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Shared Decision-Making in the Medical Encounter: What Does it Mean? (Or it Takes at Least Two to Tango)

Cathy Charles, BA, MA, PhD, Amiram Gafni, BSc, MSc, Dsc, and Tim Whelan, BSc, B.M. B.Ch., MSc

Abstract:

Shared decision-making is increasingly advocated as an ideal model of treatment decision making in the medical encounter. To date, the concept has been rather poorly and loosely defined. This paper attempts to provide greater conceptual clarity about shared treatment decision-making, identify some key characteristics of this model, and discuss measurement issues. The particular decision-making context that we focus on is potentially life threatening illnesses, where there are important decisions to be made at key points in the disease process, and several treatment options exist with different possible outcomes and substantial uncertainty. We suggest as key characteristics of shared decision-making (1) that at least two participants — physician and patient be involved; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement. Some challenges to measuring shared decision making are discussed as well as potential benefits of a shared decision-making model for both physicians and patients.

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Decision-Making in the Physician–Patient Encounter: Revisiting the Shared Treatment Decision-Making Model
Cathy Charles, BA, MA, PhD, Amiram Gafni, BSc, MSc, DSc, and Tim Whelan, BSc, B.M., B.Ch., MSc

Abstract:
In this paper we revisit and add elements to our earlier conceptual framework on shared treatment decision-making within the context of different decision-making approaches in the medical encounter (Charles, C., Gafni, A., Whelan, T., 1997. Shared decision-making in the medical encounter: what does it mean? (or, it takes at least two to tango). Social Science & Medicine 44, 681±692.). This revised framework (1) explicitly identifies different analytic steps in the treatment decision-making process; (2) provides a dynamic view of treatment decision-making by recognizing that the approach adopted at the outset of a medical encounter may change as the interaction evolves; (3) identifies decision-making approaches which lie between the three predominant models (paternalistic, shared and informed) and (4) has practical applications for clinical practice, research and medical education. Rather than advocating a particular approach, we emphasize the importance of flexibility in the way that physicians structure the decision-making process so that individual differences in patient preferences can be respected.

Communicating Uncertainty Can Lead to Less Decision Satisfaction: a Necessary Cost of involving patients in shared decision making?
Mary C. Politi, PhD, Melissa A. Clark, PhD, Hernando Ombao, PhD, Don Dizon, MD, and Glyn Elwyn, MB, BCh, MSc, PhD
Health Expectations, No. 14, pp.84–91 2010

Background: Given the large number of interventions of uncertain effectiveness, research on communicating uncertainty is needed to examine its impact on patients’ health decisions.
Objective: To examine physicians’ communication of uncertainty and its impact on patients’ decisions and decision satisfaction.
Design, Setting, and Participants: Participants included female patients seen in a breast health center whose physicians were discussing a decision with them, with no clear 'best' choice based on outcome evidence.
Main Variables: Decision communication was measured using the OPTION scale, a measure of the degree to which physicians involve patients in a decision-making process. One-to-two weeks after the discussion, patients reported their satisfaction with the decision-making process and their decision. Decisions were verified in medical charts with patient consent.
Results: Seventy-five women agreed to participate (94% response rate). The mean translated score of the OPTION scale was 68.0 (SD 18.3), but only 33.2 (SD 19.1) for the uncertainty items. Among cancer patients, communicating uncertainty was negatively related to decision satisfaction (p < 0.002), and there was an interaction between patient involvement in decisions and communicating uncertainty in relation to patients’ decision satisfaction (p<0.03).
Discussion: Communicating scientific uncertainty might lead to less decision satisfaction among women facing cancer treatment decisions; this could be a natural outcome of the decision making process. Involving patients in decisions might help them tolerate uncertainty.
Conclusion: Future studies should consider assessing other outcomes (e.g. knowledge, physician support) of the decision making process. There may be trade-offs between acknowledging uncertainty and immediate decision satisfaction.

