

# Power to the patient: the development of a literature search filter for patients' perspectives and preferences

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## Abstract

### *Introduction*

The patient perspective in guideline development is of vital importance. To find out what this perspective entails, different methods may be considered, such as participation of patients or their representatives in guideline development groups or in focus group discussions, or by conducting patient surveys. In addition, a review of the literature can provide relevant information. A search filter to identify articles regarding patient issues already existed, but the sensitivity of this filter was too high and the specificity too low for our purpose

### *Methods*

The existing search filter was used as starting point to develop a more specific filter. First we defined the scope, then we built a reference database as gold standard for the development of the filters and finally we estimated the performance of the filters (sensitivity, specificity and precision). The sensitivity of the filters was further estimated by using references of a recent Cochrane Review on *Interventions for providers to promote a patient-centred approach in clinical consultations*.

### *Results*

Sensitivity, specificity, and precision of the new filters were (%): 90.5/98/77 (Medline-OVID), 90.1/98.8/79.3 (Pubmed), and 94.7/98.9/81 (Embase). The search filters retrieved, respectively, 72 (Medline-OVID/PubMed) and 67 (Embase) of 73 references included in the Cochrane Review (mean sensitivity 96.3).

*Key words:* Patient Participation; Patient Preference; Practice Guidelines as Topic; Search Engine/methods; Sensitivity and Specificity

## Introduction

It's truly amazing that so many of you showed up this day. Not only because it's the morning after the big party, but also because it's Friday the 13<sup>th</sup>. Great that you all dared to get out of bed - just to hear about our own daring mission, on which we embarked almost two years ago. What on earth was this daring mission, you might ask. Well ... we decided to create a literature search filter for patient issues ... How exactly we managed this is the question we will try to answer in the next 20 minutes.

But we would like to start ... by asking you a question:

Is there anyone in the audience who knows who said "Listen to your patient, he is telling you the diagnosis", and/or approximately when it was said? The right answer is: the great Canadian physicist William Osler, who lived from 1849 till 1919. That's more than a century ago!

Now let us explain what Osler's remark has to do with the topic of our talk – which is the development of a literature search filter for patients' perspectives and preferences:

- firstly, listening can be difficult, for instance when a patient finds it hard to talk freely about an awkward condition,
- secondly, it's time-consuming, for instance when a patient is not apt at formulating what exactly is ailing him or her,
- and finally, consultation is not only about making the right diagnosis but also about choosing the best therapy with or for a particular patient in a particular situation. Put differently: it's about shared decision making or steering, depending on the nature or severity of the disease at hand.

In all these cases it is helpful when there is as much evidence as possible on what other patients said, wanted or asked. We think that the literature search filter - that is: the standardized set of search terms - we developed, helps to find this kind of evidence.

By the way, we are:

Lian Hielkema, medical information specialist at the Dutch College of General Practitioners and Monique Wessels, medical information specialist of the Dutch Knowledge Institute of Medical Specialists. The department Lian works in develops **primary care** guidelines, and Monique's department develops **secondary care** guidelines.

So, we cover separate fields but there is cooperation all the same:

- sometimes, both our organizations participate in the development of multidisciplinary guidelines,
- at other times, we work together to develop separate guidelines that all the same share the same basis, which is: all recommendations are supposed to be mutually consistent. For it obviously cannot be that one guideline gives different information from the other!

To achieve this goal - that is, consistent recommendations - we, for instance, make use of the same search filters - when available. As, nowadays, the patient perspective is of vital

importance in guideline development we went in search of a filter that addresses these issues.

We first went in search of an existing search filter. For obviously, if a filter exists, then why make one of our own? After a while, we found the filter of SIGN, the Scottish Intercollegiate Guidelines Network, but unfortunately this filter turned out to be too sensitive and at the same time not specific enough for our needs.

Let us try to enlighten what these needs entail:

Generally, for us it is not quite as important as - for instance - for writers of a systematic review to retrieve absolutely every article on a certain subject. It is, however, all the more important not to have to mill through too many articles that turn out to be not relevant to the subject at hand. After all, time is money for Dutch guideline developers who are on a tight schedule. And, sadly enough, we always are.

