were mentioned.

Most often, patients and the public helped develop CPGs by participating in a CPG working group (28/71),<sup>22, 23, 27-30, 33, 34, 39, 42, 43, 45, 47, 50, 51, 53, 54, 57, 60, 61, 65-67, 71, 75, 78, 85, 89</sup> a workshop, meeting or seminar (10/71),<sup>23, 33, 39, 43, 48, 61, 71, 75, 82, 85</sup> a literature review (7/71),<sup>23, 35, 40, 42, 43, 45, 78</sup> or a consultation such as a focus group (24/71),<sup>25, 27, 28, 30, 32, 33, 39, 41, 44, 47-49, 55, 61, 65, 69, 70, 72, 79, 80, 84, 86, 88, 89</sup> an individual interview (11/71),<sup>24, 25, 32, 36, 39, 41, 44, 46, 64, 81, 87</sup> or a public poll or survey (9/71).<sup>33, 47, 52, 61, 63, 65, 68, 73, 77</sup>

Patients and the public were mainly involved at the stage of formulating recommendations (28/71),<sup>22, 25, 28, 30, 34, 35, 39, 40, 46, 48, 50, 51, 54, 55, 57, 60-62, 64, 67-70, 77-80, 88</sup> synthesizing the knowledge (25/71)<sup>23, 27, 28, 30, 32-35, 39-43, 45, 51, 54, 59, 60, 62, 68, 71, 78, 84, 89</sup> and revising drafts (23/71).<sup>25, 30, 32, 33, 39, 41-43, 49-51, 54, 56, 57, 59, 67, 72, 74, 84-87, 90</sup> In some reports, patients and the public helped make strategic decisions about the CPG development process (e.g., the scope, what actors to involve) (15/40)<sup>28, 33, 34, 39, 41, 47, 50, 55, 59-61, 67, 91</sup> or the development of products for patients or the public (e.g., information material, decision aids) (14/40).<sup>28, 30, 33, 34, 41, 42, 47, 50, 57, 58, 60, 65, 76, 89</sup>

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3 The studies and reports indicated that PPIPs require the following material resources:  
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5 written documentation (publications, reports, reminders, booklets, handbooks) (15/71),<sup>26,</sup>  
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7 28, 31, 33, 36, 40, 43-45, 47, 54, 60, 71, 77, 81 draft or existing CPGs (14/71),<sup>23, 32, 33, 40, 42, 43, 45, 49, 56, 71,</sup>  
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9 72, 85, 87, 90 questionnaires (e.g. validated, self-administered questionnaires or interview  
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11 guides) (12/71),<sup>32, 37, 38, 44, 45, 48, 70, 72, 77, 79, 80, 82</sup> recording material (tape recorders and  
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13 video cameras) (9/71)<sup>25, 28, 44, 46, 48, 49, 79, 85, 90</sup> and financial resources (4/71).<sup>60, 70, 85, 91</sup> The  
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15 human resources required by PPIPs were a facilitator or chairperson (6/71),<sup>30, 48, 64, 79, 82, 90</sup>  
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17 a project coordinator (4/71),<sup>28, 30, 33, 60</sup> a translator,<sup>49</sup> a trained interviewer<sup>44</sup> and a trained  
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19 moderator.<sup>44</sup>  
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### 27 *Lessons learned by CPG development organizations*

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29 Few documents reported detailed lessons learned by CPG development organizations that  
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31 had employed a PPIP. Some organizations held a positive opinion of their experience  
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33 with the PPIP, feeling that the PPIP had helped formulate extra key questions, had  
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35 changed existing questions,<sup>30</sup> or had encouraged patients to join healthcare practitioners  
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37 in making decisions.<sup>47, 58</sup> For example, for one organization, patients' input helped ensure  
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39 that the complex medical terminology used in the CPG would be widely understood. This  
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41 was felt to be necessary for enhancing the community's understanding of current health  
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43 and disability issues and increasing community access to the most appropriate health  
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45 services.<sup>91</sup>  
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53 Another organization reported extensively on its experience with the PPIP.<sup>85</sup> This  
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55 organization felt that patients experienced difficulty with the technical language and  
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3 contributed infrequently to the discussion. The organization therefore developed a series  
4 of workshops in which it explained the technical elements of CPG development to  
5 patients, who then made relevant suggestions. However, this process was resource-  
6 intensive. This organization also felt that involving an “expert” patient was helpful but  
7 acknowledged that this “expert patient may not be representative.” The organization  
8 concluded that a range of methods for involving patients and the public was ideal<sup>85</sup> and  
9 suggested that involving consumers both in CPG development groups and in other  
10 structures, such as focus groups or surveys that informed the CPG development groups,  
11 should be considered. Two organizations opined that it was necessary to involve patients  
12 or the public at every stage of the CPG development process and at individuals’ desired  
13 level of involvement.<sup>66, 85</sup> Other organizations suggested that it was better to involve  
14 patients before the process officially began.<sup>55, 65, 67</sup> The organizations also pointed out that  
15 participation in a CPG development group requires abilities or skills necessary for  
16 effective group processes, such as communication skills,<sup>30, 41, 50, 60</sup> teamwork skills,<sup>33, 50, 60</sup>  
17 and the ability to represent the views of a wider group.<sup>30, 50, 60</sup>

### ***Feedback by PPIP participants***

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20 One organization reported that patients felt that they had little or no influence on finance,  
21 group composition, literature searches, and the measurement of the effects of the CPG.<sup>55</sup>  
22 However, patients considered they had some influence on defining key questions for the  
23 CPG, writing questions used to search the literature, selecting and reviewing the  
24 literature, writing text, implementing the CPG, and developing information for patients.  
25 Patients believed their greatest influence was defining key problems for CPGs to address,  
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3 writing recommendations, and reviewing draft guidelines.<sup>55</sup> This feedback is congruent  
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5 with what other organizations have reported: the impact of patients' involvement is felt to  
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7 be small (e.g., patients help choose the words used to formulate recommendations) and  
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9 their influence on debates is rarely measured.<sup>28</sup> Some experts expressed reserve toward  
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11 PPIPs because of what they felt was patients' inability to act on highly technical  
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13 documents.<sup>28</sup>  
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20 Few organizations formally assessed patients' and the public's satisfaction following  
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22 their participation in a CPG development process. Overall, and despite the variability of  
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24 the experiences reported, the respondents were generally satisfied with having been part  
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26 of a CPG development group. For example, 72 percent of participants in CPG  
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28 development groups led by the National Institute for Health and Clinical Excellence  
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30 (NICE) rated their overall experiences as excellent or very good. These participants were  
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32 generally positive about the methodology adopted and the final CPG. Lay members were  
33  
34 enthusiastic about the version for patients and caregivers and its intended use and they  
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36 valued the personal development opportunities that involvement in the guideline  
37  
38 development group had afforded them.<sup>63</sup> In a study by Wilson et al, 90 percent of parents  
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40 felt that participating in a CPG development group was an informative process and nearly  
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42 67 percent said that they gained valuable knowledge and felt more confident in caring for  
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44 their sick children.<sup>88</sup>  
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53 The New Zealand Guidelines Group (NZGG) conducted an evaluation survey of  
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55 consumers involved in the development of their CPGs<sup>52</sup>. Although respondents were  
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3 generally satisfied with the final guideline, some had experienced resistance to their input  
4 and had felt isolated, while others had felt accepted and valued. Interestingly, 11 of 12  
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6 respondents said that they would be willing to participate in a CPG development group  
7  
8 again.<sup>52</sup> In contrast, some participants mentioned that they were often concerned that the  
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10 hard work that had gone into developing the recommendations had not translated into  
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12 actual changes in practice.<sup>63</sup> Some parents involved in focus groups in the Wilson study  
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14 mentioned that more information at the outset would have been useful and felt that the  
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16 discussions had been one-sided.<sup>88</sup> Other patients reported having had great difficulty in  
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18 understanding the complexity and technicality of the subject, and having felt maladjusted  
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20 to the procedure. These feelings were compensated by a strong sense of belonging to the  
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22 working group.<sup>28</sup>  
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### 32 *Barriers and facilitators to PPIPs*

