

Important Considerations for Design and Implementation of Decision Aids for Shared Medical Decision Making

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ABSTRACT

Introduction: Decision aids are software or paper-based tools that enable patients and health care practitioners to work together to make optimal treatment decisions. Although there are decades of favorable research for the use of decision aids, there is wide variation in their development and implementation.

Objective: To review the literature and provide a summary of best practices for the design, implementation, and assessment of decision aids.

Methods: A literature search and screening process was employed with a focus on systematic review articles. The resulting articles were synthesized and summarized into recommendations regarding the optimal design, implementation, and appraisal of shared decision-making tools.

Results: Designers of decision aids should initially focus on engagement by involving health care practitioners and patients to ensure the decision aids are pertinent to the situation and not perceived as time consuming. The International Patient Decision Aids Standards help ensure quality in design. Patients should be able to select information in a manner that suits them and view it in a way that allows them to evaluate trade-offs. In reporting of statistical risks, format bias should be avoided through careful and consistent choice of format and by adding visual representations. Decision aids should be tested in real settings with iterative improvements. For appraisal of the implemented decision aids, consider using the Control Preference and Decisional Conflict scales.

Discussion: Further research is recommended regarding optimal engagement of users with decision aids and exploration of the distinct opportunities that computerized decision aids and online patient communities may present.

Conclusion: Decision aids can be a valuable tool for shared medical decision making. Their quality and usefulness can be maximized by involving users in their creation and by attending to key considerations in their design, implementation, and appraisal.

INTRODUCTION

Decision aids are software or paper-based tools that enable patients and health care practitioners to work together to make optimal treatment decisions by educating patients about the risk and benefit of different options and aligning those options with their personal values. Although informational handouts or patient instructions are helpful, decision aids take a more targeted approach by “making explicit the decision that needs to be made, providing information about treatment options and outcomes, and helping the patient clarify personal values.”¹ Certainly, shared decision making can be done without decision aids, however these tools may help to standardize and facilitate that process.² In a Cochrane Review³ of 105 studies involving 31,043 participants, the authors conclude:

Compared to usual care ... people exposed to decision aids feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision making and more accurate risk perceptions. There is growing evidence that decision aids may improve values-congruent choices.

Although there are basic standards for what constitutes high-quality decision aids,⁴⁻⁶ there is neither consensus around best practices nor any holistic and practical commentary regarding the development, implementation, and evaluation of decision aids. Therefore, the aims of this article were to complete a narrative review of the use of decision aids in shared decision making and to summarize the key considerations for developing, implementing, and assessing decision aids as tools to support effective shared decision making. Such a summary could serve as a reference for any health care professional or team who wishes to design, implement, and assess decision aids.

The preponderance of research has lent itself to many systematic reviews and meta-analyses that serve as the basis for this narrative synthesis. With the aim of supporting the creation and effective use of decision aids, the following questions were considered:

1. Which overall approach should be used when designing a decision aid?
2. Which specific decision-support features are most effective?
3. Which factors should be considered in implementation?
4. How should the effectiveness of a decision aid be assessed?

METHODS

A literature search, screening, and appraisal process was implemented using the National Library of Medicine’s PubMed database with Medical Subject Headings (MeSH) terms. A literature search was performed in PubMed and constrained to the MeSH term *Decision Support Techniques*. (This was the only term that included patient involvement in decision making.)

Searches were performed within “Decision Support Techniques” using the terms: *Shared decision*, *decision aid*, and *decision aids*. Duplicates were removed, resulting in 1031 total articles. Because the goal of this study was to obtain generally applicable insights with a broad, established evidence base, the search was further constrained to review articles only. This returned 188 articles across all terms. Citations were reviewed, and articles not

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pertaining to design, implementation, and assessment of decision aids were removed, with 12 articles remaining. This search approach did not retrieve any systematic review that addressed the question of assessment of decision aids. Because of this, the prior search was repeated without constraint to review articles and with the addition of *appraisal* and *evaluation* search terms. Thus, the search used the MeSH term *Decision Support Techniques* with the following terms: *Shared decision*, *decision aid*, *decision aids*, *appraisal*, and *evaluation*. With this second search, 354 citations were found, resulting in 1 pertinent review article not found previously (which had perhaps been erroneously classified as a research support article instead of a review).