Therefore, in our case, this means that high specificity is more important than high sensitivity. This is especially the case for the filter concerning patient issues, as this filter at our organizations will mainly be used in the initial phase of guideline development - to get a general overview of the patient issues regarding a specific disease or condition.

So in the end it turned out that we had to develop our own filter.

## **Methods**

First we will address the question of the scope of the filter, followed by the building of the "gold standard" database, and finally the construction of the filters.

As was mentioned before, our colleagues of SIGN developed a search filter to identify articles regarding patient issues that turned out to be too sensitive and at the same time not specific enough for our purpose. Nevertheless, the SIGN definition of the scope of patient issues in guidelines seemed in line with our own perspective and was - after discussion in our organizations - adopted as a starting point for developing our own filters. In this scope central concepts are experiences, information needs, unfulfilled needs, preferences, participation in decision making and satisfaction with care received.

We developed two filters for Medline - one for the PubMed-interface and one for the OVID-interface -, and one for Embase.com. The terms of the filters were derived from the filter for patient issues of our Scottish colleagues, from the book *User involvement in health care* (1) and from MESH-terms and free text from the titles and the abstracts of known relevant articles. We also constructed a database, and used this database to test and further refine the filters.

The building of a database consisting of an independent set of known relevant records, serving as a gold standard for creating the concept-filters, turned out to be quite challenging. Most authoritative publications on the subject of patient issues, focused on participation in health care, and not on the patients' experiences and preferences concerning their health and the care received. Eventually we looked for references on patient issues in guidelines developed by SIGN, the assumption being that these were references that were proven relevant on patient issues in the context of guideline development, which turned out to be so. Other sources were the references in a recent article on patient participation (2), a recent guideline on diabetes self-management education (3) and references derived from a Cochrane

review on *Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material* (4). The result was a database consisting of 176 references.

Thereafter the MESH-terms of all the references in this database were analyzed with 3 open source MESH-analyzing programs (docmobi, gopubmed en pubmedreminer). We also manually analyzed the references that were missed by the filter. Based on both analyses we adjusted the concept-filters so that all the references of the gold standard set of records were eventually retrieved. This resulted in three concept-filters that could be tested in real practice.

We validated the filters by testing them for three subjects in primary care (the PubMed-filter), for three subjects in secondary care (the OVID-filter) and - later on - for two subjects in primary/secondary care (the Embase filter). The subjects were chosen to go along with ongoing guideline development. Every subject was combined with the filter and limited by publication date to get a reasonable number of in- and excluded references. For each subject all the references that were retrieved with the filter were assessed by one of our colleagues to determine whether this was appropriate. The same colleague also determined if the references that were not retrieved by the filter were rightfully excluded.

So, for each subject we determined the true positives, the false positives, the true negatives and the false negatives, from which we computed the sensitivity, specificity, precision and accuracy. As a comparison we did this also for the SIGN-filter for the three subjects in secondary care.

First, let us give you, as a reminder, an overview of the basic concepts (Table 1).

Table 1

	+	-	total
filter +	a	b	a+b
filter -	c	d	c+d
total	a+c	b+d	a+b+c+d

Precision is the proportion of the retrieved references that was rightfully retrieved:  $a/(a+b)$ . In diagnostic terms this is the positive predictive value.

The sensitivity is the proportion of the relevant retrieved references of all the relevant references:  $a/(a+c)$

The specificity is the proportion of the rightfully not retrieved references of all the irrelevant references:  $d/(b+d)$ . The higher the specificity, the lower is the “noise”.

The accuracy is the proportion of all the appropriately classified references of all the references in the set:  $(a+d)/(a+b+c+d)$ .

## Results

In table 2 you'll see the results of the PubMed-filter for the subject of dyspepsia.

The precision is reasonable (74%), sensitivity not so high (83%), specificity quite high (98%).

Table 2

	+	-	total
filter +	20	7	27
filter -	4	358	362
total	24	365	389

To have a more balanced assessment over more subjects and assessors, we computed the mean results of three subjects in primary care (Table 3). As you can see, the overall performance is much better with a precision of 79.3%, a sensitivity of 90.1%, and a specificity of 98.8%.