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The DECISIONS Study: A Nationwide Survey of United States Adults Regarding 9 Common Medical Decisions
Brian J. Zikmund-Fisher, PhD, Mick P. Couper, Eleanor Singer, PhD, Carrie A. Levin, PhD, Floyd J. Fowler, PhD, Sonja Ziniel, Peter A. Ubel, MD, Angela Fagerlin, PhD

Abstract:
Background: Patient involvement is required before patients’ preferences can be reflected in the medical care they receive. Furthermore, patients are a vital link between physicians’ assessments of patients’ needs and actual implementation of appropriate care. Yet no study has specifically examined how and when a representative sample of patients considered, discussed, and made medical decisions. Objective: To identify decision prevalence and decision-making processes regarding 1) initiation of prescription medications for hypertension, hypercholesterolemia, or depression; 2) screening tests for colorectal, breast, or prostate cancer; and 3) surgeries for knee or hip replacement, cataracts, or lower back pain. Design: Computer-assisted telephone interview survey. Setting. Nationally representative sample of US adults in households with telephones. Participants. 3010 English-speaking adults age 40 and older identified using a stratified random sample of telephone numbers. Measurements: Estimated prevalence of medical decisions, defined as the patient having initiated medications, been screened, or had surgery within the past 2 years or having discussed these actions with a health care provider during the same interval, as well as decision-specific data regarding patient knowledge, attitudes and patient-provider interactions. Results. 82.2% of the target population reported making at least 1 medical decision in the preceding 2 years. The proportion of decisions resulting in patient action varied dramatically both across decision type (medications [61%] v. screening [83%] v. surgery [44%]; P < 0.001), and within each category (e.g., blood pressure medications [76%] v. cholesterol medications [55%] v. depression medications [48%]; P < 0.001). Respondents reported making more decisions if they had a primary care provider or poorer health status and fewer decisions if they had lower education, were male, or were under age 50. Limitations. Retrospective self-reports may incorporate recall biases.

Conclusions: Medical decisions with significant life-saving, quality of life, and cost implications are a pervasive part of life for most US adults. The DECISIONS dataset provides a rich research environment for exploring factors influencing when and how patients make common medical decisions.

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The Diabetes Mellitus Medication Choice Decision Aid A Randomized Trial
Rebecca J. Mullan, MS, Victor M. Montori, MD, MSc, Nilay D. Shah, PhD, Teresa J. H. Christianson, BSc, Sandra C. Bryant, MS, Gordon H. Guyatt, MD, MSc, Lilisbeth I. Perestelo-Perez, PhD, Robert J. Stroebel, MD, Barbara P. Yawn, MD, Victor Yapuncich, MD, Maggie A. Breslin, MDes, Laurie Pencille, BSc, Steven A. Smith, MD
*Arch Intern Med.* 169(17):1560-1568, 2009

Abstract:
Background: Patient involvement in the choice of antihyperglycemic agents could improve adherence and optimize glycemic control in patients with type 2 diabetes mellitus.

Methods We conducted a pilot, cluster randomized trial of Diabetes Medication Choice, a decision aid that describes 5 antihyperglycemic drugs, their treatment burden (adverse effects, administration, and self-monitoring demands), and impact on hemoglobin A1c (HbA1c) levels. Twenty-one clinicians were randomized to use the decision aid during the clinical encounter and 19 to dispense usual care and an educational pamphlet. We used surveys and video analysis to assess postvisit decisional outcomes, and medical and

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pharmacy records to assess 6-month medication adherence and HbA1c levels.
Results: Compared with usual care patients (n = 37), patients receiving the decision aid (n = 48) found the tool more helpful (clustered-adjusted mean difference [AMD] in a 7-point scale, 0.38; 95% confidence interval [CI], 0.04-0.72); had improved knowledge (AMD, 1.10 of 10 questions; 95% CI, 0.11-2.09); and had more involvement in making decisions about diabetes medications (AMD, 21.8 of 100; 95% CI, 13.0-30.5). At 6-month follow-up, both groups had nearly perfect medication use (median, 100% of days covered), with better adherence (AMD, 9% more days covered; 95% CI, 4%-14%) and persistence (AMD, 12 more days covered; 95% CI, 3-21 days) in the usual care group, and no significant impact on HbA1c levels (AMD, 0.01; 95% CI, −0.49 to 0.50).
Conclusion: An innovative decision aid effectively involved patients with type 2 diabetes mellitus in decisions about their medications but did not improve adherence or HbA1c levels.