RESULTS

The literature searches revealed a total of 13 pertinent review articles (Figure 1). These articles were organized and synthesized into the following narrative review describing basic insights and considerations for all stages of the decision aid lifecycle (Table 1).

Design Process

Given that decision aids require engagement from both patients and health care practitioners, creating a design process that explores the users' needs (user-centered design) and workflows could potentially increase usage. Matlock and Spatz⁷ form a theoretical framework for the design of decision aids that embraces a user-centered design perspective. They suggest 1) understanding the decision, including risks and benefits and an idea of "what's important" for practitioners; 2) creating a first draft; 3) iteratively modifying or adjusting the tool with potential end users; and 4) testing the tool in a real setting. A similar approach is described by Coulter et al.⁸ A study in progress by Witteman et al⁹ will evaluate what aspects of user-centered design are currently used in developing decision aids and to establish a "measure of the user-centeredness of development processes and identify practices that are likely to be optimal." To support the overall quality of decision aid design, the International Patient Decision Aids Standards (IPDAS)⁴⁻⁶ were developed from an expert consensus approach and provide a detailed checklist addressing aspects of the content, development, and effectiveness of decision aids. The items on this checklist are key considerations and should be addressed in the design of new decision aids.

Design Features

Many of the findings in this review pertain to the use of specific features in decision aids. They are organized here in the emergent categories of educational material, representing risk, values clarification, and use of narrative.

Educational Material

The foundation of decision aids is the education of patients about treatment options. Having accurate, up-to-date information is essential to the basic quality of a decision aid,¹⁰ which now may be facilitated by both electronic libraries and computer-based decision aids.

A study of computer-based decision aids by Syrowatka et al¹¹ suggests that designers avoid tailoring information to specific patients, but rather give users control over how much and what

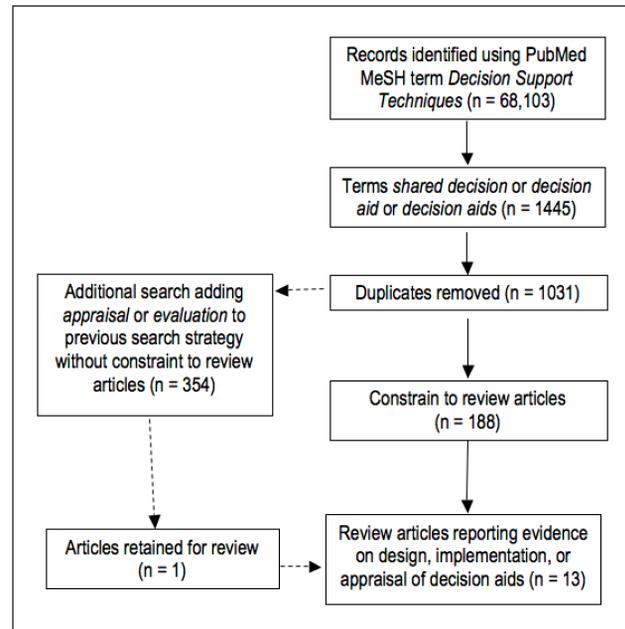


Figure 1. PRISMA diagram of literature search.

MeSH = Medical Subject Headings; PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

type of information they view and "allow patients to select the order, level of detail and type of information presented." Providing patients with a "notebook" for them to record their learnings or questions was helpful as well. When representing information, Abhyankar et al¹² found that a side-by-side display tends to give patients a greater sense of having a balanced approach to decision making, possibly by enabling patients to see decision trade-offs.¹¹

Representing Risk

An essential aspect of education involves communicating risk. A group of 14 researchers developed an expert consensus document addressing the need to effectively represent treatment risks.¹³ They suggest using a consistent format throughout documents (ie, using percentages or using simple frequency formats such as 3/100). Also, "1 in x" formats (ie, where the denominator is the variable) should generally be avoided. They suggest that the risk of a single event can be adequately described with either percentages or simple frequency formats (eg, 3/100) but that comparing the risk of 2 or more independent events (ie, "chance of improvement with drug X compared with placebo") is better represented with percentages. The magnitude of numbers should be considered as a source of format bias (ie, comparing 0.001 and 0.0003). The use of visual formats may reduce format bias, but it is also important to generally "take into account the numeracy and graph literacy of the audience."¹³ It is also important to make time frames explicit, such as "10% risk per year" vs "10% lifetime risk." Caution with tailoring risk assessments to individual patients may also be prudent. A study by Scherer et al¹⁴ found that 20% of the patients did not believe their personalized risk numbers for a variety of reasons. The researchers concluded that "the benefits of tailored risk statistics may be attenuated by

a tendency for people to be skeptical that these risk estimates apply to them personally.”

