An introduction to patient decision aids

Patient decision aids are a means of helping people make informed choices about healthcare that take into account their personal values and preferences. Decision aids are a part of a shared decision making process, encouraging active participation by patients in healthcare decisions. Decision aids are relevant in many common healthcare decisions. They have been developed to make it easier for patients and healthcare professionals to discuss treatment options. Here, we give an overview of the rationale for the use of patient decision aids, what they contain, the evidence of their efficacy, and examples of their current and potential uses.

Decision aids in the context of shared decision making

Shared decision making is a process in which clinicians and patients work together to decide about interventions based on clinical evidence and the patient’s informed preferences. It involves the provision of evidence based information about options, benefits, risks, and uncertainties, together with decision support counselling and a system for recording and implementing patients’ informed preferences. There is evidence that patients want to take part in decision making. A recent systematic review of peer reviewed journal articles found that, in 63% of articles most patients expressed a wish to actively participate in decisions around their treatment. Also, the wish to participate appears to have increased over time. In studies published before 2000, only around 50% of articles found that most patients wished to be active partners in their treatment decisions, whereas from 2000, the percentage rose to 71%. This was especially clear for cancer patients, where most patients in 85% of the 27 studies published since 2000 wished to be involved in treatment decisions. However, patients’ preferences for involvement in decision making are variable and are affected by factors such as age, sex, and education.

Shared decision making is appropriate for many types of healthcare decisions, including whether to undergo screening or a diagnostic test, whether to undergo a medical or surgical procedure, whether to participate in a self management programme, whether to take medication, or whether to attempt a lifestyle change.

For patients to be able to play a part in the decision making process, they need clear, easy to understand information about the condition and the treatment or support options. A decision aid can be used to inform patients and help them think about the different options and to reach an informed preference.

What is a patient decision aid?

Decision aids are available in a variety of media (online, print, video). However, they share common aims:

- To inform people about the available options, from an evidence based perspective
- To encourage active engagement with the decision making process
- To help people think through what is important to them, so that they can make choices that reflect their own values and preferences.

An example for helping to decide between mastectomy or lumpectomy for early breast cancer can be found on the NHS Direct website (www.nhsdirect.nhs.uk/DecisionAids/PDAs/PDA_BreastCancer.aspx).

Most decision aids are being made available online, although some are only available as printed material. Ideally, patients need to work through the decision aid in their own time (although some are brief enough to use during the consultation). Patients may then wish to discuss use of the decision aid with the clinician, before finalising their decision.

What is in a decision aid?

At a minimum, a decision aid describes the decision to be taken, the options available, and the outcomes of these options (including benefits, harms, and uncertainties) based on a careful review of the evidence. Defining the decision involves framing it in a way that makes clear that this is a decision for the patient to make. Patients may not be aware that they have a choice but expect the clinician to tell them what treatment they “need.” Presentation of options can be done in a variety of formats. Tables that present all the options together, along with headline...
outcomes, have emerged as a popular format (see fig 1), more examples can be viewed at www.optiongrid.co.uk).

Explanation of risk is a key part of a decision aid, and work is ongoing as to how this can best be achieved, so as to present the information clearly and without bias. Use of visual aids such as “smiley faces” or “Cates plot” (see fig 2) is recommended (see www.mntonline.net).

Decision aids go beyond simple provision of information, seeking also to help people think about their own values. For example, in a decision aid for osteoarthritis of the hip, patients might be asked to consider the importance to them of returning to a high level of mobility, or of reducing pain to a minimum, compared with the importance they place on avoiding the risks of surgical complications, or a lengthy recovery from treatment. Patients are asked to explicitly address the “trade-offs” they need to make, accepting that treatments have risks as well as benefits. They can then make decisions based on an exploration of their own attitudes to risk, and to the importance they personally place on potential outcomes.

Evidence

Evidence supporting the use of decision aids is accumulating. A Cochrane systematic review of decision aids for screening or medical interventions concluded that when patients use decision aids they

- Improve their knowledge of the options
- Are helped to have more accurate expectations of possible benefits and harms
- Reach choices that are more consistent with their informed values
- Participate more in decision making.

The reviewers found 86 randomised controlled trials (involving a total of over 20,000 participants) covering 35 condition-specific decisions and comparing use of a decision aid to a variety of control interventions. Improved knowledge of the options and their likely outcomes led to more accurate risk perceptions, especially when the decision aid expressed probabilities in numbers.

Decision aids also reduced decisional conflict, reducing the numbers of people who felt they were unable to make a decision, either through feeling insufficiently informed or being unclear about their personal values. In line with this, patients were less likely to be passive in decision making after using a decision aid.

The evidence appears to show that people are more likely to choose more conservative treatment options. In studies focused on choices regarding more major elective surgery, people were 20% less likely to choose major invasive elective surgery, compared with usual care, after using a decision aid; likewise, in studies on prostate specific antigen (PSA) testing people were 15% less likely to choose the screening test. However, the results for these secondary outcomes should be treated with caution. This is because the research looked at an initial decision, and does not represent a long term assessment of decisions and cost. It is not unreasonable to assume that patients might choose a conservative route first, then opt for surgery at a later stage if the conservative option does not meet their needs. Until the results of long term research are available, we cannot assume that total healthcare resource use would be significantly different.

Development

A great many decision aid resources already exist. Pioneering work was done in this area by the Informed Medical Decisions Foundation (a US non-profit organisation, http://informedmedicaldecisions.org/), initially in the US but also in the UK. Subsequently, the International Patient Decision Aids Standards (IPDAS, http://ipd.as.ohri.ca/) organisation was established to propose standards for the development of these materials.