Authoritarian Physicians and Patients’ Fear of Being Labeled ‘Difficult’ Among Key Obstacles to Shared Decision-Making
Dominick L. Frosch, PhD, Suepattra G. May, PhD, MPH, Katharine A.S. Rendle, MA, MSW, PhD, Caroline Tietbohl, BA, and Glyn Elwyn, MB, BCh, MSc, PhD
Health Affairs Vol. 31, No. 5, pp.1030-1038, 2012

Abstract:
Relatively little is known about why some patients are reluctant to engage in a collaborative discussion with physicians about their choices in health care. To explore this issue further, we conducted six focus-group sessions with forty-eight people in the San Francisco Bay Area. In the focus groups, we found that participants voiced a strong desire to engage in shared decision making about treatment options with their physicians. However, several obstacles inhibit those discussions. These include the fact that even relatively affluent and well-educated patients feel compelled to conform to socially sanctioned roles and defer to physicians during clinical consultations; that physicians can be authoritarian; and that the fear of being categorized as “difficult” prevents patients from participating more fully in their own health care. We argue that physicians may not be aware of a need to create a safe environment for open communication to facilitate shared decision making. Rigorous measures of patient engagement, and of the degree to which health care decisions truly reflect patient preferences, are needed to advance shared decision making in clinical practice.

Introducing Decision Aids at Group Health was Linked to Sharply Lower Hip and Knee Surgery Rates and Costs
David Arterburn, MD, MPH, Robert Wellman, MD, Emily Westbrook, MHA, Carolyn Rutter, PhD, Tyler Ross, MA, David McCulloch, MD, Matthew Handley, MD, and Charles Jung, MD
Health Affairs Vol. 31, No. 9, 2012

Abstract:
Decision aids are evidence-based sources of health information that can help patients make informed treatment decisions. However, little is known about how decision aids affect health care use when they are implemented outside of randomized controlled clinical trials. We conducted an observational study to examine the associations between introducing decision aids for hip and knee osteoarthritis and rates of joint replacement surgery and costs in a large health system in Washington State. Consistent with prior randomized trials, our introduction of decision aids was associated with 26 percent fewer hip replacement surgeries, 38 percent fewer knee replacements, and 12–21 percent lower costs over six months. These findings support

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the concept that patient decision aids for some health conditions, for which treatment decisions are highly sensitive to both patients’ and physicians’ preferences, may reduce rates of elective surgery and lower costs.

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Interventions to Improve Patient Comprehension in Informed Consent for Medical and Surgical Procedures: A Systematic Review
Yael Schenker, MD, MAS, Alicia Fernandez, MD, Rebecca Sudore, MD, and Dean Schillinger, MD

Abstract:
Background: Patient understanding in clinical informed consent is often poor. Little is known about the effectiveness of interventions to improve comprehension or the extent to which such interventions address different elements of understanding in informed consent. Purpose: To systematically review communication interventions to improve patient comprehension in informed consent for medical and surgical procedures. Data Sources: A systematic literature search of English-language articles in MEDLINE (1949–2008) and EMBASE (1974–2008) was performed. In addition, a published bibliography of empirical research on informed consent and the reference lists of all eligible studies were reviewed. Study Selection: Randomized controlled trials and controlled trials with nonrandom allocation were included if they compared comprehension in informed consent for a medical or surgical procedure. Only studies that used a quantitative, objective measure of understanding were included. All studies addressed informed consent for a needed or recommended procedure in actual patients. Data Extraction: Reviewers independently extracted data using a standardized form. All results were compared, and disagreements were resolved by consensus. Data Synthesis: Forty-four studies were eligible. Intervention categories included written information, audiovisual/multimedia, extended discussions, and test/feedback techniques. The majority of studies assessed patient understanding of procedural risks; other elements included benefits, alternatives, and general knowledge about the procedure. Only 6 of 44 studies assessed all 4 elements of understanding. Interventions were generally effective in improving patient comprehension, especially regarding risks and general knowledge. Limitations: Many studies failed to include adequate description of the study population, and outcome measures varied widely. Conclusions: A wide range of communication interventions improve comprehension in clinical informed consent. Decisions to enhance informed consent should consider the importance of different elements of understanding, beyond procedural risks, as well as feasibility and acceptability of the intervention to clinicians and patients. Conceptual clarity regarding the key elements of informed consent knowledge will help to focus improvements and standardize evaluations.

