

# The development and preliminary evaluation of a decision aid based on decision analysis for two treatment conditions: Benign Prostatic Hyperplasia and Hypertension

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## Abstract

This paper discusses the development and evaluation of a computerised decision aid that provides individualised information about Benign Prostatic Hyperplasia (BPH) and Hypertension to patients. The program is based on decision analysis, using decision trees as a way of providing users with information regarding the probability of different outcomes occurring, obtaining an individual evaluation of the different outcomes, before providing guidance on what might be the ‘best’ option for that patient. It is intended that the program can be used as the basis for helping patients to become more involved in decisions about their medical treatment. Eight health care professionals and 19 patients (9 with BPH and 10 with Hypertension) evaluated the program. Overall it was assessed positively by both health care professionals and patients. However, before it can be integrated into health care practice, the program is to be evaluated further in a randomised trial.

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## 1. Introduction

There is an increasing focus on patient involvement in treatment decisions within much of Western medicine, mainly as a result of a rise in consumerism, the focus on patient centred care [1] and the influence of the evidence-based medicine movement [1,2]. The involvement of patients in the decision making process surrounding their health care is hypothesised to have a number of benefits. These include improving the quality of care patients receive [3,4], increased cost-effectiveness [4], increased adherence to eventual treatment choices, increased satisfaction with the intervention and increased appropriateness of interventions [5]. There seems to be a general consensus that providing patients with up to date research evidence, taking into account their values or preferences for different treatment choices, and involving them in the decision making process

is therefore ‘a good thing’. However, a number of barriers to implementing such actions in practice have been highlighted, such as limitations with the evidence available, and the attitudes of both doctors and patients [2].

One of the ways in which it has been suggested that patients could be provided with the information they need in order to become involved in decision making is through the use of decision aids [6–10]. Decision aids are deemed to aid shared decision making between health care professionals and patients, by ‘providing information of the options and outcomes relevant to their state of health’ [8]. It is suggested that decision aids go beyond providing information to patients, by also enabling patients to consider their own values or preferences for particular treatments or outcomes [9], before making decisions upon appropriate treatment. Two systematic reviews that have examined the effects of using decision aids on patient decisions have suggested that their use appears to increase knowledge about the condition and treatment, and in some cases have appeared to reduce decision conflict, increase satisfaction with the decision

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making process and produce more realistic expectations of the outcomes of treatment [9,10]. However, there is little evidence regarding what the most effective way of designing a decision aid may be [6].

One way of providing patients with evidence-based information about their condition and treatment, as well as taking their values or preferences into account, may be through the use of decision analysis [11]. Decision analysis is based on a rational choice theory of decision making which suggests that a rational decision maker will choose the plan of action that provides him/her with the greatest utility or value as an individual [12]. Decision analysis is usually expressed through the use of decision trees, where different options and possible outcomes are graphically displayed. The probability attached to certain outcomes occurring is attached to the tree, before a measure of utility or value is attached to each outcome. The probabilities and utilities are multiplied, then added together to give a measure of 'expected utility'. The branch with the highest number, and therefore the highest utility, is the option the decision maker should take [13].

Decision analysis, as an approach to evidence-based decision making has a number of advantages. These include being able to clarify complex decision situations, making the evidence that has been used to inform the decision explicit, and including a measure of patient preference or utility [12,14]. Criticisms of the approach include concerns surrounding using a numerical value as a measure of patient preference [15]. Different methods used to measure patient preference have led to variations in the utility or value obtained [16,17], which reinforce such concerns. Patient values may also vary over time, and with experience of different health states [18]. However, it is argued that having some measure of patient preference formally incorporated into a decision model is better than ignoring them completely [18].

Decision analysis has also been the basis of the development of decision aids for treatment decisions, such as whether or not to take warfarin for atrial fibrillation [19], and the type of surgery for women having a hysterectomy [5]. Although both these decision aids have used decision analysis as a theoretical basis, their main focus is to elicit patient preferences for different outcomes to inform a

decision analysis, which the professional then uses to discuss treatment options with the patient.