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34 Table 2 details barriers and table 3, facilitators to PPIPs in the development of CPGs,  
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36 based on excerpts from the publications included in our review.  
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41 Notably, a discrepancy between the perspectives of experts and patients/the public was  
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43 the most frequently reported barrier (8/71).<sup>28, 38, 55, 57, 63, 65, 66, 91</sup> Other frequently  
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45 mentioned barriers were the difficulty of recruiting patients or representatives of the  
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47 public (7/71),<sup>27, 28, 37, 39, 47, 66, 67</sup>, the lack of representativity of patients and members of the  
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49 public (6/71),<sup>52, 65 28, 39, 55, 66</sup> and PPIP participants' lack of familiarity with the scientific  
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51 and medical terminology (5/71).<sup>27, 28, 67, 85, 91</sup>  
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3 The two most frequently reported facilitators were training (14/71)<sup>28, 30, 33, 36, 39, 50-53, 60, 63,</sup>  
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5 <sup>65-67</sup> and support from the staff and the organization (12/71).<sup>27, 28, 30, 33, 36, 39, 50, 53, 60, 63, 65, 85</sup>  
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8 For example, some organizations offered training days and seminars to assist PPIP  
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10 participants with technical matters and critical appraisal skills.<sup>30, 33, 50, 52, 60</sup> Support took  
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12 the form of telephone and email assistance,<sup>28, 30, 33</sup> mentoring,<sup>53, 55, 66</sup> a supportive chair of  
13  
14 the guideline development group,<sup>33, 55</sup> an analysis grid for knowledge synthesis,<sup>28</sup> or a  
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16 “welcome pack” for selected patients.<sup>50</sup> Providing assistance with complex scientific and  
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18 technical issues was another valuable way to optimize the participation of patients and  
19  
20 public,<sup>36, 52, 53, 65, 91</sup> as was offering participants opportunities to interact with other  
21  
22 patients who had participated in the development of CPGs<sup>28, 52, 60</sup>. Other facilitators  
23  
24 included clear expectations about the process (e.g., who was involved and what role they  
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26 were expected to fill, disclosure of the funds available, and specification of the time  
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28 commitment expected) (9/71)<sup>33, 36, 50-52, 55, 91, 65, 66</sup> and involving a group of patients rather  
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30 than a single patient (8/71).<sup>41, 47, 51-53, 55, 65, 67</sup>  
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## 39 Discussion

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43 We identified 71 documents that reported on PPIPs in the context of the development and  
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45 implementation of CPGs. Only a few of these documents contained substantial  
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47 information about the key components of PPIP and the resources needed including  
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49 financial resources. Very few documents provided information on the impact of PPIPs on  
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51 the development and implementation of CPGs in clinical practice and none discussed  
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53 health outcomes. Although reports were more likely than studies to provide information  
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3 on participants' perceptions of their experience, very little quantitative impact assessment  
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5 took place. Nonetheless, this knowledge synthesis is among the first to provide decision-  
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7 makers with several elements of practical guidance.  
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12 First, there is a perception that it is difficult to reconcile the preferences of patients and  
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14 the public with the views of experts (health professionals). Also, patients find it difficult  
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16 to affirm their views and experiences in the presence of evidence-based information and  
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18 complex scientific and medical terminology.<sup>28, 55, 65</sup> Several CPG organizations have  
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20 developed structured training and support to address these issues. Therefore, it is possible  
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22 to adapt PPIPs so as to deepen patients' and the public's understanding of and confidence  
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24 in scientific information.  
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32 Second, many fear that patients or members of the public who participate in a PPIP may  
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34 not be representative.<sup>28</sup> The World Health Organization has reviewed NICE's experience  
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36 of involving patients and public in CPGs and concluded that it is uncertain whether the  
37  
38 right stakeholders were involved and whether their input was as efficient as it could have  
39  
40 been. However, prevalent participation methods (such as involving patients in CPG  
41  
42 development groups) dictate small numbers of participants,<sup>92</sup> and it may be inappropriate  
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44 to expect one or two patients to represent the views of large segments of the population.  
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47 Other authors have challenged PPIP sponsors to clarify their understanding of  
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49 representativeness and adapt their involvement methods and recruitment strategies  
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51 accordingly.<sup>93</sup> Some organizations have responded by using structured open recruitment  
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3 strategies and by complementing their participation methods with larger consultations  
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5 such as surveys and online comment options.<sup>51</sup>  
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10 Third, and related to the above, better evaluations of the methods used to involve patients  
11 and members of the public are essential. A Cochrane systematic review on methods of  
12 involving consumers in developing healthcare policy and research, CPGs and patient  
13 information material found 6 eligible trials.<sup>14</sup> None focused on CPGs.  
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20 Fourth, training and supporting patients and members of the public who are participating  
21 in a PPIP should focus not only on critical appraisal skills but also on the skills needed to  
22 participate in a group process. Attention should also be paid to the role that chairs and  
23 other guideline developers can play in supporting PPIP participants.  
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34 Notwithstanding its interesting results, this knowledge synthesis has limitations. First, the  
35 significant proportion of grey literature in our source material (33/71) is evidence of the  
36 extensiveness of our search for eligible documents. However, we cannot exclude that we  
37 may have overlooked important documents. Second, we did not contact the authors of the  
38 studies or reports for elaboration on their findings. More research is needed to identify the  
39 key components of successful PPIPs and the resources they need, and to assess their  
40 impact on the quality of care.  
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52 Nonetheless, our knowledge syntheses' provides an extensive knowledge base for  
53 elaborating effective PPIPs in the context of developing and implementing CPGs in the  
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3 future. This could also help standardize PPIP reporting. The review provides three main  
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5 lessons. First, there are many ways to involve patients in developing CPGs and patient  
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7 information material. Second, patients' involvement tends to produce material that is  
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9 more relevant, readable, understandable, and less likely to make the reader anxious.  
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11 However, future research will need to assess the impact of PPIP in the context of CPGs  
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13 on the quality of care and health outcomes.  
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For Peer Review

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For Peer Review



**Table 1. Characteristics of included patient and public involvement programs (PIIP) in the context of clinical practice guidelines**

First author	Source, Year	Author's institution or organization	Disease/health problem addressed by the CPG	Objective of the PIIP	Description of activity (ies)	Who was involved	Participation at what stage of CPG development
McConnell	Report by organization	U.S. Department of Health and Human Services	Benign prostatic hyperplasia (BPH)	To evaluate the preferences of actual patients in regards to the simplified version of the CPG	Public polls or surveys	Individual patients	Unclear
1994							
Duff	Published study; descriptive study; qualitative	Royal College of Nursing	Not mentioned	To promote patient/public influence over the process	Seminar	Individual patients	Strategic decisions
1996							
Rischer	Published study; intervention study	HealthInsight, Utah - Nevada	Cancer	Not mentioned	Participation in the CPG working	Representatives of patients' group(s)	Dissemination/ implementation
1996							