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IPDAS Collaboration Background Document
Aileen Clarke, MSc, MJ Jacobsen, RN, MEd, Mary Ann O’Connor, MA, MSc, Diana Stilwell, BS, MPH, Deb Feldman-Stewart, PhD
International Patient Decision Aid Standards Collaboration February, 2005

Patient decision aids are meant to support informed values-based decision making. They are usually developed when there is more than one reasonable option and there is considerable variation in how patients value the features of different options. Practitioners and patients may find it challenging to arrive at a good decision without advance preparation using a patient decision aid that helps patients understand the options and clarify the personal value of their different features. Patient decision aids take considerable effort to
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develop, and can have an important effect on decision quality and the use of health services. Therefore, it is important that they are developed using a systematic and replicable process.

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IPDAS Patient Decision Aid Evaluation Checklist

Patient decision aids are tools to help people participate in their health decisions in ways they prefer. They are used when there is more than one medically reasonable option to diagnose or treat a health problem. Each of the options has good and bad features that people value differently. Even when two people are in the same situation, what is important for one person may be different for another person. Therefore, there is no clear answer that applies to everyone. Patient decision aids aim to do three things to prepare a person for decision-making. They provide facts about a person’s condition, the options and their features. They help people to clarify their values (the features that matter most to them). They help people to share their values with their health care practitioner and others, so a course of action can be planned that matches their values. Patient decision aids do not advise people to choose one option over another. The International Patient Decision Aid Standards (IPDAS) Collaboration is a group of researchers, practitioners and stakeholders from around the world. The goal is to establish an internationally approved set of criteria to determine the quality of patient decision aids. These criteria will be helpful to a wide variety of individuals and organizations that use and/or develop patient decision aids.

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Development of Instruments to Measure the Quality of Breast Cancer Treatment Decisions

Clara N. Lee, MD MPP, Rosalie Dominik, PhD, Carrie A. Levin, PhD, Michael J. Barry, MD, Carol Cosenza MSW, Annette M. O’Connor MScN PhD FCAHS, Albert G. Mulley Jr, MD MPP and Karen R. Sepucha, PhD

Health Expectations, Vol.13, pp.258–272, 2010

Abstract:

Background: Women with early-stage breast cancer face a multitude of decisions. The quality of a decision can be measured by the extent to which the treatment reflects what is most important to an informed patient. Reliable and valid measures of patients’ knowledge and their goals and concerns related to breast cancer treatments are needed to assess the decision quality.

Objective: To identify a set of key facts and goals relevant to each of three breast cancer treatment decisions (surgery, reconstruction and adjuvant chemotherapy and hormone therapy) and to evaluate the validity of the methods used to identify them.

Methods: Candidate facts and goals were chosen based on evidence review and qualitative studies with breast cancer patients and providers. Cross-sectional surveys of patients and providers were conducted for each decision. The accuracy, importance and completeness of the items were examined.

Results: Thirty-eight facts (11–14 per decision) and 27 goals (8–10 per decision) were identified. An average of 17 patients and 21 providers responded to each survey. The sets of facts were accurate and complete for all three decisions. The sets of goals and concerns were important for surgery and reconstruction, but not chemotherapy/hormone therapy. Patients and providers disagreed about the relative importance of several key facts and goals.

Conclusions: Overall, breast cancer patients and providers found the sets of facts and goals accurate, important and complete for three treatment decisions. Because patients’ and providers’ perspectives are different, it is vital that instrument development should include items reflecting both views.

