Shared Decision-Making in Health Care
Achieving evidence-based patient choice

SECOND EDITION

Edited by

Adrian Edwards
School of Medicine
Cardiff University, UK

Glyn Elwyn
School of Medicine
Cardiff University, UK

OXFORD
UNIVERSITY PRESS

OXFORD
UNIVERSITY PRESS
Great Clarendon Street, Oxford OX2 6DP

Oxford University Press is a department of the University of Oxford.
It furthers the University's objective of excellence in research, scholarship,
and education by publishing worldwide in

Oxford New York

Auckland Cape Town Dar es Salaam Hong Kong Karachi
Kuala Lumpur Madrid Melbourne Mexico City Nairobi
New Delhi Shanghai Taipei Toronto

With offices in

Argentina Austria Brazil Chile Czech Republic France Greece
Guatemala Hungary Italy Japan Poland Portugal Singapore
South Korea Switzerland Thailand Turkey Ukraine Vietnam

Oxford is a registered trade mark of Oxford University Press
in the UK and in certain other countries

Published in the United States
by Oxford University Press Inc., New York

First edition published as Evidence-based patient choice: inevitable
or impossible by Oxford University Press, 2001

This edition published by Oxford University Press 2009

British Library Cataloguing in Publication Data

Data available

Library of Congress Cataloging in Publication Data

Data available

Typeset in Minion by Cepha Imaging Private Ltd., Bangalore, India
Printed in Great Britain
on acid-free paper by
Ashford Colour Press Ltd., Gosport, Hampshire, UK

ISBN 978–0–19–954627–5 (pbk)

10 9 8 7 6 5 4 3 2 1

Foreword

Practice variation, shared decision-making, and health care policy

The challenge to the research community is to provide the intellectual basis for a transition from a healthcare economy where healthcare utilization is based on physician's opinion to an economy where the demand is based on informed patient choice. The publication of the second edition of '*Shared Decision-Making in Health Care: Achieving Evidence-based Patient Choice*' signals the emergence of an international community of social scientists, epidemiologists, and clinical science dedicated to advancing the field. It summarizes the current state of knowledge and lays out the research challenges yet to be met. Its editors and contributors are to be congratulated for consolidating in one volume the essential features of this emerging science of informed patient choice.

The policy imperative behind the transition to informed patient's choice is found in the practice variation phenomenon. Largely out of concern over costs, policy makers are increasingly concerned over the striking geographic variation in the incidence of elective surgery and other preference-sensitive treatments. The variation is judged to be unwarranted because it cannot be explained on the basis of illness, medical evidence, or patient preference. One important reason for unwarranted variation is the weakness in clinical science. In the absence of the constraints that sound clinical science place on clinical ideas, professional opinions on the value of the treatments they prescribe are necessarily subjective, with inferences made from personal experience and anecdote or on the basis on an untested clinical theory that might or might not prove true, were it subjected to clinical investigation.

Another important reason for unwarranted variation resides in flaws in the clinical decision-making—in the willingness to delegate decision-making to physicians under the assumption that they can accurately diagnose the treatment preferences of their patients. The evidence from practice variation research challenges this assumption. Even physicians who base their decision to operate on up to date "evidence-based" guidelines risk committing a serious medical error: they risk operating on the wrong patient—on a patient who if adequately informed would not want the procedure they provide.

Reducing unwarranted variation in preference–sensitive care and establishing the 'right rate' for discretionary surgery and other preference-sensitive interventions require fundamental changes in the doctor–patient relationship and the standards governing the determination of medical necessity: delegated decision-making should be replaced by shared decision-making; and the doctrine of informed patient consent superceded by informed patient choice.

The challenge to policy makers is to promote the transition from delegated decision-making to informed patient choice: to support improvements in clinical science to assure evidence-based patient choice; and encourage practicing physicians and their patients to adopt shared decision-making as a principle strategy for avoiding the risk of operating on the wrong patient and ensuring that the utilization of preference-sensitive care is based on the decisions of informed patient.