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(before/after);

group;

qualitative

meetings

Schofield	Published study;	Cancer Education	Cancer	To incorporate	Individual	Individual	Review of draft
1996	descriptive	Research Program,		patients' values,	interviews	patients	
	study; mixed	University of		preferences,			
		Newcastle		knowledge and			
				perspectives in CPG			
				recommendations			

Collège des	Report by	Collège des	Prostate	To validate the	Focus groups;	Individual	Knowledge synthesis,
Médecins du	organization	Médecins du	cancer	clarity and	participation	citizens	evaluation of specific
Québec		Québec		acceptability of	in the		products for
1998				information leaflet	CPG working		patients/public
				designed for the	group		
				public			

Friedman	Published study;	Lovelace Health	Diabetes	Not mentioned	Patient	Individual	Knowledge synthesis,
1998	descriptive	System			information	patients	dissemination/
	study;				material;		implementation
	qualitative				participation		

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in the CPG  
working  
group;  
team meetings

Schulberg  
1998  
Published study;  
review of  
literature; mixed  
The Agency for  
Health Care Policy  
and Research  
(AHCPR)  
Depression  
Not mentioned  
Participation  
in the CPG  
working  
group;  
literature  
review  
Individual  
citizens;  
representatives  
of citizens'  
group(s)

Knowledge synthesis,  
formulation of  
recommendations

Steward  
1998  
Report by  
organization  
Clinical Decision  
Making Group,  
Massachussets  
Institute of  
Technology  
Not  
mentioned  
To incorporate  
patient's  
values, preferences,  
knowledge and  
perspectives in CPG  
recommendations

Individual  
Individual  
citizens  
Unclear

Rymer  
1999  
Report by  
organization  
Saint Luke's  
Hospital Stroke  
Stroke  
To increase the  
general population's  
Patient  
version of  
Individual  
patients and  
Development of patient  
products

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			Center, Kansas		understanding of the	guideline	patients'	
			City, Missouri		CPG		representatives	
Lanza	Published study;	Nurse Manager	Assaultive	To increase the	Focus groups;	Individual	Review of draft	
2000	descriptive	Veterans Center	behavior	general population's	written	patients		
	study; mixed	for Addiction		understanding of the	consultations.			
		Treatment; Edith		CPG				
		Nourse Rogers						
		Memorial						
		Veterans Hospital,						
		Bedford,						
		Massachusetts						
Shoultz	Published study;	Frances A.	Alcohol,	To adapt CPGs to the	Focus groups	Individual	Formulation of	
2000	descriptive	Matsuda	smoking and	population's		patients	recommendations	
	study;	Foundation;	drug use	characteristics				
	qualitative	Hawaii						
		Community						
		Liaisons Nurse's						
		Association;						

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7 van Wersch      Report by      North of England      Asthma,      To promote      Meetings;      Individual      Strategic decisions,  
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9      2000      organization      Evidence Based      angina,      patients'/the public's      workshops;      patients;      review of draft  
10  
11                Guideline      myocardial      influence over the      CPG working      patients'  
12                Development      infarction      process;      group      representatives  
13  
14                Programme           to incorporate  
15                          patient's values,  
16                          preferences,  
17                          knowledge and  
18                          perspectives in CPG  
19                          recommendations;  
20                          to increase the  
21                          general population's  
22                          understanding of the  
23                          CPG  
24                          CPG

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37 Wilson      Published study;      Information not      Acute      To promote      Focus groups      Patients'      Formulation of  
38  
39      2000      randomized      available      respiratory      patient/public      representatives      recommendations

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controlled trial;  
qualitative

infection

influence over the  
process

Women's Health  
Action  
2000

Report by  
organization

Women's Health  
Action

Not  
mentioned

To ensure that the  
rights  
of consumers are  
upheld and  
consumers' input is  
valued

Unclear

Individual  
patients,  
patients'  
representatives,  
representatives  
of citizens'  
groups

Strategic decisions

Egger  
2001

Report by  
organization

Department of  
Health and Aged  
Care

Excessive  
weight and  
obesity

To increase the  
general population's  
understanding of the  
CPG

Focus groups

Individual  
citizens

Review of draft

Southern African  
Hypertension  
Society  
2001

Report by  
organization

Southern African  
Hypertension  
Society

Hypertension

Not mentioned

Consensus  
meeting

Representatives  
of citizens'  
group

Review of draft

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2								
3	Braun	Published study;	The Pacific	Diabetes	To adapt the CPG to	Training of	Individual	Formulation of
4		intervention	Diabetes Today		the population's	community	citizens and	recommendations
5	2002	study	Resources Center		characteristics	members to	representatives	
6		(before/after);	(PDTRC)			lead	of citizens'	
7		qualitative				discussion	groups	
8						groups;	Individual	
9						focus groups	patients and	
10							patients'	
11							representatives	
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22								
23	Kelson	Report by	National	Not	To develop fair,	Unclear	Individual	Unclear
24		organization	Guidelines and	mentioned	transparent and		patients and	
25	2002		Audit Patient		defensible methods		patients'	
26			Involvement Unit		for patient/caregiver		representatives	
27			in collaboration		involvement;			
28			with National		to ensure that patient			
29			Institute for		issues and			
30			Clinical		perspectives are			
31			Excellence (NICE)		directly addressed			
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and presented in  
ways that are  
meaningful and  
acceptable to patients

National Kidney Foundation 2002	Report by organization	National Kidney Foundation	Chronic kidney disease	To review National Kidney Foundation clinical practice guidelines	Unclear	Individual citizens	Review of draft
Pell 2002	Published study; intervention study (before/after); mixed	Information not available	Prophylactic oophorectomy	To use patient- specific information on risks and preferences to provide guidance	Focus groups	Representatives of citizens' group	Formulation of recommendations, review of draft
Scherer 2002	Published study; descriptive study; mixed	The Institute for Matching Person & Technology Inc	Rehabilitation	To incorporate patients' values, preferences, knowledge and perspectives in CPG	Survey; nominal group technique	Individual patients	Formulation of recommendations



recommendations

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7	Shoultz	Published study;	University of	Violence	To adapt CPG to the	Focus groups	Individual	Formulation of
8								
9	2002	descriptive	Hawaii School of	against	population's		citizens	recommendations
10								
11		study;	Nursing and	women	characteristics			
12								
13		qualitative	Dental Hygiene,					
14								
15			Kauai Community					
16								
17								
18			College					
19								
20	Behets	Published study;	The	Sexually	To promote	CPG working	Representatives	Determining what
21								
22	2003	descriptive	nongovernmental	transmitted	patients'/the public's	group	of citizens'	intervention options,
23								
24		study; mixed	"67 Ha Clinic" in	infections	influence over the		group (sex	recommendations, and
25								
26			Antananarivo; the				workers)	information to include in
27								
28			public dispensary		process			
29								the CPG
30			in Tamatave					
31								
32								
33	Bond	Published study;	Grampian	Vulvovaginal	Not mentioned	Meetings;	Patients'	Knowledge synthesis,
34								
35	2003	descriptive	Evidence Based	candidiasis		literature	representatives	development of a draft,
36								
37		study;	Community			review;		revision of the final CPG
38								
39		qualitative	Pharmacy			nominal group		
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Guidelines Group

technique;  
participation  
in the CPG  
working  
group

Global Program on Evidence for Health Policy 2003	Report by organization	World Health Organization	Not mentioned	Not mentioned	Participation in the CPG working group	Individual patients	Unclear
Hadjistavropoulos 2003	Published study; descriptive study; qualitative	Regina Qu'Appelle Health Region	Community case management for elderly clients	To adapt the CPG to the population's characteristics	Individual interviews; focus groups	Individual patients' representatives	Evaluation of case management time, review of draft
NZGG 2003	Report by organization	New Zealand Guidelines Group Inc. (NZGG)	Atrial fibrillation, elders' health, women's	To better advocate for an approach to participation that meets consumers'	Public polls and surveys	Individual patients	Evaluation survey of consumers involved in CPGs

health needs and  
 (caesarean), expectations  
 mental health  
 (depression,  
 suicide  
 prevention),  
 hormone  
 replacement  
 therapy,  
 diabetes