### 1.1. Benign Prostatic Hyperplasia and Hypertension

Decision aids are not considered to be suitable for all kinds of treatment decision. They are thought to be particularly useful for decisions that require trade-offs between short and long-term outcomes; where options have major differences in outcome or complications; where one choice can result in a small chance of a grave outcome or where there are marginal differences in outcome between choices, so that patient preferences are important [1]. Benign Prostatic Hyperplasia (BPH) and Hypertension are two very different medical conditions, that involve different types of treatment decision, but where the use of a decision aid may be effective (see Table 1).

BPH is a condition that can affect men as they grow older. In BPH the prostate gradually enlarges in size with ageing [20], which can cause a number of urinary symptoms that may vary in severity and that may impact to different degrees on a sufferer's quality of life. There are three possible treatments for BPH (watchful waiting, medication or surgery) all of which have varying degrees of success and different side effects. The benefits of surgical treatment, in the form of symptom improvement, may also be immediate. The optimum treatment option for BPH therefore depends on the man's preferences for particular courses of action [21].

In contrast, Hypertension is a condition where sufferers will probably not have symptoms, and where the benefits of treatment are not immediately observable, in that treatment is attempting to reduce an individual's risk of a future negative event (such as a heart attack or stroke). In this instance the individual may suffer from side effects from particular treatments, making them feel worse than they did before. Hypertension therefore is an example of a decision where patients are trading off between drug side effects, having to take a tablet and possible long-term benefits of therapy.

The Cochrane inventory of existing patient decision aids [22] has identified four existing decision aids for BPH, two

Table 1  
Characteristics of decisions for BPH and Hypertension

	BPH	Hypertension
Type of decision	Reversible if decide on drug therapy or watchful waiting; irreversible if decide on surgery	Reversible
Benefits	Watchful waiting—may be delayed improvement in symptoms; drug therapy—symptoms improve with minor delay; surgery—immediate improvement in urinary symptoms	Long-term reduction in risk of heart disease or stroke
Risks	Watchful waiting—gradual increase in severity of symptoms; drug therapy—immediate effect of side effects; surgery—immediate effect of surgical complications	Immediate effect of side effects from drug therapy; long-term risk of heart disease or stroke
Sex of sufferers	All male	Male and female
Age	Mostly $\geq 50$	Mostly $\geq 40$

of which have been evaluated [23–26] and one for Hypertension, which has also been evaluated [27]. The four aids for BPH vary in their delivery mechanism from Internet to the use of interactive videodisk technology, and also vary in their content. Of the three aids delivered via the Internet, one consists of a meta-analysis of the effectiveness of terazosin as a treatment for BPH, and provides the patient with a probability of their symptoms improving [23]. The other two aids provide information regarding different treatments for BPH with no form of individualisation to the patient [22]. The remaining aid consists of an interactive videodisk package, which uses patient details to individualise the information they receive. This particular aid has been evaluated in the USA, Canada and the UK [24–26]. The decision aid for Hypertension uses a decision analysis and separate utility assessment exercise to provide guidance to patients about drug treatment for their condition. At present no decision aid exists for either BPH or Hypertension which uses decision analysis as a way of providing individualised information to the patient, together with guidance on the best option for them, based on their preferences, as an integrated package.

This paper outlines the development and preliminary evaluation of a decision aid that uses decision analysis as a means of providing individualised information about these two medical conditions and their treatment to patients. The long-term aim of the study is to evaluate how useful this type of approach may be for patients who are involved in different types of treatment decision. The core computer program that is used to operate the decision trees is generic, so theoretically it could be adapted for any medical condition.

## 2. Stages of development of the decision aid

There were two main strands to the development of the decision aid, the development of the computer program that runs the aid, and the development of the content within the aid.

