

# Shared decision making: what do clinicians need to know and why should they bother?

## Tammy C Hoffmann

PhD, BOCcThy(Hons)  
Associate Professor of  
Clinical Epidemiology,<sup>1</sup> and  
NHMRC Research Fellow<sup>2</sup>

## France Légaré

MD, PhD, FCFP  
Canada Research Chair in  
Implementation of  
Shared Decision Making in  
Primary Care<sup>3</sup>

## Magenta B Simmons

PhD  
Research Fellow<sup>4</sup>

## Kevin McNamara

PhD, MSc, BSc  
Research Fellow,<sup>5</sup>  
and Adjunct Lecturer<sup>6</sup>

## Kirsten McCaffery

PhD, BSc(Hons)  
Principal Research Fellow<sup>7</sup>

## Lyndal J Trevena

MBBS(Hons), MPhilPH, PhD  
Associate Professor<sup>7</sup>

## Ben Hudson

MBBS, MRCP, FRNZCGP  
Senior Lecturer<sup>8</sup>

## Paul P Glasziou

MBBS, PhD  
Professor<sup>1</sup>

## Christopher B Del Mar

MD, FRACGP  
Professor of Public Health<sup>1</sup>

<sup>1</sup> Centre for Research in  
Evidence-Based Practice,  
Bond University,  
Gold Coast, QLD.

<sup>2</sup> School of Health and  
Rehabilitation Sciences,  
University of Queensland,  
Brisbane, QLD.

<sup>3</sup> Centre Hospitalier  
Universitaire de Québec,  
Québec, Canada.

<sup>4</sup> Orygen Youth Health  
Research Centre,  
Melbourne, VIC.

<sup>5</sup> Greater Green Triangle  
University Department of  
Rural Health,  
Flinders University and  
Deakin University,  
Warrnambool, VIC.

<sup>6</sup> Centre for Medicine Use and  
Safety, Monash University,  
Melbourne, VIC.

<sup>7</sup> School of Public Health,  
University of Sydney,  
Sydney, NSW.

<sup>8</sup> Department of Public  
Health and General Practice,  
University of Otago,  
Christchurch, New Zealand.

thoffmann@  
bond.edu.au

Lucille is a 2.5-year-old who has had a cold for 3 days. Last night, it became worse — Lucille was restless and had a fever. Her mother was up with her for much of the night, and she settled eventually with paracetamol. The mother and Lucille come to see you today and both look exhausted. The only positive findings on clinical examination are a congested nose and bulging red left ear drum. You diagnose acute otitis media. “OK”, you say, “Lucille has a middle ear infection”. Her mother asks, “What can be done to help her?” ◆

Shared decision making is a consultation process where a clinician and patient jointly participate in making a health decision, having discussed the options and their benefits and harms, and having considered the patient’s values, preferences and circumstances. Shared decision making is not a single step to be added into a consultation, but can provide a framework for communicating with patients about health care choices to help improve conversation quality. It is a process that can be used to guide decisions about screening, tests and treatments. It can also be thought of as a mechanism for applying evidence with an individual patient through personalising the clinical decision. Although, to date, most research about shared decision making has focused on medical practitioners, it is relevant to clinicians of all disciplines, including nursing and allied health.<sup>1</sup>

Shared decision making can be viewed as a continuum,<sup>2</sup> along which the extent to which a patient or a clinician takes responsibility for the decision-making processes varies. At the extremes are clinician-led decisions and patient-led decisions, with many other possible approaches in between.<sup>2,3</sup> The extent of involvement will vary between individuals and between consultations, and according to the patient’s preferences and the context in which the decision is occurring. Regardless of whether the patient or clinician takes the lead in the decision-making process, joint discussion should occur.

## How can shared decision making help?

Internationally, shared decision making is seen as a hallmark of good clinical practice, an ethical imperative,<sup>4</sup> and as a way of enhancing patient engagement and activation. Increasingly, it is being advocated for in clinical guidelines and health care policies.<sup>5-7</sup> While shared decision making is applicable to most situations, it is especially important in certain circumstances; for example, where the evidence does not strongly support a single clearly superior option (most clinical decisions) or where a preference-sensitive decision is involved. That is, when there is uncertainty as to which option is superior, each option has different inherent benefits and harms, or the decision is likely to be strongly influenced by patients’ preferences and values.<sup>8,9</sup>

## Summary

- Shared decision making enables a clinician and patient to participate jointly in making a health decision, having discussed the options and their benefits and harms, and having considered the patient’s values, preferences and circumstances. It is not a single step to be added into a consultation, but a process that can be used to guide decisions about screening, investigations and treatments.
- The benefits of shared decision making include enabling evidence and patients’ preferences to be incorporated into a consultation; improving patient knowledge, risk perception accuracy and patient–clinician communication; and reducing decisional conflict, feeling uninformed and inappropriate use of tests and treatments.
- Various approaches can be used to guide clinicians through the process. We elaborate on five simple questions that can be used: What will happen if the patient waits and watches? What are the test or treatment options? What are the benefits and harms of each option? How do the benefits and harms weigh up for the patient? Does the patient have enough information to make a choice?
- Although shared decision making can occur without tools, various types of decision support tools now exist to facilitate it.
- Misconceptions about shared decision making are hampering its implementation. We address the barriers, as perceived by clinicians.
- Despite numerous international initiatives to advance shared decision making, very little has occurred in Australia. Consequently, we are lagging behind many other countries and should act urgently.