Values Clarification

The goal of decision aids is to help patients to make treatment choices that fit their own values.^{3,6} The most common approach is the implicit approach, which involves listing the features and outcomes of each treatment option for the patient to reflect on, including possible physical, emotional, and social consequences.⁶ Explicit approaches require the patient to explicitly declare their values by having them write them out or by having them numerically rate the importance of each potential outcome, for example, “impact on bowel function.” Fagerlin et al¹⁵ explored the impact of explicit values clarification methods and found mixed results in general and no consensus on the best approach. Syrowatka et al¹¹ also found mixed results. At a minimum, the simple implicit approach of listing features and outcomes should be used, and representing these treatment differences in terms of trade-offs may be the preferred approach to doing that.¹¹

Use of Narrative

Many decision aids use a video or written vignette that describes another patient’s thoughts about treatment options. In their review, Bekker et al¹⁶ suggest that the effectiveness of the use of patient narratives is unclear. The facts and issues that the narrator may focus on may not represent those that are important to the patient. The patient may also have a reaction to the narrator,

which can bias their decision. It is also difficult to compare narratives for different treatment options, and the persuasiveness of a narrative can undermine the statistical data about risks and benefits.¹⁶ The benefit of using stories or video may vary depending on health literacy.¹⁵

Implementation

Elwyn et al,¹⁷ in their review, reveal major barriers to implementation because of “indifference on the part of health care professionals” and fear that the decision aids would disrupt workflows or not have appropriate content. Similarly, in a systematic review, Légaré et al¹⁸ found that the most common barriers to use of decision aids had to do with clinician engagement. Primary concerns were that the decision aids did not fit the characteristics of the patients and that the decision aid would increase visit length. Interestingly, in their review, decision aids had a variable effect on consultation length, from shorter to longer durations, so perhaps confronting the perception of time consumption would be important to physician engagement. Also noted was that decision aids were more likely to be used if the clinicians were motivated and if they perceived that shared decision making would have a positive impact on the clinical process or patient outcomes. In terms of encouraging the use of decision aids, Légaré et al¹⁸ found that interventions targeting both patients and clinicians were most effective.

Table 1. Activities and recommendations for decision aids

Activity	Recommendation	Source
Design	Employ a user-centered, iterative design approach with testing in real settings.	Matlock and Spatz, ⁷ 2014 Coulter et al, ⁸ 2013 Witteman et al, ⁹ 2015
	Use the International Patient Decision Aid Standards (IPDAS) checklist to ensure quality.	Elwyn et al, ⁴ 2006 O'Connor et al, ⁶ 2005
Features Educational material	Maintain decision aids with accurate, up-to-date information.	Montori et al, ¹⁰ 2013
	Don't tailor information for the patient. “Allow patients to select the order, level of detail and type of information presented.”	Syrowatka et al, ¹¹ 2016
	Provide patients with a “notebook” to record learnings.	Syrowatka et al, ¹¹ 2016
	Use a side-by-side display for a balanced approach to decision making and support evaluation of trade-offs.	Abhyankar et al, ¹² 2013
Representing risk	Use a consistent format throughout documents, such as a consistent denominator, avoiding “1 in x” formats. Clarify timeframes, eg, “10% risk in 1 year” vs lifetime risk.	Trevena et al, ¹³ 2013 Scherer et al, ¹⁴ 2013
	Present the chance of a single event with percentage or simple frequency format (“3/100”).	
	Present the chance of 2 or more independent events with percentages (eg, “X% chance of symptom relief with drug A compared with placebo”).	
	Consider the magnitude of numbers (eg, comparing 0.001 and 0.0003 may be difficult for some).	
	Use visual formats to reduce format bias.	
	Consider the numeracy and graph literacy of the audience.	
Values clarification	Use caution with tailoring risk statistics; individuals may disbelieve them.	Fagerlin et al, ¹⁵ 2013 Syrowatka et al, ¹¹ 2016
	There is mixed evidence for correct approach and overall effectiveness in having patients declare their values explicitly. Consider using a “trade-off” approach.	
Use of narrative	Use with caution given mixed evidence and the potential for introducing bias.	Bekker et al, ¹⁶ 2013
Implementation	Engagement of health care professionals is the major challenge. Address concerns about disruption of workflows, appropriateness of content, and perception of time impact.	Elwyn et al, ¹⁷ 2013 Légaré et al, ¹⁸ 2014
Appraisal	Consider using the Control Preference Scale and the Decisional Conflict Scale to assess effectiveness. Use consensus-based IPDAS to review the design quality.	Kryworuchko et al, ¹⁹ 2008 Elwyn et al, ⁴ 2006