### 2.1. Construction of the decision trees

Comprehensive literature reviews were carried out to identify all the different options available for the treatment of BPH or Hypertension, together with the likely outcomes of treatment. For both conditions Medline was searched from 1995 to present, together with the Cochrane database of systematic reviews and the Cochrane controlled trials register. This search identified 225 research studies that were subsequently used to inform the BPH decision trees and 211 research studies that were used to inform the Hypertension trees. A summary of the evidence for each treatment, for each condition was constructed, that outlined the probability of outcomes occurring (where possible for sub-groups of the patient population). The decision trees constructed from these reviews are the basis of the decision aid.

Once the decision trees had been constructed, they were assessed for validity by a number of medical experts in the fields of BPH and Hypertension. In particular experts were asked to ensure that all appropriate treatment options had been included, and that the summary of evidence was comprehensive and accurate (to the best of their knowledge).

### 2.2. Development of the program and content

The interface and content of the computer program was assessed iteratively for ease of use with a group of 19 healthy volunteers, all of whom were over 50 years of age (to match with the age profile of the potential user group for BPH and Hypertension), with varying experience of using computers. On the basis of their feedback the computer interface was changed, and content altered. This iterative process continued until the program was assessed by healthy volunteers to be usable, with understandable content. A fuller discussion of the concepts used by the computer program has been reported elsewhere [28].

## 3. Characteristics of the decision aid

The decision aid has a number of characteristics that are common to both decision trees, but that are expressed in different ways according to the medical condition. For each decision tree, there is information regarding the medical condition, what different treatments consist of, a description of the possible outcomes, and the probability of the outcome occurring for that particular individual, expressed as a rating out of 100 (e.g. You have a 4 in 100 chance of developing heart disease). The program also contains a value elicitation exercise, that asks users to rate different treatment outcomes on a visual analogue scale, before providing them with guidance on what might be the best treatment option for them based on the probability and utility values provided during the program.

Each tree also enables information to be individualised to the user, with the user having the ability to decide how much or how little information they access, an assessment of the individual's own values for particular treatment outcomes, and the provision of a detailed record of information individualised to the user.

### 3.1. Individualisation to the user

The program is able to tailor the information that the patient sees to their individual characteristics. In the BPH decision tree the severity of the man's urinary symptoms is assessed using a standardised assessment tool, the American Urology Association (AUA) score [29]. This questionnaire asks a number of questions regarding common urinary symptoms associated with BPH, providing an overall score that relates to severity of symptoms (with a higher score relating to more severe symptoms). The information regarding

appropriate treatments for BPH that the man subsequently sees is related to the severity of score (for instance for a man classed as having ‘mild’ symptoms, surgery is not a recommended treatment option, so the tree will not show him this information).

In the Hypertension tree, the user’s risk of having coronary heart disease or a stroke over the next 10 years is assessed using the Framingham risk assessment equation [30]. The tree also allows for a detailed assessment of the user’s lifestyle habits that may contribute to Hypertension, which then tailors the information that users see regarding lifestyle changes in the next part of the program. Users are asked if they might be prepared to change particular aspects of their lifestyle that are potentially health damaging, and on the basis of their responses their individualised risk is reassessed and presented to them. The program also makes an assessment of medical conditions that need to be taken into account when medications are prescribed, tailoring information regarding appropriate treatments for Hypertension to their condition (for instance if they are asthmatic they would not see information about beta-blockers, as they are contra-indicated in individuals with asthma).

### 3.2. Users ability decide how much or how little information they access

The decision aid is completely interactive, with the decision tree structure shown on the bottom half of the computer screen, and relevant information for the particular branch where the user is located at the top of the screen. In this way the user of the program can navigate the tree in their own way, ignoring information regarding certain treatments if they wish to do so. The program also has the facility of a dictionary, so if there are any words or phrases the user does not understand, they can access the dictionary for more information. The person using the program can spend as much, or as little time as they like

looking at the information, and can ‘go back’ to look at information whenever they like.