Table 3

	+	-	total
filter +	73	19	92
filter -	8	1568	1576
total	81	1587	1668

As a comparison we now show you the results of the filter of our SIGN-colleagues, which was available for the OVID interface (Table 4). As you can see, the sensitivity is much higher (98%), but - as a result - the precision is much lower (21.2%), as are specificity (69.1%) and accuracy (71.4%).

Table 4

	+	-	total
filter +	62	231	293
filter -	1	517	518
total	63	748	811

And these are the results of the new OVID filter for the same set of references (Table 5). As you can see, precision (77.0%) and specificity (98.0%) are much higher and sensitivity is lower (90.5%). Overall accuracy is also higher (97.0%).

Table 5

	+	-	total
filter +	57	17	74
filter -	6	731	737
total	63	748	811

These results are very comparable to the PubMed filter - which is as would be expected, as both filters are more or less the same.

For convenience and discussion we have put all the figures in one table (Table 6).

Table 6

%	OVID-SIGN	OVID-new	Pubmed-new	Embase-new
<b>Precision</b>	<b>21.2</b>	<b>77.0</b>	<b>79.3</b>	<b>81.8</b>
<b>Sensitivity</b>	<b>98.4</b>	<b>90.5</b>	<b>90.1</b>	<b>93.1</b>
<b>Specificity</b>	<b>69.1</b>	<b>98.0</b>	<b>98.8</b>	<b>98.4</b>
<b>Accuracy</b>	<b>71.4</b>	<b>97.0</b>	<b>98.3</b>	<b>98.7</b>
<b>N =</b>	<b>811</b>	<b>811</b>	<b>1668</b>	<b>597</b>

As you can see, specificity and sensitivity of the filters were quite satisfactory, although sensitivity could have been a bit better.

For this reason we were looking for an opportunity to further evaluate the sensitivity of the filters, which presented itself as we came across a recent Cochrane review entitled: *Interventions for providers to promote a patient-centred approach in clinical consultations* (5). Assuming that the references on which the review was based were all relevant articles on the subject of patient issues, we assessed the percentage of references that were actually retrieved by our filter.

As you can see in table 7, the sensitivity of the filters for Medline and PubMed now turned out to be higher than in the original validation process. We felt quite reassured by these results.

Table 7

	Medline (OVID)	Pubmed	Embase
<b>Filter +</b>	<b>72</b>	<b>72</b>	<b>67</b>
<b>Filter -</b>	<b>1</b>	<b>1</b>	<b>6</b>
<b>Cochrane</b>	<b>73</b>	<b>73</b>	<b>73</b>
<b>Sensitivity</b>	<b>98.6 (90.5)</b>	<b>98.6 (90.1)</b>	<b>91.8 (93.1)</b>

The performance of the Embase filter, though, was a bit disappointing compared with the original validation, because it missed 6 out of the 73 Cochrane references. The main reason for this seems to be sparse indexing in Embase. Through a minor adaptation, though, sensitivity was enhanced without negatively affecting specificity, after which the sensitivity equaled that of the original validation process.

## **Closing remarks**

All in all, by checking the original search filter against the Cochrane review, we found that the filter not only is adequately specific but also adequately sensitive, and therefore it's a very useful tool for retrieving literature on patient's values and preferences.

Please allow us to make some additional remarks:

- firstly, we want to stress that the filter not only is useful in the early stages of guideline development but also for answering specific questions, for prioritizing findings, considerations and recommendations, and for increasingly important decision aids like option grids.
- secondly, we believe that the filter not only can be used in support of but also - if necessary - as a substitute for the participation of 'real patients'.

We hope our filters can contribute to making doctors more aware of the patient's perspective and to giving patients tools and opportunities to participate in decisions concerning their health and quality of life. In other words: we hope our filters can contribute to the **empowerment** of patients - which, by the way, is one of the free text search terms in our filters.

One last remark: recently, we submitted an article on this matter to the "G-I-N PUBLIC Toolkit: Patient and Public Involvement in Guidelines" (<http://www.g-i-n.net/working-groups/gin-public/toolkit>).