The implications seem clear. More effort is needed to develop models for implementing shared decision-making into everyday practice and measuring the quality of patient decision-making. Policy makers need to undertake experiments in reimbursement reform that support the necessary infrastructure and reward clinicians who successfully implement shared decision-making.

Chapter 20

Measuring 'decision quality': Irresolvable difficulties and an alternative proposal

Glyn Elwyn, Benjamin Elwyn, and Talya Miron-Shatz

Introduction

Although the task of involving patients in decision-making tasks has become the focus of increasing attention over the last decade, there is also a realization that we struggle to measure what would constitute success in this area. Important questions remain, such as what constitutes a good decision or a high-quality decision and how to measure decision quality. We recognize that definitions of decision quality and other similar terms have been put forward. In this paper, it is our intention to examine these definitions, to highlight the ways in which they converge, and to explain why we have some concerns about their emphasis on post hoc evaluations. We proceed to offer an alternative, which parses 'decisions' into a pre-decisional *process* and a post-decisional *outcome*.

The emphasis on involvement in decisions comes about partly because of the realization that in many medical scenarios evidence for the effectiveness of interventions is scarce and partly because the patients' contribution – their views and preferences – is being given a central place in clinical encounters (Schneider, 1998). This marks a definite shift away from paternalism to a process where patients are offered support to become actively engaged in decision-making tasks (Elwyn *et al.*, 1999). Efforts are therefore being made to involve patients in decision-making steps and research into this topic has expanded significantly over the last decade, with terms such as 'shared decision-making' (Charles *et al.*, 1997), 'evidence-based patient choice' (Hope, 1996), and 'informed choice' (Raffle, 2001) becoming common parlance.

The main approaches made to improve the quality of decision-making in health care to date have been as follows. Firstly, there has been an interest in developing the skills of practitioners to involve patients in decisions – a process often known as shared decision-making – with the aim of increasing the role patients play and ultimately – although arguably implicitly – to improve decision quality. Secondly, decision support technologies (decision aids) (O'Connor *et al.*, 2007) – information resources that are also designed to help patients take part in health care decisions – are being introduced as additional tools to assist this process of enhancing engagement in decision-making and enhance decision quality. Both approaches suggest that the patient becomes actively engaged in deciding a course of rather than the professional acting alone. We start by examining different approaches to the assessment of decisions and continue to pose the question of whether decisions can be attributed as having high or low quality and how this can be measured. Finally, we offer an alternative, perhaps the more modest approach, focusing on the quality of the decision process, rather on the end result.

We feel that this examination is necessary because in addition to the move away from paternalism to a patient-centred choice model (Coulter, 1999; Elwyn *et al.*, 2003), evidence-based medicine has emphasized the need to integrate empirical research data into clinical practice. However, paradoxically, this emphasis has drawn attention to the considerable uncertainty that surrounds most medical interventions and to the fact that a single correct course of action can seldom be advocated. Therefore, there is recognition that patient preferences should be given central voice in decision-making processes. Given the prominence and importance of this trend to involve patients in decision-making and the lack of consensus over metrics, we are motivated to add to the debate on what would constitute a high-quality decision. A better answer would help make progress in designing and evaluating decision support and doctor–patient communication strategies, as well as improve decisions and decision-making processes (Ratliff *et al.*, 1999). We start by considering a range of definitions. Below we offer our perspective on some converging aspects of these definitions and propose a modest alternative which leaves the decision outcome outside the evaluation picture and which places emphasis on the quality of deliberative processes, which *de facto* have to be founded on the acquisition of knowledge and the construction of preferences.