Appraisal

The IPDAS checklist describes key considerations in the design of decision aids,⁴ but there is no specific instrument that is recognized as superior for measuring the quality of decision aids. Kryworuchko et al¹⁹ studied 8 different instruments comprising more than 35 outcome measures. With strong consideration of the IPDAS design model in their appraisal process, the authors found that 2 instruments met at least 6 of 8 of their appraisal criteria. These were the Control Preference Scale, which measures the ability of a patient to participate in a decision to the degree s/he desires and the Decisional Conflict Scale, which assesses the patient's degree of feeling supported, informed, certain about his/her decision, clear about values, and the effectiveness of the decision process in creating a satisfying decision.

DISCUSSION

The aim of this article was to explore the current research on decision aids and to offer a concise summary that would serve as a reference for any health care practitioner or team who wished to design and implement these useful tools. As such, this review identified several key considerations for the design, implementation, and evaluation of decision aids.

Although these considerations may be helpful for the design of high-quality decision aids, such improvements are of little benefit if the decision aids are not used by health care practitioners and patients. Health care professionals have expressed concerns that decision aids will disrupt workflows, create unnecessarily long visits, and not contain appropriate content.^{17,18}

With this in mind, perhaps engagement is the most useful lens through which to view the findings of this review. Engagement could begin at the design level by involving physicians in a user-centered, iterative design approach.⁹ Input from physicians may ensure appropriate and up-to-date content¹⁰ and ensure that the quality of the tool is suitable by the IPDAS.⁴⁻⁶ Early physician involvement may also alleviate issues around "inappropriate content" or "disrupted workflows."^{17,18}

Removing decision aid features that are time consuming but that offer unclear benefits may be useful to increase engagement. For example, complex "explicit" values clarification approaches could be time consuming and may not add greatly to decision efficacy or satisfaction.¹⁵ Similarly, narrative features might require the patient to view multiple videos or read narratives that could be disruptive to workflow and timeliness and may not provide a clear benefit to decision making.¹⁶

Ideally, a decision aid should increase the effectiveness of the patient visits while decreasing the clinicians' effort. For example, patients could use the decision aid at home, working at their own pace, which would allow them to "select the order, level of detail and type of information presented."¹¹ Educational material should include simple and appropriate descriptions of risk¹³ that allow patients to compare options in terms of trade-offs.¹¹ Patients could conceivably come to a visit with a foundational understanding of the risks, discuss notes they have taken,¹¹ and ask informed questions that are pertinent to their own situation.

By engaging physicians in implementation, concerns about time loss, content, or workflow disruption could be addressed

and alleviated.^{17,18} Discussion about expected benefits in clinical processes or patient outcomes as well as the expectation that the cost of time may be negligible or even favorable¹⁸ might all serve to improve the engagement and use of the tool in clinical settings.

Iterative improvement may be needed to develop a decision aid that is increasingly useful and engaging for patients and health care professionals.⁹ The Control Preference and the Decisional Conflict scales may be useful to assess and improve the usefulness of the tool from the patient perspective.¹⁹

This study has some limitations. In a topic area that contains nearly 70,000 citations, it was difficult to ensure that important articles were not omitted in the search strategy. In part, the focus here on review articles, of which there are many, was an attempt to surface the key findings in the literature. A more thoroughgoing approach would be a systematic review of the whole corpus of literature. Given that the aim of this article was to summarize research across the entire lifecycle of decision aids (design, implementation, assessment), a systematic review would be quite ambitious and beyond the scope of this review.