IPDAS produced a quality criteria framework in 2006. Agreed standards include the following requirements:

- A systematic development process
- The provision of information about options and probabilities
- Clarification of values
- Disclosure of conflicts of interest
- A balanced presentation of options
- Use of plain language
- Information based on current evidence.

A list of decision aids appraised against the IPDAS criteria is available on the IPDAS website (http://decisionaid.ohri.ca/AZinvent.php).

The NHS has commissioned the development of a suite of patient decision aids. Decision aids on the following topics are already available on the NHS Direct website (www.nhsdirect.nhs.uk/en/DecisionAids):

- Advanced kidney disease—planning for end of life care
- Benign prostatic hyperplasia
- Cataracts
- Localised prostate cancer
- PSA testing
- Chorionic villus sampling and amniocentesis
- Breast cancer
- Knee arthritis
- Osteoarthritis of the hip.

More decision aids, commissioned by NHS RightCare, are under development (www.rightcare.nhs.uk/index.php/shared-decision-making/).

A selection of decision aids relating to the use of medicines has been produced by the National Prescribing Centre (now known as the Medicines and Prescribing Centre, which is part of the National Institute for Health and Clinical Excellence).

Use and integration

Patients might have difficulty using decision aids if they have difficulty reading or have no access to, or ability to use, a computer, or if they do not understand English. Alternative formats and presentations need to be developed for these people.

An important issue for clinicians is the effect of using a decision aid on the length of the consultation. A Cochrane review showed a variable effect, ranging from reducing the consultation by 8 minutes to increasing it by 23 minutes compared with a standard consultation (median +2.5 minutes). However, the review did not distinguish between primary or secondary care consultations. There was also considerable heterogeneity depending on the clinical condition. Of course, the effect on consultation length will depend on when decision aids are used, where in the patient...
journey they are introduced, and whether they are used in the consultation or outside it. This will vary depending on the decision under consideration. For example, a decision about preferred treatment options for osteoarthritis of the hip is probably best undertaken before an appointment is made with an orthopaedic surgeon. In this situation, the decision aid could be offered after probable diagnosis, but before a secondary care referral is made. The referral, if required, would follow on from the patient’s expressed preferences.

Reported “facilitators” to implementing shared decision making are the motivation of health professionals and their perception that putting shared decision making into practice will lead to improved patient outcomes and improved healthcare processes. The use of decision aids as part of a shared decision making process will have implications for training of healthcare professionals. Embedding decision aids into clinical systems is likely to make them more accessible to clinicians. There are several initiatives to promote shared decision making in the NHS. They include

• The NHS RightCare Shared Decision Making project (www.rightcare.nhs.uk/index.php/shared-decision-making/)
• The Health Foundation’s MAGIC (www.health.org.uk/areas-of-work/programmes/shared-decision-making/) and Co-Creating Health programmes (www.health.org.uk/areas-of-work/programmes/co-creating-health/).

Conclusion

People increasingly want to be involved in making decisions about treatment choices. Patient decision aids help inform patients about the options available to them and involve them in the decision making process. They also help improve communication between clinicians and patients. A number of decision aids have been produced, and a quality criteria framework and set of standards have been developed for those involved in designing them. The NHS is developing a collection of patient decision aids as a resource for clinicians. However, it is probably not enough to make decision aids easily available. If they are to become part of routine clinical practice, they need to be embraced by the clinical community as well as by patients, established as part of the clinical workflow, and included in education, training, and development programmes for healthcare professionals.


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Figures

Fig 1 An example of an Option Grid (reproduced with permission)

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Lumpectomy with radiotherapy</th>
<th>Mastectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which surgery is best for long term survival?</td>
<td>There is no difference between surgery options</td>
<td>There is no difference between surgery options</td>
</tr>
<tr>
<td>What are the chances of cancer coming back in the breast?</td>
<td>Breast cancer will come back in the breast in about 10 in 100 women in the 10 years after a lumpectomy</td>
<td>Breast cancer will come back in the area of the scar in about 5 in 100 women in the 10 years after a mastectomy</td>
</tr>
<tr>
<td>What is removed?</td>
<td>The cancer lump is removed with a margin of tissue</td>
<td>The whole breast is removed</td>
</tr>
<tr>
<td>Will I need more than one operation on the breast?</td>
<td>Possibly, if cancer cells remain in the breast after the lumpectomy. This can occur in up to 5 in 100 women</td>
<td>No, unless you choose breast reconstruction</td>
</tr>
<tr>
<td>How long will it take to recover?</td>
<td>Most women are home 24 hours after surgery</td>
<td>Most women are home 2-3 days after surgery</td>
</tr>
<tr>
<td>Will I need radiotherapy?</td>
<td>Yes, for up to 6 weeks after surgery</td>
<td>Unlikely, radiotherapy is not routine after mastectomy</td>
</tr>
<tr>
<td>Will I need to have my lymph glands removed?</td>
<td>Some or all of the lymph glands in the axillae are usually removed</td>
<td>Some or all of the lymph glands in the axillae are usually removed</td>
</tr>
<tr>
<td>Will I need chemotherapy?</td>
<td>Yes, you may be offered chemotherapy as well, usually after surgery and before radiotherapy</td>
<td>Yes, you may be offered chemotherapy as well, usually after surgery and before radiotherapy</td>
</tr>
<tr>
<td>Will I lose my hair?</td>
<td>Hair loss is common after chemotherapy</td>
<td>Hair loss is common after chemotherapy</td>
</tr>
</tbody>
</table>

Fig 2 An example of a Cates plot illustrating the effect of antibiotic therapy for acute otitis media: out of 100 children with acute otitis media, 11 will suffer diarrhoea, vomiting, or a rash. If 100 children are given an antibiotic for the condition, an additional 8 children will suffer diarrhoea, vomiting, or a rash. The number needed to harm (NNH)=13 (CER=control event rate) (reproduced with permission)