

# Lessons learned from the Decision Board: a unique and evolving decision aid

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## Abstract

One session of the conference was devoted to the presentation of different types of decision aids. This paper reports the experience and lessons learned through the development and use of the Decision Board. This is a uniquely interactive decision aid administered by the clinician during the medical consultation. The instrument has been developed in a number of clinical contexts, primarily regarding treatment options for cancer patients. Studies have shown the instrument to improve patient understanding and facilitate the shared decision-making process. Randomized trials are ongoing, evaluating the addition of the Decision Board to the traditional medical consultation. The instrument continues to evolve to meet patients' need for information and flexibility in presentation. Computer-based versions of the Decision Board are currently being developed.

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## Introduction

Many patients have indicated a desire for more information about their disease and the need to be more involved in decisions about their care.<sup>1-3</sup> The concept of shared decision-making has been advocated by both patients and physicians.<sup>4,5</sup> Shared decision-making has been variably defined.<sup>6,7</sup> In its simplest form, it involves both the physician and patient sharing information and taking steps to build consensus about the preferred treatment.

In treatment decision-making, we are interested in finding the answer to the question, 'What is the best treatment for an individual patient?' Treatment decisions often represent difficult trade-offs between potential morbidity and inconvenience now due to therapy, and potential reduction in morbidity and disability later. The uncertainty of the outcome at the individual level further complicates the problem and makes the choice a very difficult one. In

order to make treatment decisions which involve trade-offs, two components are required: full knowledge of the risks and benefits of each course of action, and the values an individual places on these. In many other real life situations both components, knowledge and values, are found in the same person. However, in the case of treatment decision-making, often the knowledge exists in one body, i.e. the medical professional, and the values in another, the patient. In order to make an informed decision, one either has to transfer the physician's knowledge to the patient, or the patient's values to the physician. For shared decision-making, the patient has to be informed to enable discussion of treatment options with their clinician.<sup>7</sup>

Various types of decision aids that have been developed approach this problem somewhat differently. In classic decision analysis, an attempt is made to determine a patient's utility for various outcomes as an assessment of his/her values.<sup>8-10</sup> Utilities are then combined

mathematically with the probabilities of each outcome to determine a patient's overall expected utility for different courses of action. The physician makes a recommendation for treatment based on the option with the highest expected utility.

Other methods attempt to transfer information to patients to permit them to incorporate their values and express a preference for treatment.<sup>11-13</sup> Many of these methods differ from traditional patient education materials in that they provide an explicit presentation of different treatment options with associated benefits and risks, and information is often tailored to the patient's individual characteristics.

Previous studies have indicated that there can be problems with the communication of information between physicians and patients. Siminoff *et al.* studied 100 consecutive physician-patient encounters regarding adjuvant chemotherapy for breast cancer.<sup>14</sup> They observed that physicians practiced unvarying communication patterns and exchanged little in the way of specific information. For example, benefits and risks of treatment often were discussed in general terms. Not surprisingly, the majority of patients (60%) overestimated their chance of cure, and underestimated the likelihood of severity of common side-effects. Similarly, Rimer and colleagues reviewed 116 consultations between physicians and patients. Clinicians, on average, told patients less than 70% of the information relevant to their disease and treatment.<sup>15</sup> These studies suggest that difficulty with patient understanding may be attributed, in part, to an inability by physicians to communicate information clearly. As a result, many decision support devices or aids (e.g. videodisc and audiotape/booklet) target patients directly, presenting information to them before or following discussion with their physician.<sup>11,12</sup>

The Decision Board is a unique decision aid which targets the physician-patient interaction recognizing the patient's preference in receiving information from their physician and the importance of this interaction for patients' treatment decisions.<sup>16,17</sup> The instrument is aimed at trying to solve some of the communication

problems identified in the literature. It endeavours to improve communication by presenting information simply, using spoken and written language supported by the use of visual aids, and relying on repetition. The Decision Board is administered by the clinician and can be used at the bedside (hence the previous term 'bedside instrument') or at the office. The instrument takes advantage of the interaction between the clinician and the patient by facilitating two-way communication and encouraging questions from patients and responses from physicians. Other attributes of the instrument are that it is easy to administer, inexpensive to produce, and easily modified to incorporate local variations in practice (or new clinical information that becomes available).

Over the last several years, we and others have been actively involved in the development of the Decision Board for different clinical situations and evaluation of its impact on the medical encounter. The purpose of this article is to update the reader regarding our experience and lessons learned from the development and use of the instrument, and to introduce new and ongoing research.