Pijnenborg	Report by	Dutch College of	Low back	To improve CPG	Focus groups	Individual	Strategic decisions,
2003	organization	General	pain, eczema,	implementation and		patients	formulation of
		Practitioners;	rheumatoid	quality			recommendations
		Dutch Institute for	arthritis,				
		Healthcare	psoriasis				
		Improvement					
Royal Australian	Published study;	The Royal	Panic	Not mentioned	Not	Individual	Review of draft
and New	descriptive	Australian and	disorder,		mentioned	patients	

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Zealand College  
of Psychiatrists  
Clinical Practice  
Guidelines Team  
for Panic  
Disorder and  
Agoraphobia  
2003

study; mixed

New Zealand  
College of  
Psychiatrists

agoraphobia

Guihan  
2004

Report by  
organization

The Veterans  
Health  
Administration,  
Department of  
Veterans Affairs

Spinal cord  
injury

To foster patients'  
adherence to  
recommendations

Patient  
information  
material

Individual  
patients

Dissemination/implement  
ation

Jarett  
2004

Report by  
organization

National Institute  
for Health and  
Clinical  
Excellence (NICE)

Not  
mentioned

To explore the  
experiences of  
patients/caregivers  
involved in CPG  
development groups;

Individual  
interviews;  
participation  
in the CPG  
development

Individual  
patients and  
patients'  
representatives

Unclear

to identify good group  
practices, highlight  
problems, and  
improve the process  
for future groups

14	Landier	Report by	Children's	Children's	Not mentioned	Participation	Representatives	Knowledge synthesis,
15	2004	organization	Oncology Group	cancer		in the CPG	of patients'	development of a draft,
16			(National Cancer	aftermath		working	group(s)	review of draft;
17			Institute)			group;		development of patient
18						Literature		products
19						review		
20								
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26								
27	Luboldt	Published study;	The German	Prostate	Not mentioned	Participation	Representatives	Literature review, final
28	2004	descriptive	Urology	cancer		in the CPG	of patients'	revision
29		study;	Association,			working	group(s)	
30		qualitative	European			group;		
31			Randomised			literature		
32			Screening for			review;		
33			Prostate Cancer			nominal group		

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(ERSPC), German  
Association of the  
Scientific Medical  
Societies or  
AWMF

technique

Phelan  
2004

Report by  
organization

Cincinnati  
Children's Hospital  
Medical Center

Children's  
health

To incorporate  
patient's  
values, preferences,  
knowledge and  
perspectives in CPG  
recommendations

Participation  
in the  
CPG working  
group

Patient  
representatives  
(parents of  
affected  
children)

Knowledge synthesis,  
formulation of  
recommendations, review  
of draft

van Vuuren  
2004

Report by  
organization

Dutch Institute for  
Healthcare  
Improvement

Not  
mentioned

To improve CPG  
implementation

Participation  
in the  
CPG working  
group

Individual  
patients,  
patients'  
representatives

Unclear

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2								
3	Marshall	Report by	German Agency	Not	To incorporate	Participation	Stakeholders,	Strategic decisions,
4								
5	2005	organization	for Quality in	mentioned	patients'	in	individual	unclear;
6								
7			Medicine		values, preferences,	stakeholders'	citizens	development of products
8								
9			and		knowledge and	groups;		for patients/the public,
10								
11			New Zealand		perspectives in CPG	participation		dissemination/
12								
13			Guideline Group		recommendations	in the CPG		implementation
14								
15			(NZGG)			working		
16								
17						group; focus		
18								
19						groups; public		
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23						polls or		
24								
25						surveys		
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27								
28	Sänger	Report by	German Agency	Not	To better adapt CPGs	Unclear	Representatives	Strategic decisions,
29								
30	2005	organization	for	mentioned	to patients' needs;		of patients and	knowledge synthesis,
31								
32			Quality in		to address patients'		representatives	development of a draft,
33								
34			Medicine		most important		of patients'	review of the draft, final
35								
36								
37					problems;		groups	revision
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39					to encourage patient		(6 patient	
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to foster acceptance  
are involved in  
of patients' version  
each CPG  
of CPGs;  
process)  
to improve  
implementation by  
supporting the  
implementation  
process

Suppes	Published study;	The Texas	Bipolar 1	To review the newest	Consensus	Individual	Knowledge synthesis,
2005	descriptive	Department of	disorder	available evidence to	conference	patients and	formulation of
	study;	State Health		guide the selection of		patients'	recommendations
	qualitative	Services (TDSHS),		treatments,		representatives	
		formerly the Texas		maintenance			



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3			Department of		treatment, and issues			
4								
5			Mental Health and		regarding safety and			
6								
7			Mental		adverse effects in the			
8								
9			Retardation		treatment of bipolar			
10					disorder			
11								
12								
13								
14	van Vaanandaal	Report by	Dutch Institute for	Not	To improve CPGS	Focus groups;	Individual	Development of
15		organization	Healthcare	mentioned	and their	public polls or	patient, patients'	products for patients/the
16	2005		Improvement		implementation	surveys;	representatives	public and dissemination/
17						participation		implementation
18								
19								
20								
21								
22								
23						in the CPG		
24						working		
25						group		
26								
27								
28								
29	de Joncheere	Report by	National Institute	Nutrition,	Not mentioned	Individual	Individual	Unclear
30		organization	for Health and	tuberculosis,		interviews	patients,	
31	2006		Clinical	anxiety,			representatives	
32			Excellence (NICE)	obsessive-			of patients'	
33				compulsive			group	
34				disorder,			(stakeholders'	
35								
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contraception, representatives)  
pressure  
ulcers

Deschepper	Published study;	Information not	End-of-life	To promote	Focus groups;	Individual	Review of draft,
2006	descriptive	available	(heterogeneity	patients'/the public's	quality circle	patients and	formulation of
	study;		regarding	influence over the	(consecutive	patients'	recommendations
	qualitative		disease)	process;	discussion	representatives	
				to incorporate	sessions) with		
				patient's	various		
				values/preferences	caregivers;		
				knowledge and	individual		
				perspectives in CPG	interviews		
				recommendations			
Dijkstra	Published study;	Centre for Quality	Type 2	To improve	Patient	Individual	Development of products
2006	randomized	of Care Research	diabetes	implementation of	information	patients	for patients;
	controlled trial;			CPG	material;		dissemination/
	quantitative				educational		implementation
					meetings		