The relationship between shared decision making and evidence-based practice is becoming increasingly recognised. Shared decision making provides a process for bringing evidence into the consultation and incorporating it into discussions with the patient, along with discussion about the patient’s values and preferences. In other words, it is an important, if under-recognised, component to evidence translation, a route by which evidence is incorporated into clinical practice. Shared decision making may also help reduce the unwarranted variation in care<sup>10</sup> that may partially arise from clinicians’ opinions dominating decision making, with insufficient consideration of both empirical evidence and patients’ preferences.<sup>11</sup>

Patients and clinicians typically overestimate the benefits of interventions and underestimate their harms.<sup>12-14</sup> Shared decision making can provide the opportunity for resolving this mismatch between clinician and patient expectations and the demonstrated benefits and harms of screening, tests and interventions. Consequently, shared decision making may reduce the inappropriate use of tests and treatments,<sup>15</sup> such as those that are not beneficial for the majority or are

1 An example of one approach to shared decision making

Five questions that clinicians can use to guide shared decision making <sup>16</sup>	Example phrases (for the opening clinical scenario of a child with acute otitis media)	Comments
1. What will happen if we wait and watch?	“In children, most middle ear infections get better by themselves, usually within a week. The best options to control pain and fever are paracetamol or ibuprofen.”	Quantitative information can be provided where possible, either at this step or in step 3 where each option is described. When this is not possible, descriptive information can be provided (eg, “most people find that the symptoms go away by ...”). Eliciting patient’s expectations about management of the condition (eg, “what have you heard or do know about ...?”), including previously tested approaches and experiences, along with fears and concerns, is important and may occur here or later in the process.
2. What are your test or treatment options?	“Waiting for it to get better by itself is one option. Another option is to take antibiotics. Do you want to discuss that option?”	For some decisions (such as in this example), the options may be familiar to patients and need little elaboration at this step. In others, a more detailed explanation of each option and its practicalities, including options which are time-urgent, will be required.
3. What are the benefits and harms of these options?	“We know from good research that of 100 children with middle ear infection who <i>do not</i> take antibiotics, 82 will feel better and have no pain after 2–3 days. Out of 100 children who <i>do</i> take antibiotics, 87 will feel better after about 3 days of taking them. So, about five more will get better a little faster. We can’t know whether your child will be one of the five children who benefit or not.” (A graphic representation of these numbers can also be shown at this point, and again after the harms information is discussed [Box 2].) “There are some downsides to antibiotics though. Out of 100 children who <i>do</i> take antibiotics, 20 will experience vomiting, diarrhoea or rash, compared with 15 who <i>do not</i> take them. That means about five children out of 100 will have side effects from antibiotics. But again, we can’t know whether your child will have any of these problems. The other possible downside is antibiotic resistance — would you like to hear more about it?” (The option of delayed prescribing could also be discussed here. Numbers used in this scenario are from Venekamp et al. <sup>17</sup> )	In addition to descriptively discussing the benefits and harms of each option, the probability of each occurring, where this is known, should be provided. For dichotomous outcomes (eg, having a myocardial infarction), this should be in the form of natural frequencies (ie, the number out of 100 or 1000 people who experience the event) rather than relative risk. For continuous outcomes (eg, number of days of pain, and level of anxiety as reported on an anxiety measure), this may be expressed by the estimated size of the effect (eg, the average reduction in 20 points on anxiety on a tool that measured it as a score from 0 to 100). Decision support tools, if available, can be useful at this stage. Simple visual graphics can be particularly useful in helping to communicate the numbers. Principles of effectively communicating statistical information to patients should be followed, such as using natural frequencies (ie, x out of 100), being aware of framing effects, and using multiple formats. <sup>18</sup> The discussion of harms should extend beyond the risk of side effects and include other impacts that the option could have on the patient, such as cost, inconvenience and interference with daily roles, and reduced quality of life.
4. How do the benefits and harms weigh up for you?	“With all I’ve said, which option do you feel most comfortable with?”	This step includes eliciting patients’ preferences and working with them to clarify how each option may fit with their values, preferences, beliefs and goals. Some decision aids include formal value clarification exercises that may be used to supplement the conversation and/or enable the patient to reflect further following the consultation. Clarifying the patient’s understanding of what has been discussed so far, using the teach-back method, can help to identify if any information needs to be repeated or explained in another way.
5. Do you have enough information to make a choice?	“Is there any more you want to know? Do you feel you have enough information to make a choice?”	This provides another opportunity to ask if the patient has additional questions. Patients may feel ready to make a decision at this stage or it may be jointly decided to defer the decision and plan when it should be revisited. The patient may wish to seek further information before deciding, discuss with family, or take time to process and reflect on the information received.