## **REFERENCES**

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## Appendix 1 – the filters

### *SIGN-filter*

1. exp Patients/
2. patient\$.tw.
3. inpatient\$.tw.
4. outpatient\$.tw.
5. client\$.tw.
6. survivor\$.tw.
7. user\$.tw.
8. consumer\$.tw.
9. exp persons/
10. person\$.tw.
11. people\$.tw.
12. individual\$.tw.
13. victim\$.tw.
14. amputee\$.tw.
15. personal\$.tw.
16. adult\$.tw.
17. caregiver\$.tw.
18. (care adj giver\$).tw.
19. carer\$.tw.
20. guardian\$.tw.
21. exp family/
22. family.tw.
23. families.tw.
24. relative\$.tw.
25. relation\$.tw.
26. spouse\$.tw.
27. partner\$.tw.
28. parent\$.tw.
29. stepparent\$.tw.
30. step-parent\$.tw.
31. husband\$.tw.
32. wife.tw.
33. wives.tw.
34. chld\$.tw.
35. offspring.tw.
36. daughter\$.tw.
37. father\$.tw.
38. stepfather\$.tw.
39. step-father\$.tw.
40. mother\$.tw.
41. brother\$.tw.
42. sister\$.tw.
43. sibling\$.tw.
44. "next of kin".tw.
45. woman\$.tw.
46. women\$.tw.
47. friend.tw.
48. friends.tw.
49. exp focus groups/
50. stepmother\$.tw.
51. step-mother\$.tw.
52. (focus adj group\$).tw.
53. exp Self-Help Groups/
54. "self-help group\$".tw.
55. "support group\$".tw.
56. exp Community Networks/
57. "community network\$".tw.
58. exp social support/
59. "social support".tw.
60. "social network\$".tw.
61. "terminally ill".tw.
62. sufferer.tw.
63. sufferers.tw.
64. or/1-63
65. view\$.tw.
66. experience\$.tw.
67. perspective\$.tw.
68. perception/
69. social perception/
70. perception\$.tw.
71. narrative\$.tw.
72. discourse\$.tw.
73. story.tw.
74. stories.tw.
75. satisfaction.tw.
76. perceived.tw.
77. concern\$.tw.
78. issue\$.tw.
79. exp attitude/
80. attitude\$.tw.
81. exp emotions/
82. emotion\$.tw.
83. anger\$.tw.
84. fear\$.tw.
85. disappoint\$.tw.
86. angry.tw.
87. afraid.tw.
88. sadness.tw.
89. distress\$.tw.
90. nervous\$.tw.
91. anxiety.tw.
92. anxieties.tw.
93. anxious\$.tw.
94. euphoria.tw.

95. euphoric.tw.
96. frustate\$.tw.
97. guilt\$.tw.
98. hate\$.tw.
99. hatred.tw.
100. hostility.tw.
101. jealous\$.tw.
102. loneliness.tw.
103. lonely.tw.
104. grief.tw.
105. grieving.tw.
106. bereavement\$.tw.
107. mourn\$.tw.
108. mood\$.tw.
109. feeling\$.tw.
110. happiness.tw.
111. happy.tw.
112. joy\$.tw.
113. laugh\$.tw.
114. love.tw.
115. loving.tw.
116. honest\$.tw.
117. despair\$.tw.
118. hope\$.tw.
119. hoping.tw.
120. exp empathy/
121. empathy.tw.
122. compassion\$.tw.
123. exp Negativism/
124. faith\$.tw.
125. ethics/
126. morale.tw.
127. exp morale/
128. "unmet need\$.tw.
129. exp human rights/
130. exp stress, psychological/
131. exp adaptation, psychological/
132. ((psycho\$ or social) adj adjust\$.tw.
133. cope.tw.
134. coping.tw.
135. exp psychology, social/
136. "social values".tw.
137. worry\$.tw.
138. worries.tw.
139. exp quality of life/
140. "quality of life".tw.
141. qol.tw.
142. "quality of recovery".tw.
143. dignity.tw.
144. dignif\$.tw.
145. "right to die".tw.
146. "patient advocacy".tw.
147. exp suicide/
148. suicid\$.tw.
149. exp euthanasia/
150. euthanasia.tw.
151. "right to live".tw.
152. "right to choose".tw.
153. (choice\$ or empower\$.tw.
154. "self esteem".tw.
155. exp decision making/
156. (decision adj making).tw.
157. exp communication/
158. "access to information".tw.
159. exp confidentiality/
160. confidentiality.tw.
161. privacy.tw.
162. (truth adj3 disclosure\$.tw.
163. ((psycho\$ or cultural) adj depriv\$.tw.
164. social isolation/
165. "social isolation".tw.
166. "access to services".tw.
167. exp information services/
168. exp counseling/
169. counsel\$.tw.
170. (pastoral adj (care or psychology)).tw.
171. spiritual\$.tw.
172. exp religion/
173. (beliefs or prayer\$ or customs).tw.
174. exp sexuality/
175. sexuality.tw.
176. exp culture/177. ((psycho\$ or social) adj support).tw.
178. exp social support/
179. exp self-help groups/
180. "self-help group\$.tw.
181. "support group\$.tw.
182. exp community networks/
183. "community network\$.tw.
184. "social network\$.tw.
185. misperception\$.tw.
186. suffer\$.tw.
187. exp pain/
188. pain.tw.
189. comfort\$.tw.
190. comfortable.tw.
191. 189 not 190
192. or/65-188,191
193. 64 and 192