### **Decision Board for adjuvant chemotherapy in node-negative breast cancer**

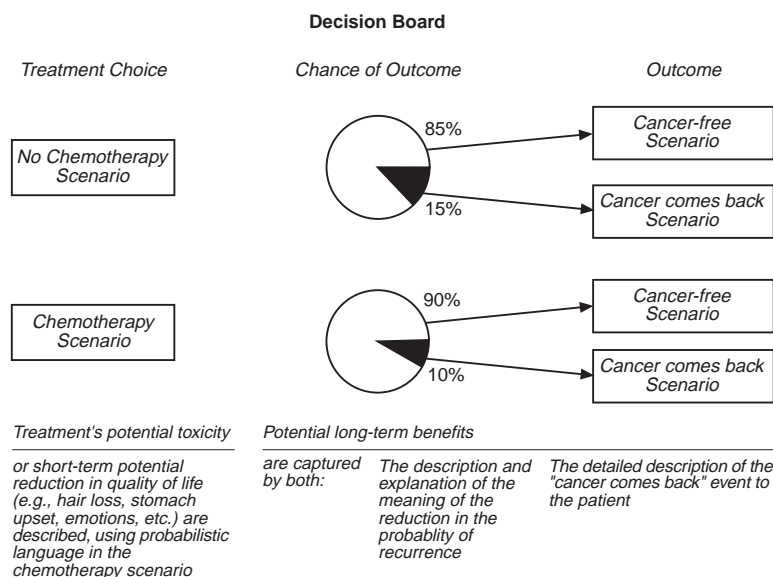
The first Decision Board was developed for use in the situation of adjuvant chemotherapy for node-negative breast cancer. At that time, results from clinical trials demonstrated that adjuvant chemotherapy decreased recurrence and improved survival in node-negative breast cancer.<sup>18,19</sup> However, the use of chemotherapy was controversial because the risk of recurrence was small, the benefit in absolute terms was modest and adjuvant chemotherapy was associated with considerable adverse effects on patients' quality of life during treatment. The purpose of the original Board was to develop a method where the best available information on risks and benefits of chemotherapy could be presented in an unbiased fashion, and to develop a simple process where an informed patient could voice a preference for treatment or not.<sup>11</sup>

The Board was developed in a systematic fashion. A careful review of the literature was performed for studies evaluating the role of adjuvant chemotherapy in node-negative breast cancer. The information gathered was presented to separate focus groups of patients and clinicians to determine the importance of the information for decision-making, and to identify a framework for presentation of the information and the decision aid. Following this, scenarios were developed describing the treatment choices and outcomes, probability of the outcomes and their meaning, and quality of life associated with treatment choice and outcome. At the same time, probabilities of risks of outcomes were determined using data from the literature. The scenarios were tested for clarity and comprehensibility in an iterative fashion with focus groups of patients and oncologists. A prototype decision aid was then developed and pretested on a sample of patients who had completed adjuvant chemotherapy.

The Decision Board is a visual aid that presents information in an efficient and standardized manner. (see Fig. 1) The original instrument had three subtitles: treatment choice, chance of outcome, and outcome. The Board presented information on treatment choices, chance of outcomes resulting from the treatment

choice, outcomes, and quality of life associated with choices and outcomes in a systematic and balanced manner. The treatment choices and outcomes were described by detailed written information cards. Probability of outcomes were presented by colour-coded probability wheels. Probability risks for recurrence with or without chemotherapy were tailored to the patient's underlying risk based on tumor size and histologic grade. The prototype Board measured approximately 26 inches wide by 20 inches high. It was large enough to permit the patient to read the display, but was not so large that it was cumbersome to store or carry. The Board was made of foam core because of its light weight and greater durability than cardboard.

The instrument was tested for validity and reliability in a group of healthy volunteers. The instrument was administered on two occasions by a skilled interviewer. On the first occasion, the instrument was administered using standard information. The patient was asked to state a preference. Validity was then assessed by changing the information provided in a predetermined way to determine whether the patient's preferences changed in a predictable manner. On the second visit, 3–4 weeks later, the instrument was re-administered with standard information only, and the patient was asked to state a preference.