associated with substantial risks or harms. As such, it can play a role in reducing the problem of overdiagnosis and overtreatment. Patients tend to choose more conservative options than their clinicians when fully informed about the benefits and harms.<sup>15</sup>

Most evidence about the effectiveness of shared decision making comes from trials of decision aids, where most research has been conducted to date. Decision aids have demonstrated effectiveness for increasing knowledge and risk-perception accuracy; improving patient–clinician communication; and reducing decisional conflict, feeling uninformed, passivity in decision making, and indecision about the choices made.<sup>15</sup>

### The process of shared decision making

A common misperception is that shared decision making is synonymous with the use of decision aids. However, the core of shared decision making is a process, which might additionally use decision support tools but is not dependent on them. This process varies according to numerous factors related to the patient, clinician and other circumstances. One set of questions that can be used to

guide the process is shown in Box 1. Originally phrased for use by patients,<sup>16</sup> we have amended the wording to the clinicians’ perspective.

As many patients are unfamiliar with being invited to share in decision making, it may help to briefly explain the process. Outlining that they have some choices that you would like to go through with them before deciding together about the next step may reassure patients who might otherwise feel overwhelmed, uncertain or even abandoned. If the problem or diagnosis is clear, and a decision about the next step is necessary, the next step involves describing the nature of the problem or condition (question 1, Box 1). This should usually include providing information about the natural history of the condition — that is, what is likely to happen without any intervention (“watch and wait”). Eliciting the patient’s expectations about management of the condition, including previously tried approaches and experiences, along with fears and concerns, is important and allows for discussion and correction of misperceptions where necessary (either at this stage or later in the process). The second question triggers a discussion of the options and identification of those that the patient would like to hear more about (Box 1). The third





## 3 Examples of types of decision support tools to facilitate shared decision making

Type of tool	Brief description	Examples
<b>Condition-specific</b>		
Decision aids	Describe the options, and the benefits and harms of each option, along with a values clarification exercise and sometimes a guide to decision making. The International Patient Decision Aid Standards Collaboration ( <a href="http://www.ipdas.ohri.ca">http://www.ipdas.ohri.ca</a> ) provides information about assessing the quality of decision aids	Ottawa Hospital Research Institute A to Z Inventory of Decision Aids: <a href="http://decisionaid.ohri.ca/AZinvent.php">http://decisionaid.ohri.ca/AZinvent.php</a>
Decision or fact boxes	A short summary of the benefits and harms of an intervention, often presented in two columns	Dartmouth Medicine drug facts box: <a href="http://dartmed.dartmouth.edu/spring08/html/disc_drugs_we.php">http://dartmed.dartmouth.edu/spring08/html/disc_drugs_we.php</a> ; University of Laval decision box: <a href="http://www.decisionbox.ulaval.ca/index.php?id=810&amp;L=2">http://www.decisionbox.ulaval.ca/index.php?id=810&amp;L=2</a>
Option grids	A one-page summary of the evidence for the possible options, addressing patient-centred outcomes, and questions and concerns frequently raised by patients; can be useful within the consultation for a patient to highlight what is important to them	Option Grid Collaborative: <a href="http://www.optiongrid.org">http://www.optiongrid.org</a>
Question prompt lists	A predefined list of condition-specific questions for patients to consider using in a consultation	Cancer Institute NSW: <a href="http://www.cancerinstitute.org.au/patient-support/what-i-need-to-ask">http://www.cancerinstitute.org.au/patient-support/what-i-need-to-ask</a>
Evidence summaries	Clinical practice guidelines and other summaries of the body of evidence	<i>Clinical Evidence</i> : <a href="http://www.clinicalevidence.bmj.com">http://www.clinicalevidence.bmj.com</a> ; UpToDate: <a href="http://www.uptodate.com">http://www.uptodate.com</a>
<b>Generic</b>		
Communication frameworks	A generic set of questions or scripts and a structure for clinicians and patients to use during decision making	Ask Share Know: <a href="http://www.askshareknow.com.au">http://www.askshareknow.com.au</a> ; Ottawa Personal Decision Guide: <a href="http://decisionaid.ohri.ca/decguide.html">http://decisionaid.ohri.ca/decguide.html</a>

poor health literacy) is important but presents additional challenges, and there is less research to guide implementation in these areas.<sup>36</sup>

Australia is drastically lagging behind many other countries in all aspects of shared decision making — policies, lobbying, advocacy, research funding, training, resources and implementation.<sup>41,42</sup> In the absence of a coordinated national effort, we encourage individual clinicians to begin incorporating shared decision making into their consultations with patients when a health decision is needed. Australia's health training and delivery organisations need urgently to begin prioritising and planning to make shared decision making a reality in Australia.