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2								
3	Landsman	Report by	New York State	Cerebral palsy	To promote	Participation	Patients'	Knowledge synthesis,
4								
5	2006	organization	Department of	and motor	patients'/the public's	in the CPG	representatives	development of a draft,
6								
7			Health	delay	influence over the	working		review of a draft
8								
9					process	group;		
10								
11						meetings;		
12								
13						literature		
14								
15						review		
16								
17								
18	Maputle	Published study;	University of	Childbirth	To adapt CPG to the	Participant	Individual	Formulation of
19								
20	2006	descriptive	Limpopo; Level III		population's	observation;	patients	recommendations
21								
22		study;	hospital in		characteristics	individual		
23								
24		qualitative	Limpopo Province			interviews;		
25								
26						unstructured		
27								
28						conversations		
29								
30								
31	Murie	Published study;	Royal College of	Coronary	To promote	Workshops;	Individual	Formulation of
32								
33	2006	descriptive	General	heart disease	informed, value-	focus groups.	patients	recommendations;
34								
35		study;	Practitioners		based healthcare			development of patient
36								
37		qualitative			decisions by			products
38								
39					individual patients;			
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to foster patients’  
adherence to  
recommendations

NICE	Report by	National Institute	Not	To incorporate	Patient	Individual	Strategic decisions,
2006	organization	for Health and	mentioned	patients’ values,	version of	patients,	formulation of
		Clinical		preferences,	CPG; written	patients’	recommendations, review
		Excellence (NICE)		knowledge and	consultation;	representatives,	of draft, development of
				perspectives in CPG	participation	individual	products for patients/the
				recommendations; to	in the CPG	citizens	public;
				improve	working		dissemination/implementa
				implementation	group		tion
Tunmer	Published study;	Two large mental	Schizophrenia	To incorporate	Individual	Individual	Formulation of
2006	descriptive	health agencies in		patients’ values,	interviews	patients	recommendations
	study;	Philadelphia,		preferences,			
	qualitative	Pennsylvania		knowledge and			
				perspectives in CPG			
				recommendations			

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Baumann	Report by	American College	Not	To incorporate	Unclear	Unclear	Unclear
2007	organization	of	mentioned	patients'			
		Chest Physicians		values, preferences,			
		(ACCP)		knowledge and			
				perspectives in CPG			
				recommendations			
Fervers	Report by	Fédération	Cancer	To incorporate	Focus groups;	Individual	Strategic decisions,
2007	organization	Nationale des		patients'	participation	patients,	knowledge synthesis,
		Centres de lutte		values, preferences,	in the CPG	patients'	formulation of
		contre le cancer		knowledge and	working	representatives,	recommendations,
				perspectives in CPG	group	representatives	development of a draft,
				recommendations		of patients'	final revision,
						group	development of products
							for patients/ the public;
							dissemination/implementa
							tion
Hoes	Published study;	European League	Rheumatic	Not mentioned	Delphi	Individual	Knowledge synthesis,
2007	review of	Against	diseases		process;	patients	formulation of

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literature;	Rheumatism				literature		recommendations
qualitative	(EULAR)				review;		
					generate and		
					validate		
					recommen-		
					dations		

Kelson	Report by	American	Chronic	To incorporate	Workshops;	Individual	Strategic decisions,
2007	organization	Thoracic Society	obstructive	patients'	focus	patients,	knowledge synthesis,
		and European	pulmonary	values, preferences,	groups;	patients'	formulation of
		Respiratory	disease	knowledge and	interviews;	representatives,	recommendations, review
		Society		perspectives in CPG	consultation	representatives	of draft
				recommendations;	on guideline	of patients'	
				to improve	products;	group,	
				implementation	participation	individual	
					in the CPG	citizens,	
					working	community	
					group,	organizations	
					separate		

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consumer  
panels

NICE 2007	Report by organization	National Institute for Health and Clinical Excellence (NICE)	Not mentioned	To incorporate patients' values, preferences, knowledge and perspectives in CPG recommendations	Participation in the CPG working group	Individual patients, patients' representatives	Knowledge synthesis, formulation of recommendations, review of draft
Yardley 2007	Published study; descriptive study; qualitative	ProFaNE Thematic Network	Falls	To foster patients' adherence with recommendations	Surveys of older people's views on falls prevention	Individual citizens	Formulate evidence-based recommendations
Zuckerbrot 2007	Published study; descriptive study; qualitative	Center for the Advancement of Children's Mental Health at	Adolescent depression	To understand the problems and obstacles faced by primary care	Focus groups	Individual patients, patients' representatives	Formulation of recommendations

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Columbia  
University  
clinicians regarding  
the management of  
adolescent  
depression

Domus Medica      Report by      Domus Medica      Chronic      Not mentioned      Focus group;  
2008      organization      illnesses,      diabetes,      depression      participation      patients,  
in the      representatives  
CPG working      of patients'  
group and      group  
consensus  
conference

Harbour      Report by      Scottish      Not      To incorporate      Written      Individual      Strategic decisions,  
2008      organization      Intercollegiate      mentioned      patients'      consultation;      patients,      knowledge synthesis,  
Guidelines      values, preferences,      public      patients'      development of a draft,  
Network (SIGN)      knowledge and      meetings;      representatives,      review of the draft,  
perspectives in CPG      public polls or      representatives      development of products  
recommendations      surveys;      of citizens'      for patients/the public,  
focus groups;      group      dissemination/



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participation  
implementation  
in the CPG  
working  
group  
Participation  
Patients’  
Strategic decisions,  
in the  
representatives  
knowledge synthesis,  
CPG working  
group  
formulation of  
group  
recommendations,  
development of products  
for patients/the public

Harris  
2008  
Report by  
organization  
Health for Kids in  
the South East  
(HFK)  
Children's  
health  
(asthma,  
croup,  
gastroenteritis  
, bronchiolitis,  
diarrhea)

Kelly  
2008  
(a)  
Published study;  
delphi study;  
qualitative  
ORYGEN  
Research Centre  
Deliberate  
non-suicidal  
self-injury  
To incorporate  
patients’ values,  
preferences,  
knowledge and  
perspectives in CPG  
recommendations  
Delphi  
process  
Individual  
patients,  
patients’  
representatives  
Development of a draft

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Kelly	Published study;	ORYGEN	Suicidal	To incorporate	Delphi	Individual	Development of a draft
2008	delphi study;	Research Centre	behaviour	patients' values,	process	patients,	
(b)	qualitative			preferences,		patients'	
				knowledge and		representatives	
				perspectives in CPG			
				recommendations			
Konety	Published study;	Iowa Prostate	Prostate	Not mentioned	Attending a 1-	Patients'	Knowledge synthesis,
2008	descriptive	Cancer Consensus	cancer		day	representatives	formulation of CPGs
	study;	Project			conference;		
	qualitative				evaluating the		
					available		
					literature		

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3 Kotzeva Report by Catalan Agency Stroke Incorporate patients' Focus groups; Individual Strategic decisions,  
4 2008 organization for Health prevention values, preferences, individual patients, knowledge synthesis,  
5  
6 Technology and treatment knowledge and interviews patients' development of a draft,  
7  
8 Assessment and of obesity in perspectives in CPG representatives, draft review,  
9  
10 Research children and recommendations representatives development of products  
11  
12 (CAHTA) adolescents, of citizens' for patients/the public,  
13  
14 tuberculosis, group dissemination/implementa  
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16 safety of the tion  
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18 surgical  
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20 patient,  
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22 dementias,  
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24 eating  
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26 disorders,  
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28 schizophrenia,  
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30 osteoporosis,  
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32 bronchiolitis  
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34 of the nursing  
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40 infant,  
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hyperactivity  
and attention  
deficit  
syndrome,  
pathological  
gambling,  
behavioural  
addictions,  
borderline  
personality  
disorders