**Figure 1** Schematic description of the decision board.

The instrument was finally evaluated by a group of 30 women with early breast cancer at the decision-making point, and was administered by a physician or nurse in the clinic. The Board was empty at the onset of the interview. The patient and clinician read each information card and attached it to the Board with Velcro. At the end of the discussion, all the information cards were on the Board. The patient was faced with an overall visual representation of her two options (in this case chemotherapy or no chemotherapy), the outcomes associated with this choice (recurrence or not), and the probability of these outcomes. The patient was encouraged to ask questions during the presentation and afterwards. Supplemental props including an introduction card were available, and the patient was given a take-home version of the Board following the presentation.

The results of the initial study were very encouraging. In tests with healthy volunteers, the instrument was shown to be reliable ( $K = 0.86$ ) and valid. Of the 30 volunteers tested, over 85% switched preferences in the predicted direction when information on the Board was altered. In the 30 patients with early breast cancer evaluated at the decision point, 29 reported that the instrument was easy to understand, 24 responded that it helped them think of questions, 26 reported that it helped with their decision, and 29 recommended that it should be used for other patients. Based on these positive findings, the Board has been evaluated in several other clinical contexts.

### Other Decision Boards

In the second study performed, a decision board was developed for physicians and their patients with chronic myeloid leukemia (CML) to decide between the therapeutic alternatives of bone marrow transplant and conservative management during the early phase of the disease.<sup>20</sup> Bone marrow transplantation is the only available potentially curative therapy for CML with a probability of long-term disease-free survival of 50–60%. The potential benefit, however, is accompanied by risk of early death due to

toxicity of therapy, as well as frequent and severe side-effects. The alternative option available to CML patients is conventional oral chemotherapy or Interferon, both of which are not associated with cure. An instrument was developed using the methodology previously described and was tested on 42 healthy hospital personnel. Subjects were randomized to receive information through the Decision Board alone or to a shorter abridged version followed by the Decision Board. The shorter version was developed to represent the more common clinical presentation of treatment options. The study demonstrated that the mean level of satisfaction with the subject's decision was higher for those exposed to the Decision Board than those exposed to the shorter version ( $P \geq 0.01$ ).

A third study compared the medical consultation with the Decision Board vs. the traditional medical consultation alone for patients with early breast cancer deciding on breast irradiation following lumpectomy.<sup>21</sup> Results of randomized trials had shown that breast irradiation post-lumpectomy substantially reduced the rate of local recurrence, but did not improve overall survival. A decision aid regarding the choice of breast irradiation postlumpectomy was developed using the approach described. The decision-making process was evaluated in a before-after design in 82 consecutive new patients seen in consultation by a radiation oncologist. The Decision Board was used in the last 30 patients in this cohort.

The study demonstrated that patient comprehension improved with the use of the Decision Board. However, in one instance regarding the lack of demonstrable survival benefit associated with breast irradiation, comprehension was not improved. The Decision Board facilitated the process of shared decision-making. Patients who used the Decision Board perceived that they were offered a treatment choice more frequently (97% with the Board vs. 70% without the Board,  $P = 0.02$ ). The instrument also appeared to empower patients in decision-making. Patients reported that when the Decision Board was used, their physician made specific treatment recommendations less

frequently and that such recommendations were less influential in patients' decision-making.

The Board itself was well accepted by physicians. It took, on average, 15 min to administer. The average time of the clinician–patient consultation with the board was not increased (36 min with the Board vs. 35 min without the Board,  $P \geq 0.5$ ).

Based on these rather positive initial studies, Decision Boards have now been developed in several other oncological situations including the choice of chemotherapy in advanced ovarian cancer,<sup>22</sup> and the choice of chemotherapy for node-positive breast cancer.<sup>23</sup> Decision Boards also have been developed for patients without cancer regarding the use of screening mammography<sup>24</sup> and hormone replacement therapy.<sup>25</sup>

### **A Decision Aid for community surgeons and their patients**

Previous instruments have been developed for use by patients and their physicians in tertiary care medical centres. Recently, we have been involved in developing an instrument for use by community surgeons and their patients regarding the choice of surgical treatment for breast cancer. Despite numerous randomized trials showing equivalent survival for mastectomy and breast conserving therapy (lumpectomy plus radiation therapy),<sup>26–29</sup> population studies continue to show wide geographic variation in the type of breast cancer surgery performed in North America and Europe.<sup>30–32</sup> These studies suggest that some of the observed variability is unlikely to be fully explained by disease or institutional factors. There remains concern that patients may not be fully informed regarding their treatment alternatives.<sup>33</sup> We developed an instrument to present information regarding the benefits and risks of breast conserving therapy (lumpectomy plus radiation therapy) and mastectomy to women with early breast cancer.<sup>34</sup> Surgeons from different communities in Ontario administered the instrument to newly diagnosed clinical stages I and II breast cancer patients over an 18-month period. Patients and surgeons were interviewed

regarding acceptability of the instrument, and the rates of breast conserving surgery performed by surgeons before and after the introduction of the instrument were compared.