194. exp Patients/ed, px [Education, Psychology]  
195. exp persons/ed, px  
196. exp family/ed, px [Education, Psychology]  
197. exp Interpersonal Relations/  
198. exp Family Relations/  
199. exp Professional-Patient Relations/  
200. Consumer Satisfaction/

201. exp Consumer Participation/  
202. exp Patient Education/  
203. exp personal satisfaction/  
204. "patient information".tw.  
205. (patient adj (leaflet\$ or booklet\$ or pamphlet\$)).tw.  
206. or/194-205  
207. 193 or 206

### *Medline (OVID) filter*

1. exp Consumer Participation/ or "Patient Acceptance of Health Care"/ or exp Attitude to Health/ or \*exp consumer satisfaction/ or patient preference/ or cooperative behavior/ or exp self efficacy/ or self-efficacy.ti,ab. or exp Adaptation, Psychological/ or exp health education/ or patient education as topic/ or exp attitude to health/ or health knowledge, attitudes, practice/ or \*"Quality of Life"/ or "Quality of Life"/px or Personal Autonomy/ or self concept/ or consumer advocacy/ or freedom/ or Needs Assessment/ or Patient Advocacy/ or Self-Help Groups/ or Life Change Events/ or Attitude to Death/ or Patient-Centered Care/ or exp Professional-Patient Relations/ or Self Care/ or focus groups/ or narration/  
2. (((patient or consumer\*) adj3 (participat\* or decisi\* or decid\*)) or patient-focused or (patient-centred or patient-centered) or (patient adj3 (attitude? or preference))).ti,ab. or "patient satisfaction".ti. or coping.ti,ab. or ("self perception" or "self concept").ti,ab. or self-efficacy.ti,ab. or ("informed choice" or "shared decision making").ti,ab. or empowerment.ti,ab. or ("focus group\*" adj3 (patient\* or parent\* or famil\* or spouse\*)).ti,ab. or (QoL or "Quality of life").ti. or self-management.ti. or ((patient\* or consumer\* or parent\* or famil\* or spouse\*) adj (attitude\* or involvement or desir\* or perspective\* or activation or view\* or preference\*)).ti,ab. or "expert patient\*".ti,ab. or "focus group\*".ti,ab. or qualitative.ti.  
3. (exp Decision Making/ or exp Communication/ or Stress, Psychological/ or Emotions/ or vignette\*.ti,ab.) and (exp Patients/px or patient\*.ti. or consumer\*.ti.)  
4. 1 or 2 or 3