Existing definitions of *decision quality*

The conceptual question 'what is a good decision' was considered by a number of experts in a series of short essays (Ratliff *et al.*, 1999), although they did not offer formal definitions and did not offer suggestions as to how to measure 'good decisions'. A notable consistency in most essays was the view that although assessing decision quality was complex, it was important to avoid dependence on the outcomes of decisions. Good (or bad) decisions have good or bad outcomes by virtue of chance, at the individual level. For instance, Fisher and Fisher (Ratliff *et al.*, 1999) place emphasis on both how the decision is achieved and how satisfied the relevant parties are with the decision. Interestingly, they conclude by stating that 'because a good or bad outcome may powerfully influence perceptions (of decision quality) . . . such a judgement is best made before the outcome is known' (page 190). As the relevant parties cannot possess *a priori* certain knowledge of the outcome, we embrace the need for pre-outcome judgement of a decision. However, we note that recent definitions, as will be shown below, do not fully attend to the difficulty of post hoc judgements.

Ratliff (Ratliff *et al.*, 1999) argues a definite need for *knowledge* – that the person is informed – and that decisions reflect an individual's *preferences*. Her views are picked up by more recent work, which reflects, almost a decade later, increasing interest in definitions and the design of measurement tools for decision quality, although these remain contentious. For instance, Sepucha *et al.* (2007) proposed that '. . . the quality of a preference-sensitive clinical decision can be defined as the extent to which the implemented decision reflects the considered preferences of a well-informed patient.' p. 262. In a similar vein, O'Connor proposed that 'decision quality can be measured by. . . knowledge about the options and outcomes, realistic perceptions of outcome probabilities, and agreement between patients' values and choices.' p. 3 (O'Connor *et al.*, 2003). Marteau, adding to O'Connor, proposes a slight variant with the construct of 'informed choice': 'an informed choice is one that is based on relevant knowledge, consistent with a decision-maker's values and behaviourally implemented' (Marteau *et al.*, 2001). Inherent in her definition, however, is that the enacted choice (the decision effectively) is one based on adequate knowledge and is consistent with the individual's views, values, or preferences.

Critique of existing definitions of decision quality

In this section, we offer a criticism of prevailing definitions of decision quality regarding three elements: the knowledge they propose to measure, the preferences they propose to use as a yardstick of 'true' will, and the timing in which they propose to evaluate the decision. Almost all attempts at defining good decisions propose that knowledge about the options and consequences is necessary. Putting aside for the moment those who propose that intuition trumps knowledge-based deliberative work (Dijksterhuis *et al.*, 2006), we need to acknowledge that the assessment of this construct is problematic – knowledge about *what* for instance? About the nature of outcomes plus the probabilities of those outcomes? About the *features* (attributes) of short-, medium-, and long-term future states, given likely pathways? About the experiences of others who have chosen different options? Can we specify the optimal degree of search for information (as a proxy for knowledge) or when to stop the search? Can we specify the degree of knowledge that is necessary and sufficient (as well as different for every clinical scenario), or is this a quantity that we allow the decision maker to determine? Do we assume that knowledge (informedness) equates to understanding or does this not worry us? Efforts so far to operationalize the knowledge component of 'decision quality' scales have proposed key 'facts', typically about the nature and outcomes of options (Sepucha *et al.*, 2007). In addition, given what we know about the tendency for knowledge retention to decay over time, when is the correct time to assess this (Edwards, 2006) knowledge? To sum, although seemingly attractive to measure, knowledge as a necessary component of decision quality is difficult to operationalize and, at a deeper level, may be an untested feature of our theoretical stance – a belief that standardized and pre-specified levels of knowledge are necessary for good decisions. Furthermore, as we claim throughout this chapter, 'good decisions' are yet to be defined.

The second area of consensus is based on declaring the importance of what are most commonly called values or preferences – that these entities are fundamental in allowing individuals to express their own control over decisions. Nevertheless, difficulties abound in this area as well. First, there is confusion over terms. The use of the term 'values' in decision-making is commonly linked to the concept of utility assessment as required by expected utility theory. Utility assessment, in the classical sense, requires a numerical estimation (typically between zero and one) using a person's global assessment of the value of different options, often characterized as likely outcomes. Sometimes, however, the term is also used to describe broader approaches or attitudes – such as risk aversion for example or a general stance on, say, the avoidance of medication. The term 'preferences' is often used interchangeably with values but seems to refer most often to *attributes* of options that some options have a more significant or more worrying range of disadvantages, e.g. drug side-effects that a patient *prefers* to avoid, and hence avoids the associated option. As Marteau notes in an accompanying chapter (Marteau, 2009), measurement of 'value-consistent choices have received less attention' and suggests that this area requires more attention.