The developed instrument was modified for use to make it more acceptable in the community. The instrument was slightly smaller in size than previous instruments. To improve ease of administration the Board had fixed panels of information, each panel was uncovered by a sliding door, and the panels were opened to reveal information in a sequential fashion. Each panel was read together by the patient and the surgeon. At the end of the presentation, all the panels were open, and the patient was faced with an overall view of her two options and the possible outcomes associated with each option.

The instrument was administered to 175 patients at the decision point. The majority of patients (86%) preferred to make the final decision or share the decision with the surgeon. Only 12% preferred that the doctor made the final decision. Interestingly, most patients (57%) made their decision during the consultation. A minority of patients made the decision a couple of days after the consultation (33%) or before the consultation itself (11%).

Ninety-eight per cent of patients reported the Decision Board was easy to understand, and 81% indicated that it helped them make a decision. Surgeons found the Decision Board equally acceptable, with over 90% reporting the instrument easy to use and helpful in presenting information to patients. When the rates of breast conserving surgery performed by surgeons were compared before and after the introduction of the instrument, the rate of breast conserving therapy decreased when the Decision Board was introduced (88% vs. 73%,  $P = 0.001$ ).

This study of community practice resulted in some key observations. It supported the impression that for breast cancer surgery, the majority of patients preferred an informed or shared decision-making process. The Decision Board was helpful both to patients and surgeons in the decision-making encounter. The study also suggested that the physician–patient consultation is an important time for decision-making

with the majority of patients making their decision during the interaction or within a couple of days. The data support the use of a decision aid at, or as close as possible to, the consultation. Finally, results suggest that in certain circumstances, the use of the Decision Board may affect a patient's choice. Such a situation could arise in a number of situations, for example, when patients are not clearly informed of different treatment options, when detailed information regarding treatment options and outcomes are not provided, or when patients are not encouraged to be actively involved in the decision-making process. Decision aids, by potentially affecting patients' preferences, may impact on the use of treatment resources, e.g. radiation therapy, as demonstrated in this study.

### Future studies

Despite several well-conducted studies, the Decision Board has yet to be compared to traditional practice in a randomized design. Two studies are currently in progress. One is a randomized comparison of the medical consultation plus the use of the Decision Board vs. the medical consultation alone regarding the decision of chemotherapy for women with node negative-breast cancer. The study is designed to evaluate several important outcomes including patient comprehension, patient satisfaction with information transfer, patient satisfaction with decision-making, anxiety, decisional conflict, and physician satisfaction with the decision-making process. In addition, another randomized trial evaluating the use of the Decision Board for the surgical treatment of breast cancer has just been initiated. Hopefully, these studies will better define the role of the Decision Board in clinical practice.

In addition, other important developments are ongoing. With increasing evidence supporting multiple treatment options for women with breast cancer, and the demands for detailed and individual cancer-specific information, there has been a perceived need for more versatility and flexibility in presentation of information.<sup>35,36</sup> Computers are increasingly used by health care

personnel and patients to organize and gain better access to information, and improve communication.<sup>37</sup> Computer-based versions of the Decision Boards are currently being developed. These instruments will capitalize on the ability to present technical information in alternative ways to suit patients' needs, to permit core information to be supplemented on an individual basis, with more in-depth information, and to improve the ability to communicate the meaning and implications of numerical data. The goal of computerizing the instrument is to maintain the Decision Board approach of direct clinician-patient interaction, ease of use and low cost, while utilizing the flexibility of the advanced technology. A more versatile decision aid will respond to the diverse needs of patients and physicians, and may facilitate its wider use throughout the medical community.

In summary, the Decision Board was developed to encourage direct two-way communication (in addition to information transfer) regarding alternative treatment options. It uses a low technology approach to present different treatment options and their associated benefits and risks. Earlier studies have been quite supportive of the Decision Board approach, but rigorous trials are now underway to evaluate its efficacy and effectiveness. Computer-based versions are also being developed to improve flexibility and versatility in the presentation and communication of information to patients. Up until now, the Decision Board has primarily been evaluated in the context of difficult treatment decisions in cancer patients. Further research is necessary to determine the role of the Decision Board compared to other approaches in different clinical contexts.

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