### 3.3. Assessment of the individual’s own values for particular treatment outcomes

Once the user has finished looking at the information regarding different treatments appropriate for their condition, and possible outcomes, they then move on to the part of the program that asks them to evaluate how they feel about different treatment options. This evaluation of options is carried out using a simple visual analogue scale. On the right is a list of possible outcomes that may occur following treatment, and users are asked to drag and drop them onto a scale from 0 (worst possible outcome for them) to 100 (best possible outcome for them). This type of utility measurement has the benefit of reflecting user’s preferences for health outcomes, whilst being easy to use [31]. Once this evaluation has been carried out, the program calculates the decision tree and suggests the treatment option that might be most appropriate for the person using the program, based on their individual probabilities and utilities.

### 3.4. Provision of a detailed record of information individualised to the user

The program also provides a printed summary of information, which the user can individualise. A minimum amount of information reflecting the information the user has put into the program, together with a summary of their optimum decision path, is automatically printed, along with any dictionary items they have accessed. Throughout their use of the program, users can select (or deselect) information they find useful through a ‘bookmark’ facility. Any information they select in this way will also be printed out for them at the end of their user session, so that they can discuss the information with their health care professional(s) at subsequent consultations.

Table 2  
Evaluation comments from health care professionals

Category	Comments
Ease of use	“Patients would definitely need guided through the tree” [NS1]; “Easy to use” [NS2]
Content	“Not too confusing or ‘high tec’” [NS1]; “Too much information provided at times” [NS1]; “Provides good clear explanations” [NS2]; “Easy to understand but occasionally annoying at not being able to see whole picture at once” [GP1]; “Figures and percentages useful” [GP1]; “Thought the display tree part the best bit” [NS3]; “Perhaps too much user text” [GP2]; “Liked the information intensely. Very straightforward and in language that people understand. Not too complicated” [PN1]; “Found drug section confusing and boring” [PN2]
Usefulness	“Impressed with display of results and agreed with treatment outcome” [NS1]; “Happy with fact that patients will receive a print out” [NS1]; “Will give assistance to people to enable them to make their own decisions, with a lot of information provided” [NS1]; “There are some patients who would love it” [NS3]; “It will be very useful for health professionals to use with patients” [NS3]; “The print summary a good idea. Useful as a risk assessment tool” [GP2]; “Found it useful, patients would learn a great deal more than the literature gives them at present” [PN1]; “Liked the idea of research evidence which professionals could see” [Cons]; “Print out a good idea to allow patients to read later” [PN2]; “Very informative and educational tool for patients” [PN2]
Things to alter	“Program too long as it stands to be of any practical role” [GP2]; “A bit time consuming as it stands to use with patients in clinics but there could be ways round this” [PN1]; “Too lengthy” [Cons]

#### 4. Evaluation of the decision aid

The decision aid was evaluated using a convenience sample of patients who already had a diagnosis of BPH or Hypertension together with health care professionals. Health care professionals were identified through the local primary care research group network, and asked if they would be willing to participate. All patients volunteered after responding to posters requesting recruits that were placed in GP surgeries.

##### 4.1. Method of evaluation

Each participant in the evaluation was asked to work their way through the program, with a researcher on hand to

clarify any issues they may have. All users were asked a number of structured questions at the end of the user session. This asked them questions regarding ease of use of the program, the content of the program (whether there were items of information they did not understand), if they would find it useful as a tool to provide them with information, and whether there were things they would alter.