Love	Published study; descriptive study; mixed	South Africa food- based dietary guidelines (FBDGs) work group	Nutrition	To foster patients' adherence to recommendations	Focus groups; individual interviews	Individual citizens	Dissemination/ implementation
Murray	Published study; descriptive	South Africa food- based dietary	Pediatric diet	To increase the general public's	Focus groups	Mothers with infants younger	Review of draft

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3 study; guidelines understanding of than 6 months  
4  
5 qualitative (FBDGs) work CPGs  
6  
7 group  
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10 SIGN Report by Scottish Not To incorporate Participation Individual Strategic decisions,  
11 2008 organization Intercollegiate mentioned patient's in the patients, knowledge synthesis,  
12 Guidelines values, preferences, CPG working representatives formulation of  
13 Network (SIGN) knowledge and group of patients, recommendations,  
14 perspectives in CPG individual development of a draft,  
15 recommendations citizens final revision,  
16  
17 development of products  
18 for patients/the public,  
19 dissemination/implementa  
20 tion  
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31 Southern Health Report by Southern Health Children's To incorporate Public Patients' Strategic decisions,  
32 2008 organization health patient's meetings; representatives formulation of  
33 values, preferences, public polls or recommendations  
34 knowledge and surveys;  
35 perspectives in CPG focus groups;  
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recommendations participation  
in the  
CPG working  
group

Thomas	Report by	National Institute	Mental health,	To evaluate lay	Public polls or	Individual	Evaluation of
2008	organization	for Health and	maternity,	members'	surveys	patients,	participants'
		Clinical	chronic and	experiences of being		patients'	experience of being part
		Excellence (NICE)	acute	part of a CPG		representatives	of the development of the
			conditions	development group			CPG

WHO	Report by	World Health	Not	To incorporate	Participation	Individual	Strategic decisions,
2008	organization	Organization	mentioned	patient's	in the	patients	formulation of
				values, preferences,	CPG working		recommendations,
				knowledge and	group		review of draft,
				perspectives in CPG			dissemination/
				recommendations			implementation

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2								
3	NZGG	Report by	New Zealand	Not	To encourage greater	Participation	Individual	Unclear
4								
5	2009	organization	Guidelines Group	mentioned	involvement by	in the	patients,	
6								
7			Inc. (NZGG)		consumers of health	CPG working	patients'	
8								
9								
10					and disability	group	representatives	
11								
12					services in the			
13								
14					activities of NZGG			
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16					and to ensure a			
17								
18					consumer-centered			
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20					approach to the			
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22					development and			
23								
24					implementation of			
25								
26					NZGG guidelines			
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28								
29	Graham	Report by	Scottish	Cancer,	To incorporate	Focus groups;	Individual	Strategic decisions,
30								
31		organization	Intercollegiate	bronchiolitis	patient's	participation	patients,	knowledge synthesis,
32								
33			Guidelines	in children,	values, preferences,	in the CPG	patients'	formulation of
34								
35			Network (SIGN)	peripheral	knowledge and	working	representatives	recommendations, review
36								
37				arterial	perspectives in CPG	group		of draft, development of
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39				disease,	recommendations			products for patients/the
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epilepsy in public  
children,  
autism  
spectrum  
disorders,  
dementia,  
coronary heart  
disease,  
chronic hearth  
failure

Sänger (a)	Report by	German Agency	Not	To incorporate	Patient	Individual	Knowledge synthesis,
	organization	for Quality in	mentioned	patient's	version of	patients,	formulation of
		Medicine		values, preferences,	guideline;	representatives	recommendations;
				knowledge and	participation	of patients'	development of the draft,
				perspectives in CPG	in CPG	group	review the draft,
				recommendations	working		development of products
					group		for patients/ the public;
							dissemination/implementa



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Sänger (b)	Report by	German Agency	Not	To establish a	Establishment	Unclear: The	Development of
	organization	for Quality in	mentioned	program	of an Internet	German Patient	products for patients/ the
		Medicine		whereby laypeople	network for	Forum	public
				can evaluate and	critical		
				improve health	appraisal		
				information posted			
				online			

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Notes: \*DISCERN is a brief questionnaire that gives users a valid and reliable way to assess the quality of written information on treatment choices for a health problem.

\*\*NICE invites all the organizations that have been stakeholders in previous clinical guidelines, to register an interest in new topics relevant to them. It also invites organizations that might be interested but have not been involved with NICE before. NICE asks them to submit nominations to the CPG development group. This request is published on the NICE website, where anyone may apply to participate. When nominations have closed, the national collaborating centre chooses whom to invite to join the group.

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3 \*\*\* NICE's Patient and Public Involvement Programme (PIIP) supports the application process for patient and caregiver members of the CPG development  
4 group. Patients, caregiver and members of the public can apply by responding to ads posted on the NICE website. The PIIP alerts all registered patient and  
5 caregiver stakeholder organizations to these ads. Applicants do not need to be members of a registered stakeholder organization to apply.  
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10 \*\*\*\*SIGN recruits a minimum of 2 patients' representatives per CPG development groups by inviting nominations from the relevant umbrella organization,  
11 national organization, and/or local patient-focused organizations in Scotland. Where organizations are unable to nominate, patients' representatives are sought  
12 through other means, e.g., consultations with health boards or public involvement staff. Prior direct patient or caregiver consultation mechanisms (e.g., a focus  
13 group) may also furnish participants  
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19  
20 CPG=clinical practice guideline; PIIP=patient and public involvement program; USA=United States of America  
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**Table 2. Barriers to patient and public involvement programs**

Barriers (total frequency)	Organizations' reports (n)	Empirical studies (n)	Excerpts
Discrepancies between experts' and patients'/the public's perspectives (n=8)	28, 55, 57, 63, 65, 66, 91 (n=6)	38 (n=2)	<ul style="list-style-type: none"> <li>- Main topics from patients' point of view differed from topics in the guideline <sup>66</sup></li> <li>- There may not be shared agreement about the most important issues <sup>91</sup></li> <li>- Experience versus evidence <sup>55</sup></li> <li>- Difficulty of integrating patients' views into professionals' recommendations <sup>66</sup></li> <li>- An evidence-biased atmosphere <sup>65</sup></li> <li>- Difficult for the patient to judge whether his/her comment regarding "evidence-based" information was relevant <sup>28</sup></li> <li>- Apparent marginalization of the evidence from patients' and caregivers' experiences (insufficient</li> </ul>

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Recruitment difficulties  
(n=7)

27, 28, 39, 47, 66, 67

(n=6)

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(n=1)

worth afforded to published qualitative studies) <sup>63</sup>

- Patients and health professionals can weigh healthcare issues differently <sup>57</sup>
- Hard to find/recruit patients capable of and interested in participating <sup>66</sup>
- Difficulty of identifying patients and caregivers who are willing and able to contribute directly to guideline development <sup>39</sup>
- Lack of a suitable consumer group <sup>67</sup>
- Caregivers were difficult to recruit for this study and, after the first round of the questionnaire, only one remained involved <sup>37</sup>
- “As one person with a large group of medical people (...) I felt the weight of being the only person specifically representing consumers” <sup>52</sup>
- A small number of patients does not guarantee representativity in terms of sex, ages, social

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Lack of familiarity with complex scientific and medical language (patients/the public found the material difficult to understand) (n=5)  
 27, 28, 67, 91 (n=4)

85  
 (n=1)