Another term used in the decision-making literature is 'the construction of preferences'. This implies that preferences do not exist in advance, waiting to be revealed. There is indeed evidence that preferences are constructed as individuals gain information, obtain representations of the options, and weigh alternatives against each other (Lichtenstein, 2006). Furthermore, people are often inconsistent in what they state as their 'values' and what they actually choose (Lichtenstein, 2006). For instance, work on transitivity, one of the axioms of the rationalistic expected utility theory, has demonstrated that people who prefer A to B and B to C often do not follow the mathematical logic of preferring A to C because the alternatives do not share the same features. The fluidity and malleability of preferences make it hard to suggest preferences as a yardstick against which decisions are made. It seems, therefore, problematic to operationalize a measure of decision quality when there is drift both in the understanding of the terms, values, and preferences and as to how these entities are integrated during deliberation processes.

The final critique is about the notion of when a decision can be evaluated. Our major concern is that decisions cannot be evaluated *after* they have been performed. Sepucha uses the term 'implemented decision' (Sepucha *et al.*, 2007), which we think implies that the decision's quality will be judged after the event, when the decision has been taken and – importantly – the outcome is known. Similarly, Marteau used the term 'behaviourally implemented' (Marteau *et al.*, 2001), suggesting that the decision or some action has been performed prior to the assessment of (in her case) informed choice. O'Connor's definition contains the phrase 'agreement between patients' values and choices made' (O'Connor *et al.*, 2003), again implying that an assessment of decision quality would be made after the decision had been made. To date, O'Connor's measurement of decision quality and, specifically, of congruence between values and actions is done post hoc. The issue of *when* the decision quality is to be measured is not spelled out in these definitions, so we may be interpreting these definitions incorrectly. Yet the way in which Sepucha *et al.* have operationalized 'decision quality' measures – i.e. as instruments to be used *after* decision-making interventions have been implemented and decisions achieved – indicates that they propose to assess decision quality, i.e. consistency between knowledge and declared preferences *after* decisions have been made, when preferences may have accordingly shifted. Marteau, in fact, explicitly proposes measurement after decisions have taken place. Our concern is that measuring decision quality after the outcome is known inevitably leads to bias in the appraisal of that decision.

Irresolvable problems with current definitions?

We cannot argue with the view that knowledge and preferences seem fundamental to the measurement of a capacity to take a decision but have concerns about the specificity of such measurement aims and about yardsticks, given the indeterminate nature of these constructs and that sufficient knowledge might vary from one person to another. The timing of measurement is also critical. As we have shown above, there are important reasons to avoid post hoc measurement of *decision quality*. The first problem with this post hoc measurement is that of time. The period of time after any decision is infinite and it is unclear at which point in time a judgement should be made about the quality of a decision. Given this indeterminate duration, appraisals are inevitably fleeting: judgements about decisions can be negative at first, and then positive (or vice versa), and then keep switching depending on the point of assessment. The second problem is that of the role of chance. Decisions are in effect wagers: 'A good decision cannot guarantee a good outcome. All real decisions are made under uncertainty. A decision is therefore a bet, and evaluating it as good or not must depend on the stakes and the odds, not on the outcome.' (p. 7, (Edwards, 1984)). While a good decision maker might assess the outcome probabilities for each option, gambles by definition cannot be predicted ahead of time. The impossibility of ever knowing *outcomes in advance* leads to the conclusion that assessments of decision 'quality' seem time-bound, and that from one moment to the next, views about their quality can shift, if judgements are based on outcomes as Fischoff, Baron, and Hershey have demonstrated (Fischhoff, 1975; Baron and Hershey, 1988). The difficulty posed by this realization is challenging and seemingly irresolvable. Whilst we can and do appraise our decisions, as good or bad decisions, based on how well we fared when we followed the path we chose, we cannot really equate this to being the same as a high-quality decision: time works against us and colours our judgement. This problem is augmented when *decision outcome* quality serves as the ultimate measure against which knowledge and preferences are evaluated.