##### 4.2. Sample

The program was evaluated by 8 health care professionals; 3 specialist nurses, 2 practice nurses; 2 General Practitioners and 1 Consultant Urologist; and 19 patients, 9 with a diagnosis of BPH and 10 (7 male and 3 female) with a diagnosis of mild to moderate Hypertension. The mean age

Table 3  
Evaluation comments from patients

Category	Comments
Ease of use	<p><i>Easy to use:</i> “Comfortable and easy to use” [BPH4]; “No problems exploring the branches” [BPH6]; “Found the program easy to use” [BPH7]; “Easy to follow if you know how to move the mouse” [BPH9]; “Very nice to use, easy to use” [HYP1]; “Easy to use with guidance” [HYP5]; “Easy to use once she got into it” [HYP8]; “Very easy to use, just need to get used to navigating around it” [HYP10]</p> <p><i>Not easy to use:</i> “Would need assistance. Would need someone to assist you through it, especially for people like him who are afraid of ‘high tec’ equipment” [BPH1]; “Some people may find it difficult and need assistance” [BPH3]; “Too difficult unless you were computer oriented” [BPH5]; “Didn’t think could use the program if they hadn’t used a computer before” [HYP6]</p>
Content	<p><i>Understandable:</i> “Readable, as anything he didn’t understand the program explained it. Very straightforward and matter of fact language” [BPH1]; “Good information contained in the program, perhaps a bit frightening at times” [BPH2]; “Thought the appearance was good and the diagrams good as well” [BPH3]; “Easy to read and not too technical. Looked okay and did not find appearance a problem” [BPH4]; “Thought the dictionary was a good thing, especially for the longer words. Looks good” [BPH6]; “Text easy to read and layout good” [BPH7]; “Just enough text to take on board and not too technical for him personally” [BPH8]; “Text easy to read and language he understood. Diagrams self-explanatory” [BPH9]; “Language okay. Introduction and explanations really good. Easy to understand” [HYP1]; “Information common sense and easy to read” [HYP3]; “Understood it well. Liked the diagrams” [HYP 4]; “Easy to read and found introduction informative. Language understandable and not too medically oriented” [HYP5]; “Text readable and understandable” [HYP7]; “Text readable and not too medically oriented” [HYP8]; “Text not too difficult to read and tells you what you need to know” [HYP10]</p> <p><i>Not understandable:</i> “Too wordy and fewer explanations needed. Some text might worry patients by giving them too much information” [HYP2]; “Text too much and would be too difficult for most people to understand” [HYP9]</p>
Usefulness	<p><i>Useful:</i> “Liked the printed summary, thought this very useful to take to professionals for further discussion and for showing his wife as he can never remember to tell her what doctors have told him at the visit” [BPH3]; “Found it very useful. Thought it gave him a much better insight into prostate disease” [BPH4]; “Liked the information in the print summary although not entirely sure what he needed with the figures. Gave great insight into prostate problems and future re potential surgical options” [BPH6]; “The amount of information gained, percentages and information to help make decisions in the space of one hour was very impressive” [BPH7]; “Liked the printed summary. It has taken him 2 years to find this level of information. Showed other treatments not even mentioned or considered” [BPH8]; “Very informative” [BPH9]; “Very enlightening, results what expected and very truthful” [HYP1]; “Very useful place in information giving within health” [HYP2]; “Has a lot of potential to help people like himself who are newly diagnosed” [HYP3]; “Found it very useful. Helps people feel more involved with the doctor about their care when they know things about blood pressure and the different drugs they could have. Liked the idea of a print out so can look at it at her leisure” [HYP4]; “Would like it on computer at home, feels that it is very important for people to be involved in their care” [HYP5]; “A very useful tool to keep patients informed of their treatment and how it may effect them” [HYP6]; “Very informative for both patient and health professional” [HYP7]; “Very informative and raises awareness of all areas that are involved in high blood pressure. Liked the idea of a print out to read at her leisure” [HYP8]; “No problem with the length of time, would use this in a clinic setting” [HYP10]</p> <p><i>Not useful:</i> “Did not think it helped him personally because of his age but in the longer term it could have been important in terms of advice and planning” [BPH1]; “Tree would cause confusion and prefers to speak to his doctor without a third interference” [BPH5]; “Would not use it as it would be too time consuming and could read from a pamphlet basically the same amount of things” [HYP8]; “Layout of program too confusing for most people. People should choose how much information they wanted instead of us giving it all to them” [HYP9]</p>
Things to alter	<p>“Nothing negative to say about it, don’t think could make it any better” [BPH1]; “Negative about the length of time it took and some people will have forgotten the beginning text by the time they are half way through” [BPH6]; “Nothing negative to say. If it was on web pages would have had more time to play around with it” [HYP1]; “No negative comments” [HYP3]</p>