Significant work commitment (n=3)  
 28, 33, 52 (n=3)

background, stage disease, etc.<sup>28</sup>

- Patient advocates may be perceived as particularly unrepresentative<sup>39</sup>
- Variability of patients' values and preferences at different stages of the disease, at different levels of the disease's severity, and with respect to different issues. Values and preferences may also differ by age, sex, socioeconomic status, ethnicity and culture. This poses a challenge to integrating consumers' values into guideline recommendations<sup>39</sup>
- Technicality and complexity of the subject does not encourage patients' participation<sup>28</sup>
- It was not possible to meaningfully discuss any of the scientific content of the guideline<sup>85</sup>
- Very hard work and exhausting<sup>52</sup>

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			- Duration of project <sup>28</sup>
			- Training is not practical for consumers with other employment responsibilities—they would have to take time off work without pay <sup>52</sup>
			- No time <sup>65</sup>
			- Professionals' resistance to patient membership <sup>39</sup>
			- Consumers can feel isolated and uneasy at guideline meetings <sup>47</sup>
			- No money <sup>65</sup>
			- Patient involvement can be resource-intensive <sup>39</sup>
			- Feeling little affected by the problem <sup>28</sup>
			- Patients' contributions are sometimes limited <sup>39</sup>
			- Patients underestimate their capabilities <sup>27</sup>
Time constraints (n=3)	52, 65, 67	(n=3)	
Professionals' resistance to patients' participation (n=2)	39, 57	(n=2)	
Feeling isolated (n=2)	47, 52	(n=2)	
Financial issues (n=1)	65	(n=1)	
Resource-intensive (n=1)	39	(n=1)	
Feeling little affected by the problem (n=1)	28	(n=1)	
Patients' contributions are sometimes limited (n=1)	39	(n=1)	
Patients underestimate their capabilities (n=1)	27	(n=1)	

For Peer Review

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5 Large documents sent by email - <sup>52</sup> (n=1)  
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7 not practical for consumers (too  
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9 expensive to print at home) (n=1)  
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- Sending large documents by email as an alternative  
to face-to-face meetings makes it difficult to  
negotiate and reach consensus <sup>52</sup>  
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**Table 3. Facilitators to patient and public involvement programs**

Facilitators (total frequency)	Organizations' reports (n)	Empirical studies (n)	Excerpts
Training (n=14)	28, 30, 33, 36, 39, 50-53, 60, 63, 65-67 (n=14)	-	<ul style="list-style-type: none"> <li>- Training in technical aspects of the guidelines <sup>52</sup></li> <li>- Training day <sup>50 30</sup></li> <li>- Training seminars <sup>30</sup></li> <li>- Critical appraisal training and seminars <sup>60 33</sup></li> <li>- SIGN ensure opportunities to attend training events <sup>33</sup></li> </ul>
Support (n=12)	27, 28, 30, 33, 36, 39, 50, 53, 60, 63, 65 (n=11)	<sup>85</sup> (n=1)	<ul style="list-style-type: none"> <li>- Telephone support <sup>28</sup></li> <li>- Telephone and email support <sup>33 30</sup></li> <li>- Select a supportive chair to lead the guideline group <sup>55</sup></li> <li>- Availability of a mentor/coach <sup>55, 66</sup></li> <li>- Chair of each guideline development group is asked to support patient representatives by ensuring they are fully engaged with the group, addressing the</li> </ul>
<ul style="list-style-type: none"> <li>o Supporting staff (mainly chair of the guideline development group) (n=7)</li> </ul>	33, 47, 50, 53, 55, 63, 65, 66 (n=7)		



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- Help with complex scientific and technical issues (to increase participants' understanding) (n=5) 36, 52, 53, 65, 91
    - group if their contributions are not acknowledged appropriately, and welcoming and encouraging their contributions <sup>33</sup>
    - Mentoring <sup>53</sup>
    - Need to take special care to ensure that consumers have a voice at meetings and to feed back to constituencies <sup>47</sup>
    - Provide extra assistance, explanations and background information, particularly if the matter under consideration is technical <sup>91</sup>
    - More time on practical statistics would have been helpful <sup>52</sup>
    - Explain evidence-based process <sup>65</sup>
    - Develop competencies in the design and development of information for consumers, including the use of plain language for all consumer-oriented documents and, where possible, the use of

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- formats that are accessible the visually impaired <sup>53</sup>
- Supporting documents/material (n=5) 28, 50, 53, 55, 66
  - Clear analysis grid for knowledge synthesis <sup>28</sup>
  - NICE’s “welcome pack” for selected patients <sup>50</sup>
  - Templates and processes for the preparation of evidence-based consumer information <sup>53</sup>
- Contact and interactions with other consumers (n=3) 28, 52, 60
  - They can explain and listen <sup>28</sup>
  - They can offer one-off or ongoing support <sup>60</sup>
- Support from organizations (n=1) <sup>53</sup> (n=1)
  - Work collaboratively with other organizations to develop strong partnerships with government and nongovernment organizations, and agencies supportive of initiatives to strengthen consumers’ voice <sup>53</sup>
- Clear expectations (details about the process, who is involved, roles, etc.) (n=9) 33, 36, 50-52, 55, 91 65, 66
  - Disclose the funds available for the service or matter under discussion <sup>91</sup>
  - Information about the time frame and expected time

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commitment<sup>52</sup>

- Why the patient is invited, who s/he represents, what is expected – tasks and level of participation – whether time and costs are reimbursed<sup>66</sup>
- Ensure that everyone recruited to the guideline development group is fully aware of the scope of the guideline and agrees to work within it<sup>36</sup>
- Well-defined goal<sup>65</sup>
- A member of the patient and public involvement program contacts patients and caregivers to give them background information about what they might expect at the first meeting<sup>50</sup>
- The NICE PPIP gives a short presentation to all members, at the first meeting, on the role of patient and caregiver members<sup>51</sup>
- SIGN provides clear guidance on patients' roles and responsibilities within the group<sup>33</sup>

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More than one patient  
(n=8)

41, 47, 51-53, 55, 65, 67 (n=8)

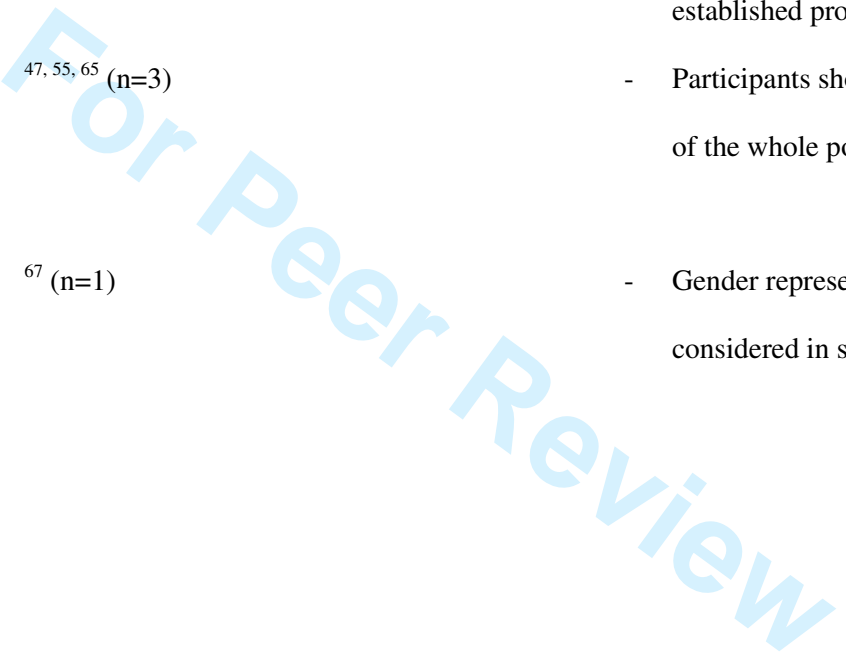
- Need to involve more than one consumer <sup>47</sup>
- Recruitment of a minimum of 2 representatives, following a transparent selection process and a well-established protocol <sup>41</sup>
- Participants should be as representative as possible of the whole population <sup>65</sup>
- Gender representation and balance should be considered in selecting group members <sup>67</sup>

o Representation of different patients' perspectives (n=3)