If not outcomes, should we measure process?

Having dismissed the possibility of using of post hoc assessment of decision quality on the grounds that they are dominated by outcomes we need to *consider what other alternatives are possible?* We face the argument that decisions, once they have been made, are always viewed retrospectively. This difficulty cannot be resolved if we accept that there is a border between the *processes of deliberating* about decisions and the *making and enactment* of decisions (Edwards, 2006). Although this may appear equivalent to dancing on the head of a pin – the distinction between decision process and decision enactment – between the deliberation process and the act of either taking route A or route B is key to the debate about the measurement of decision quality. Whoever wishes to define a good decision and to facilitate such decisions needs to differentiate clearly between the *quality* of the deliberative process and an *appraisal* of the decision – the choice made and any associated short-, medium-, or long-term outcomes. If we accept that outcomes are not a sound basis for assessing the quality of a decision, and that they taint any post-decisional evaluation, we are left with the contention that we would better focus on the quality of the deliberation and shift our measurement focus to the quality of a decision process.

Moving to a measure of deliberation – a decision process measure

An underpinning theoretical construct to measurement would be based on the following premises. First, accept that humans have to act on limited information availability when making decisions but contend that decisions made without any information are mere guesses. It follows, therefore, that data about the nature of the decision, the relevant option set, the positive and negative attributes of options, the probabilities that they occur over relevant time horizons should be both available and formatted in high-quality representations. Ample work (Gigerenzer, 1996; Miron-Shatz *et al.*, 2008) has demonstrated that certain formats (namely natural frequencies) are conducive to the comprehension of numeric risk information. Setting aside for a moment the sensitive issue of various farming effects, and the notion that information is invariably represented in one way or another, and that representation will influence understanding, a good decision process would ensure the availability of relevant, well-presented information and that a process of assimilation and, if necessary, clarification was undertaken, to gain maximum understanding. Second, accept that preference construction is a temporal and inter-subjective process that involves both cognitive and emotional contributions and is a fundamental step in decision-making, as it is ultimately the integration and the weighting of preferences, based on new information about attributes of options that leads to the ability to make a choice. For a theory of deliberation, wherein deliberation process quality is fulcrum, we make the premise that it is helpful to elicit preferences, to examine them, by discussion with other if necessary, and to either rank or weigh the negative and positive attributes of options, irrespective of the evidence that humans may not have the ability to achieve complete transitive accuracy. Given mental processing limitations and the fact that most reasoning is based on scarce input (Gigerenzer and Todd, 1999), it might suffice to allow the person to articulate what does she seek in an alternative and what she wishes to avoid. We propose that a good decision process would, therefore, provide opportunities to undertake these tasks, prior to a decision-making steps. It seems obvious but nevertheless important to state that these two processes of providing information and constructing preference assessments are co-dependent: one cannot form a view about preferences unless one has data about their attributes and probabilities. We suggest that, while it is the patient who makes the decisions, it is the professional's responsibility to present the information properly and to encourage an open preference elicitation process. Both these are prerequisites for a good quality deliberation process.

It also follows that measurement could be based on a number of data collection methods. The deliberation process could be observed and analysed; although as most deliberative processes occur over time and involve numerous interactions, the research burden is considerable.

Another method is to assess the patient's perspective on the deliberation steps. Have they received information and was it sufficient for them to be able to visualize the choice, the options and their respective attributes? Have they been able to elicit, examine, and assess their preferences, to the degree that it was sufficient for them to be in a position to make judgements? Ours is not a prescriptive tool in the sense that we do not decree how much information or how much deliberation is sufficient *for the particular patient.* Such a proposed measure suffers from being a subjective tool with no pre-set benchmarks or gold standards, but represents a method of gauging an individual's journey from a position of not understanding that choices exists, each with option attributes that need assessment, to a position of having deliberated to a level where they feel able to decide.