### *Medline (PubMed) filter*

((Patient Participation[Mesh] OR consumer participation[Mesh] OR Professional-Patient Relations[Mesh] OR Patient-Centered Care[Mesh] OR Patient Preference[Mesh] OR Patient Satisfaction[Majr] OR Patient Education as Topic[Mesh] OR Attitude to Health[Mesh] OR Attitude to Death[Mesh] OR Patient Acceptance of Health Care[Mesh] OR Health Knowledge, Attitudes, Practice[Mesh] OR Focus Groups[Mesh] OR Quality of Life[Majr] OR Self Care[mh:noexp] OR Self Concept[Mesh] OR Self-examination[Mesh] OR Cooperative Behavior[Mesh] OR Adaptation, Psychological[Mesh] OR Decision Support Techniques[Mesh] OR Self-Help Groups[Mesh] OR Community Networks[Mesh] OR Emotions[Mesh] OR Consumer Satisfaction[Mesh] OR Needs Assessment[Mesh] OR Personal Autonomy[Mesh] OR Patient Advocacy[Mesh] OR Life Change Events[Mesh]) OR (patient perspective\*[tiab] OR patient's perspective\*[tiab] OR patient desire\*[tiab] OR patient's desire\*[tiab] OR "patient's desires"[tiab] OR patient view\*[tiab] OR patient's view\*[tiab] OR patient expression\*[tiab] OR patient's expression\*[tiab] OR patient

attitude\*[tiab] OR patient's attitude\*[tiab] OR patient involvement\*[tiab] OR patient's involvement\*[tiab] OR patient decision\*[tiab] OR patient's decision\*[tiab] OR patient activation[tiab] OR patient's activation[tiab] OR patients activation[tiab] OR patient empowerment[tiab] OR patient participation[tiab] OR patient's participation[tiab] OR patients participation[tiab] OR patient collaboration[tiab] OR patient's collaboration[tiab] OR patients collaboration[tiab] OR expert patient\*[tiab] OR consumer participation[tiab] OR consumer perspective[tiab] OR consumers perspective[tiab] OR consumer's perspective[tiab] OR consumer involvement[tiab] OR patient-focused[tiab] OR patient-centred[tiab] OR patient-centered[tiab] OR patient needs[tiab] OR self-management[ti] OR self-perception[tiab]) OR (Patients[Majr] AND (Communication[MeSH Terms] OR Decision Making[Mesh]))

### *Embase filter*

'patient participation'/exp OR 'doctor patient relation'/exp OR 'nurse patient relationship'/exp OR 'patient attitude'/exp OR 'attitude to death'/exp OR 'consumer'/exp OR 'patient preference'/exp OR 'patient satisfaction'/exp/mj OR 'patient education'/exp OR 'attitude to health'/exp OR 'quality of life'/exp/mj OR 'self care'/exp OR 'self concept'/exp OR 'self examination'/exp OR 'adaptive behavior'/exp OR 'coping behavior'/exp OR coping:ab,ti OR 'needs assessment'/exp OR 'personal autonomy'/exp OR 'patient advocacy'/exp OR 'life event'/exp OR 'patient centred':ab,ti OR 'patient-centered':ab,ti OR 'patient focused':ab,ti OR 'patient satisfaction':ti OR (patient\* NEAR/3 prefer\*):ab,ti OR 'focus group':ab,ti OR 'focus groups':ab,ti OR (patient NEAR/3 participat\*):ab,ti OR (patient\* NEAR/3 involve\*):ab,ti OR (patient\* NEAR/3 perspective\*):ab,ti OR 'patient desire':ab,ti OR 'patient desires':ab,ti OR (patient\* NEAR/2 view\*):ab,ti OR (patient\* NEAR/2 activat\*):ab,ti OR (patient\* NEAR/3 empower\*):ab,ti OR (patient\* NEAR/2 attitude\*):ab,ti OR (patient\* NEAR/2 decision\*):ab,ti OR (patient\* NEAR/3 collaborat\*):ab,ti OR 'expert patient':ab,ti OR 'expert patients':ab,ti OR (patient\* NEAR/2 needs):ab,ti OR 'self management':ab,ti OR 'self perception':ab,ti OR ('patient'/exp AND ('interpersonal communication'/exp OR 'decision making'/exp OR 'cooperation'/exp OR 'distress syndrome'/exp OR 'emotional stress'/exp))