A search strategy targeting review articles tends to emphasize aspects of decision aids that have been well studied, such as "values clarification" or "use of narrative." Although such a summary may be most useful for creators of decision aids, it does little to describe the gaps in literature where future research may have merit.

Of note, shared decision making certainly occurs between patients and practitioners without the use of decision aids, but this article does not investigate what occurs in those interactions, nor do the findings here necessarily apply to shared decision making that occurs without the use of a decision aid.

Although the effectiveness of explicit values clarification approaches has been described here as inconclusive, it should be noted that there are a wide variety of these approaches, some of which may be effective but require more research.¹⁵ Similarly, the use of narrative may also deserve further exploration. For example, the emergence of online patient communities such as PatientsLikeMe,²⁰ Inspire,²¹ and HealthBoards²² allows patients to explore a great variety of patient narratives to find scenarios that more closely fit their own.

Perhaps a more intriguing potential for both values clarification and narrative lies in the aggregated insights from these online patient communities. With the key components of both highly detailed discussions and very large quantities of them, there is the potential for the use of sentiment analysis techniques²³ to gain population-level insights into what is important for patients facing different treatment decisions. Such findings could not only inform the creation of decision aids but also make it possible for patient communities' Web sites to leverage their own data and offer powerful decision-support tools directly to patients that facilitate decision making across the broad diversity of patient values and health conditions. Although such efforts may be pertinent to this review, they are outside its scope.

CONCLUSION

The literature reports several considerations in the development, implementation, and assessment of shared decision-making tools. Designers of decision aids should focus on engagement

from the start by involving health care practitioners and patients to ensure that the decision aids are pertinent to the situation and not perceived as time consuming. The IPDAS checklist helps to ensure quality in design. Patients should be able to select information in a manner that suits them and view it in a way that allows them to evaluate trade-offs. In the reporting of statistical risks, format bias can take many forms and should be avoided through careful and consistent choice of format and by adding visual representations. Decision aids should be tested in real settings with iterative improvements. For appraisal of the implemented decision aids, consider using the Control Preference Scale and the Decisional Conflict Scale. Further research is recommended regarding optimal engagement of users with decision aids as well as exploration of the distinct opportunities that computerized decision aids and online patient communities may present. ❖