Conclusion

A focus on measure of deliberation provides potential benefits: it would help to distinguish and illuminate those parts of the global decision endeavour that are in the realm of one's control and responsibility. It focuses on pre-decision and ties in with the advances in patient–professional communication, as well as in the proliferation of decision support. By disentangling the process from the outcome, we allow for the evaluation not to hinge on whether a procedure succeeded, which can colour judgements on how well prepared, how ready one is to take decisions. In the final analysis, this is as much as we can do: the rest we have to leave to chance.

Acknowledgements

We thank Dominick Frosch, Adrian Edwards, Paul White, and Natalie Joseph for comments on drafts of this chapter.

References

Baron, J. and Hershey, J.C. (1988). Outcome bias in decision evaluation. *Journal of Personality and Social Psychology*, **54**, 569–579.

Charles, C., Gafni, A., *et al.* (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Soc. Sci. Med.*, **44**, 681–692.

Coulter, A. (1999). Paternalism or partnership? *British Medical Journal*, **319**, 719–794.

Dijksterhuis, A., Bos, M.W., *et al.* (2006). On making the right choice: The deliberation-without-attention effect. *Science*, **311**, 1005–1007.

Edwards, A. and Elwyn, G. (2006). Inside the black box of shared decision making: Distinguishing between the process of involvement and who makes the decision. *Health Expect.*, 307–320.

Edwards, W. (1984). How to make good decisions. (Selected proceedings *9th research conference on subjective probability, utility and decision making*). *Acta Psychologica*, **56**, 5–27.

Elwyn, G., Edwards, A., *et al.* (1999). Shared decision making: The neglected second half of the consultation. *BJGP*, **49**, 477–482.

Elwyn, G., Rhydderch, M., *et al.* (2003). Shared decision making. In C. Silagy and N. Britten (eds) Oxford Textbook of Primary Medical Care. Oxford: Oxford University Press.

Fischhoff, B. (1975). Hindsight ≠ Foresight: The effect of outcome knowledge on judgement under uncertainty. J. *Exp. Psychol.*: Hum. Percept. Perform., **1**, 288–299.

Gigerenzer, G. (1996). The Psychology of good judgement: Frequency formats and simple algorithms. *Medical Decision Making*, **16**, 273–280.

Gigerenzer, G. and Todd, P.M. (1999). Simple Heuristics that Make us Smart. New York: Oxford University Press.

Hope, T. (1996). Evidence-Based Patient Choice. London: King's Fund Publishing.

Lichtenstein, S. and Slovic, P. (2006). The Construction of Preference. Cambridge: Cambridge University Press.

Marteau, T. (2009). Informed choice: A construct in search of a name. In A. Edwards and G. Elwyn (eds) *Evidence-Based Patient Choice*. Oxford: Oxford University Press.

Marteau, T.M., Dormandy, E., *et al.* (2001). A measure of informed choice. Health Expectations, **4**, 98–108.

Miron-Shatz, T., Hanoch, Y., *et al.* (2008). Presentation format, numeracy, and emotional reactions: The case of prenatal screening. *Journal of Health Communication* **(in submission)**.

O'Connor, A.M., Wennberg, J., *et al.* (2007). Towards the 'tipping point': Decision aids and informed patient choice. Health Aff., **26**, 716–725.

O'Connor, A. M., Stacey, D., *et al.* (2003). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews, 2*, CD001431.

Raffle, A.E. (2001). Information about screening: Is it to achieve high uptake or to ensure informed choice? Health Expectations., **4**, 92–98.

Ratliff, A., Angel, M., *et al.* (1999). What is a good decision? *Eff. Clin. Pract.*, **2**, 185–197.

Schneider, C.E. (1998). The Practice of Autonomy: Patients, Doctors, and Medical decisions. New York: Oxford University Press.

Sepucha, K., Ozanne, E., *et al.* (2007). An approach to measuring the quality of breast cancer decisions. *Patient Education and Counselling*, **65**, 261–269.