of BPH patients was 63.5 years (range 56–76 years) and Hypertension patients 61 years (range 48–77 years). Of these patients six said they were computer literate, five had basic computer skills and eight had never used a computer before.

#### 4.3. Analysis

Comments on the structured assessment form were categorised according to the ease of use of the aid, the content of the aid, its usefulness, and whether or not they would alter anything in the aid. The amount of time individuals spent using the program was also recorded.

### 5. Results

The average time that patients spent using the program was 49.4 min for the BPH decision aid and 54.6 min for the Hypertension decision aid. A summary of the comments received from the evaluation by health care professionals can be seen in Table 2, and by patients in Table 3. Overall the decision aid received positive evaluation, with the majority of users finding the content easy to understand, stating that they felt it was a useful way of receiving information. Of the 19 patients who used the aid 4 felt that it would not be something that they personally would use. The main negative finding was needing someone on hand to help individuals use the program. A number of the users found the results of the tree (in terms of an explicit recommendation about appropriate treatment) extremely useful.

### 6. Discussion and conclusion

The two decision aids that have been outlined here are based on the theoretical framework of decision analysis. From the preliminary evaluation it appears that this approach could be a useful way of providing individualised information to patients about their medical condition and treatment options, as well as taking into account their own values or preferences for different treatment options. However, there are a number of issues that need to be considered within a full evaluation of the aids.

Although, overall the results of the evaluation were positive, there were some individuals for whom this approach was clearly not something they would find useful or routinely use. Patients may vary in the amount of information they want to receive regarding their medical condition and treatment, may differ in the amount of involvement they want in the decision making process about treatment, and may have particular preferences regarding how they access and use information to inform their decision making [32]. In particular research has found that elderly patients are less inclined to want to participate in decisions about their treatment [33].

There are also limitations with decision analysis as an approach, which may affect how users of our decision aids understand the information they are given. Individuals vary in their attitude to risk [12], and also how they interpret risk information [34]. The way risk information is presented in the two decision aids discussed here is in the form of numbers, whereas other forms of presentation may aid certain individuals understand risk more clearly. There are also issues surrounding whether or not it is appropriate to ask individuals to attach numbers to outcomes as a form of utility, and methodological issues surrounding the measurement of utility [12,31], which also need to be taken into account when interpreting the outputs of a decision analysis.

#### 6.1. Conclusions

Decision aids based on the theoretical framework of decision analysis could be a useful approach to providing information to patients in order to promote shared decision making. However, further work needs to be carried out to assess whether or not there are specific groups of patients for whom the approach that is used within this decision aid is appropriate. This may be particularly relevant for elderly patients, who will be a major proportion of patients diagnosed with BPH and Hypertension, for whom these trees are designed.

#### 6.2. Practice implications

Because of the length of time that it takes to utilise the decision aid, it is not suitable for direct inclusion within formal health care consultations in primary care settings. Therefore, the main benefit of the aid is to provide patients with information (in printed form if they wish), that they can utilise in their own time, which can be used as the basis for discussion regarding treatments with health care professionals. The exact impact that this type of approach may have on 'shared decision making' consultations is therefore uncertain at present. The health care professionals who evaluated the program felt it was a useful and beneficial tool—however whether its outputs would be used in practice is again something that needs to be evaluated further.

Following the positive preliminary evaluation, the decision aids outlined here are currently being tested in a randomised controlled trial, addressing some of the issues that have been raised in the above discussion.

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