<sup>47, 55, 65</sup> (n=3)

o Gender representation and balance (n=1)

<sup>67</sup> (n=1)



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7 Development group committed to 52, 63, 65, 66  
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9 and in favor of patient involvement (n=4)  
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- Sensitivity of other group members to consumers’ non-professional status (recognition that consumers should feel that they are listened to and that their opinions are valued)<sup>52</sup>
- A belief, especially on the part of the chair and opinion leaders, that it works<sup>65</sup>
- Members of the guideline development group – mainly medical doctors – put the professionals and the laypeople on an equal footing<sup>63</sup>
- The health professionals in the group seemed open to the view that consumers can contribute a valid and valuable perspective<sup>52</sup>

33 Good preparation 28, 39, 41, 65 (n=4)  
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35 (n=4)  
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- Working group meetings preceded by preparatory meetings and training<sup>28</sup>

37 Reimbursement/sufficient financial 52, 60, 65, 91  
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39 assistance (n=4) (n=4)  
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- Ensure there is sufficient funding to pay consumers and to cover additional expenses, such as child care

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			and transportation <sup>91</sup>
			- Cover certain expenses (transportation, childcare, loss of earnings) <sup>60</sup>
			- Email is a good way to keep in touch and keep up-to-date on progress <sup>52</sup>
			- Organization gives feedback and information and acknowledges results <sup>52</sup>
			- Participation from (before) the start <sup>55, 65</sup>
			- Consumer involvement should be considered and encouraged from the start <sup>67</sup>
			- Past experience with other groups helps <sup>52</sup>
			- Smaller subgroups definitely helped progress <sup>52</sup>
			- Sense of belonging <sup>28</sup>
			- Actively involving patients at every stage of the process and at patients' desired level of involvement
Keeping patients/the public informed and maintaining dialogue (n=3)	<sup>52, 65, 91</sup> (n=3)		
Involving patients from the start (n=3)	<sup>55, 65, 67</sup> (n=3)		
Past experiences (n=1)	<sup>52</sup> (n=1)		
Smaller subgroups (n=1)	<sup>52</sup> (n=1)		
Sense of belonging (n=1)	<sup>28</sup> (n=1)		
Actively involving patients at every stage of the process and at patients'	<sup>66</sup> (n=1)		

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5 desired level of involvement (n=1) 66

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7 Combining methods of involving <sup>66</sup> (n=1)  
8 patients (n=1)

- Combining methods of involving patients <sup>66</sup>

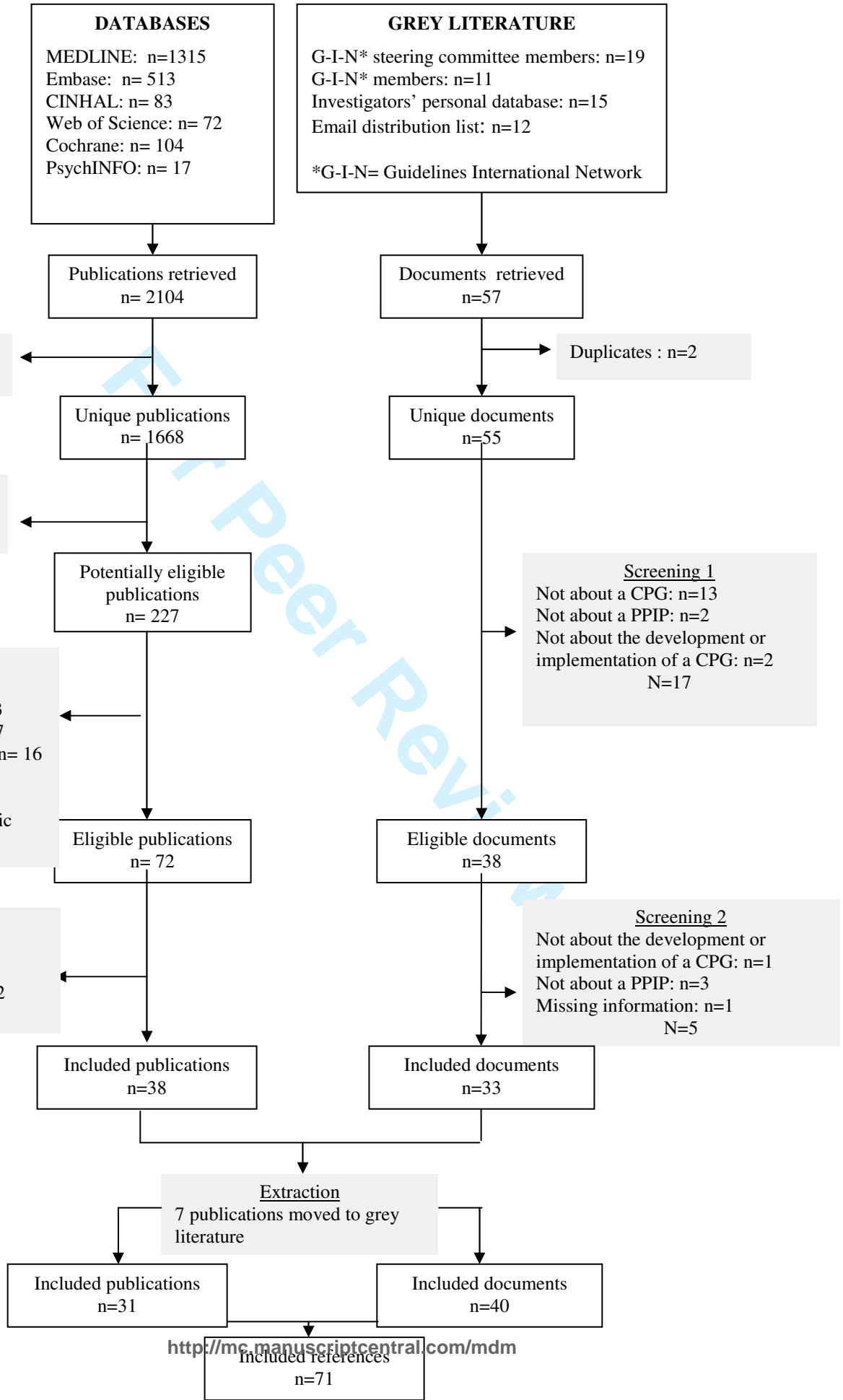
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11 Atmosphere of mutual respect and <sup>63</sup> (n=1)  
12 positive working relationships with  
13 other members of the group (n=1)

- Leads to constructive debate and agreement <sup>63</sup>

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18 Notes: NICE = National Institute for Health and Clinical Excellence; SIGN = Scottish Intercollegiate *Guidelines* Network  
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Figure 1. Flow of Data Synthesis



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