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## 4 Misconceptions about shared decision making and key research findings that refute them

Misconception	Research findings
<b>The duration of the consultation will be lengthened</b> This concern is the most frequently reported barrier to shared decision making. Indeed, time constraint is the most frequently reported barrier to any clinical change. <sup>25</sup>	Three systematic reviews (on interventions to implement shared decision making, and impact of decision aids on processes of care and patient outcomes) indicate that there is no systematic increase in consultation duration when shared decision making is implemented or decision aids are used. <sup>15,26,27</sup>
<b>Patients will be unsupported when making health care decisions</b> There is a fear that shared decision making will make patients feel abandoned during difficult decisions.	This is a misinterpretation of the intent of shared decision making. The definition of shared decision making explicitly describes patients and their clinicians sharing the decision together. <sup>3</sup> Shared decision making is not about insisting that every patient make the decision (not all patients wish to); rather it helps to ensure that patients are informed about their options and are offered the opportunity to participate in the process.
<b>Not every patient wants to share in the decision-making process with their clinician</b> Critics of shared decision making argue that not every patient wants to be involved in making decisions with their clinician.	An Australian survey reported that > 90% of women preferred a shared role with their doctor in making decisions about screening and diagnostic tests. <sup>28</sup> A European survey of > 8000 people reported a high desire for shared health decision making (> 70% of the sample). <sup>29</sup> A systematic review of 14 studies that examined the match between patient preferences about information and decision making with clinician–patient communication found that a substantial number of patients (26%–95%; median, 52%) were dissatisfied with the information given and would have preferred a more active role in decisions concerning their health, especially when they understood the expectations attached to this role. <sup>30</sup> A time trend in desired involvement in decision making has also been reported. Of the studies conducted in 2000 and later, 71% reported that most respondents preferred a role in sharing decisions, compared to 50% of studies that were conducted before 2000. <sup>31</sup>
<b>Most people are not able to participate in shared decision making</b> Critics of shared decision making question its complexity, believing most people will not be able to manage it.	Shared decision making is comprised of a set of behaviours on the part of the clinician and the patient that can be learnt. <sup>32,33</sup> An increasing number of studies have demonstrated that shared decision making can be implemented successfully in clinical practice. <sup>27,34</sup>
<b>Shared decision making cannot be used with vulnerable people</b> Shared decision making requires a special set of skills that may be too complex for all patients to acquire, and vulnerable people may not ever be able to share decisions with their clinicians.	Most surveys of patients' willingness to engage in shared decision making show that the most vulnerable people are less willing to participate. <sup>30</sup> Therefore, we need to be careful not to increase health inequities by offering shared decision making solely to the most privileged patients. Individuals with low health literacy want to be involved in health decisions but often lack the knowledge, skills and confidence to communicate with clinicians, navigate the health system and engage in shared decision making. <sup>35</sup> They receive less information, ask fewer questions and are less satisfied with health care provider communication. <sup>36</sup> More vulnerable patients may be less likely to engage in shared decision making because of lower self-efficacy — a modifiable factor to increase their willingness to do so. <sup>34</sup> Indeed, in order to decrease health inequities, more needs to be done to engage the most vulnerable patients to make informed decisions. <sup>36,37</sup>
<b>"I already do this"</b> Most clinicians feel that they already successfully engage their patients in shared decision making — a belief that may arise from not really understanding what it is and how to do it.	A systematic review of 33 studies that assessed shared decision making using the OPTION (Observing Patient Involvement in Decision Making) scale found low levels of patient-involving behaviours. In studies where no intervention was used to facilitate shared decision making, the mean OPTION score was 23±14 (0–100 scale, where higher scores indicate higher levels of patient involvement in decision making). <sup>21</sup> Lack of familiarity with shared decision making by clinicians has been found to be a barrier to shared decision making in a number of studies. <sup>38</sup>
<b>Engaging patients in shared decision making will raise their anxiety level</b> Some clinicians are afraid that shared decision making will raise patients' anxiety levels as they become aware of the inherent uncertainty of evidence.	A Cochrane review of decision aids refutes this misconception, finding no effect on anxiety. <sup>15</sup> Anxiety should not be confused with decisional conflict, an intrapsychological construct that reflects the difficulty that individuals can experience when comparing the pros and cons of different options. <sup>39</sup>

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