Disclosure Statement

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References

- Herrin J, Harris KG, Kenward K, Hines S, Joshi MS, Frosch DL. Patient and family engagement: A survey of US hospital practices. *BMJ Qual Saf* 2016 Mar;25(3):182-9. DOI: <https://doi.org/10.1136/bmjqs-2015-004006> PMID:26082560
- Spatz ES, Krumholz HM, Moulton BW. Prime time for shared decision making. *JAMA* 2017 Apr 4;317(13):1309-10. DOI: <https://doi.org/10.1001/jama.2017.0616> PMID:28384834
- Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017 Apr 12;4:CD001431. DOI: <https://doi.org/10.1002/14651858.CD001431.pub5> PMID:28402085
- Elwyn G, O'Connor A, Stacey D, et al.; International Patient Decision Aids Standards (IPDAS) Collaboration. Developing a quality criteria framework for patient decision aids: Online international Delphi consensus process. *BMJ* 2006 Aug 26;333(7565):417. DOI: <https://doi.org/10.1136/bmj.38926.629329.AE> PMID:16908462
- IPDAS versions & use [Internet]. International Patient Decision Aids Standards (IPDAS) Collaboration; updated 2018 Jul 25 [cited 2019 Jun 5]. Available from: <http://ipdas.ohri.ca/using.html>
- O'Connor AM, Llewellyn-Thomas H, Dolan J, Kupperman M, Wills C. Clarifying and expressing values. In: O'Connor AM, Llewellyn-Thomas H, Stacey D, editors. *IPDAS Collaboration background document* [Internet]. IPDAS; 2005:17-20 [cited 2019 Oct 23]. Available from: http://ipdas.ohri.ca/IPDAS_Background.pdf
- Matlock DD, Spatz ES. Design and testing of tools for shared decision making. *Circ Cardiovasc Qual Outcomes* 2014 May;7(3):487-92. DOI: <https://doi.org/10.1161/CIRCOUTCOMES.113.000289> PMID:24714602
- Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ, van der Weijden T. A systematic development process for patient decision aids. *BMC Med Inform Decis Mak* 2013;13(S2 Suppl 2):S2. DOI: <https://doi.org/10.1186/1472-6947-13-S2-S2> PMID:24625093
- Witteman HO, Dansokho SC, Colquhoun H, et al. User-centered design and the development of patient decision aids: Protocol for a systematic review. *Syst Rev* 2015 Jan 26;4(1):11. DOI: <https://doi.org/10.1186/2046-4053-4-11> PMID:25623074
- Montori VM, LeBlanc A, Buchholz A, Stilwell DL, Tsapas A. Basing information on comprehensive, critically appraised, and up-to-date syntheses of the scientific evidence: A quality dimension of the International Patient Decision Aid Standards. *BMC Med Inform Decis Mak* 2013;13(S2 Suppl 2):S5. DOI: <https://doi.org/10.1186/1472-6947-13-S2-S5> PMID:24625191
- Syrowatka A, Krömker D, Meguerditchian AN, Tamblin R. Features of computer-based decision aids: Systematic review, thematic synthesis, and meta-analyses. *J Med Internet Res* 2016 Jan 26;18(1):e20. DOI: <https://doi.org/10.2196/jmir.4982> PMID:26813512
- Abhyankar P, Volk RJ, Blumenthal-Barby J, et al. Balancing the presentation of information and options in patient decision aids: An updated review. *BMC Med Inform Decis Mak* 2013;13(S2 Suppl 2):S6. DOI: <https://doi.org/10.1186/1472-6947-13-S2-S6> PMID:24625214
- Trevena LJ, Zikmund-Fisher BJ, Edwards A, et al. Presenting quantitative information about decision outcomes: A risk communication primer for patient decision aid developers. *BMC Med Inform Decis Mak* 2013;13(S2 Suppl 2):S7. DOI: <https://doi.org/10.1186/1472-6947-13-S2-S7> PMID:24625237
- Scherer LD, Ubel PA, McClure J, et al. Belief in numbers: When and why women disbelieve tailored breast cancer risk statistics. *Patient Educ Couns* 2013 Aug;92(2):253-9. DOI: <https://doi.org/10.1016/j.pec.2013.03.016> PMID:23623330
- Fagerlin A, Pignone M, Abhyankar P, et al. Clarifying values: An updated review. *BMC Med Inform Decis Mak* 2013;13(S2 Suppl 2):S8. DOI: <https://doi.org/10.1186/1472-6947-13-S2-S8> PMID:24625261
- Bekker HL, Winterbottom AE, Butow P, et al. Do personal stories make patient decision aids more effective? A critical review of theory and evidence. *BMC Med Inform Decis Mak* 2013;13(S2 Suppl 2):S9. DOI: <https://doi.org/10.1186/1472-6947-13-S2-S9> PMID:24625283
- Elwyn G, Scholl I, Tietbohl C, et al. "Many miles to go ...": A systematic review of the implementation of patient decision support interventions into routine clinical practice. *BMC Med Inform Decis Mak* 2013;13(S2 Suppl 2):S14. DOI: <https://doi.org/10.1186/1472-6947-13-S2-S14> PMID:24625083
- Légaré F, Stacey D, Turcotte S, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev* 2014 Sep 15;(9). DOI: <https://doi.org/10.1002/14651858.cd006732.pub3> PMID:25222632
- Kryworuchko J, Stacey D, Bennett C, Graham ID. Appraisal of primary outcome measures used in trials of patient decision support. *Patient Educ Couns* 2008 Dec;73(3):497-503. DOI: <https://doi.org/10.1016/j.pec.2008.07.011> PMID:18701235
- PatientsLikeMe [Internet]. Cambridge, MA: PatientsLikeMe Inc; updated 2019 Jun 7 [cited 2019 Jul 3]. Available from: www.patientslikeme.com/
- Inspire health and wellness support groups and communities [Internet]. Arlington, VA: Inspire; 2005-2019 [cited 2019 Jul 3]. Available from: www.inspire.com
- HealthBoards health message boards [Internet]. El Segundo, CA: Internet Brands; 2019 [cited 2019 Jul 5]. Available from: www.healthboards.com
- Moussa ME, Mohamed EH, Haggag MH. A survey on opinion summarization techniques for social media. *Future Computing and Informatics Journal* 2018;3(1):82-109. DOI: <https://doi.org/10.1016/j.fcij.2017.12.002>