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**Barriers and Facilitators to Implementing Shared Decision-Making in Clinical Practice: Update of a Systematic Review of Health Professionals' Perceptions**

France Légaré, PhD, MD, Stéphane Ratté, Karine Gravel, PhD, Ian D. Graham, PhD, FCAHS


**Abstract:**
Objective: To update a systematic review on the barriers and facilitators to implementing shared decision-making in clinical practice as perceived by health professionals.

Methods: From March to December 2006, PubMed, Embase, CINHAL, PsycINFO, and Dissertation Abstracts were searched. Studies were included if they reported on health professionals’ perceived barriers and facilitators to implementing shared decision-making in practice. Quality of the included studies was assessed. Content analysis was performed with a pre-established taxonomy.

Results: Out of 1130 titles, 10 new eligible studies were identified for a total of 38 included studies compared to 28 in the previous version. The vast majority of participants (n = 3231) were physicians (89%). The three most often reported barriers were: time constraints (22/38) and lack of applicability due to patient characteristics (18/38) and the clinical situation (16/38). The three most often reported facilitators were: provider motivation (23/38) and positive impact on the clinical process (16/38) and patient outcomes (16/38).

Conclusion: This systematic review update confirms the results of the original review. Practice implications: Interventions to foster implementation of shared decision-making in clinical practice will need to address a range of factors.

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**Making Shared Decision-Making a Reality: No Decision About Me, Without Me**

Angela Coulter, PhD, Alf Collins, MD

*The King’s Fund, 2011*

The paper outlines the importance of communication skills and sets out how clinicians might approach consultations to arrive at shared decisions. It also suggests that tools that help patients in making decisions are just as important as guidelines for clinicians.

Clinicians will find evidence for the benefits of shared decision-making and practical support in implementing it.

The principle of shared decision-making in the context of a clinical consultation is that it should:

- Support patients to articulate their understanding of their condition and of what they hope treatment (or self-management support) will achieve
- Inform patients about their condition, about the treatment or support options available, and about the benefits and risks of each
- Ensure that patients and clinicians arrive at a decision based on mutual understanding of this information
- Record and implement the decision reached.

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Arduous Implementation: Does the Normalisation Process Model Explain Why it’s So Difficult to Embed Decision Support Technologies for Patients in Routine Clinical Practice
Glyn Elwyn, MB, BCh, MSc, PhD, France Légaré, PhD, MD, Trudy van der Weijden, PhD, Adrian Edwards, PhD, and Carl May, PhD BScEcon

Abstract:
Background: Decision support technologies (DSTs, also known as decision aids) help patients and professionals take part in collaborative decision-making processes. Trials have shown favorable impacts on patient knowledge, satisfaction, decisional conflict and confidence. However, they have not become routinely embedded in health care settings. Few studies have approached this issue using a theoretical framework. We explained problems of implementing DSTs using the Normalization Process Model, a conceptual model that focuses attention on how complex interventions become routinely embedded in practice.

Methods: The Normalization Process Model was used as the basis of conceptual analysis of the outcomes of previous primary research and reviews. Using a virtual working environment we applied the model and its main concepts to examine: the ‘workability’ of DSTs in professional-patient interactions; how DSTs affect knowledge relations between their users; how DSTs impact on users’ skills and performance; and the impact of DSTs on the allocation of organizational resources.

Results: A conceptual analysis using the Normalization Process Model provided insight on implementation problems for DSTs in routine settings. Current research focuses mainly on the interactional workability of these technologies, but factors related to divisions of labor and health care, and the organizational contexts in which DSTs are used, are poorly described and understood.

Conclusion: The model successfully provided a framework for helping to identify factors that promote and inhibit the implementation of DSTs in health care and gave us insights into factors influencing the introduction of new technologies into contexts where negotiations are characterized by asymmetries of power and knowledge. Future research and development on the deployment of DSTs needs to take a more holistic approach and give emphasis to the structural conditions and social norms in which these technologies are enacted.

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Patients’ Preferences Matter: Stop the Silent Misdiagnosis
Al Mulley, MD, PhD, Chris Trimble, BSc, MBA Glyn Elwyn, MB, BCh, MSc, PhD
The King’s Fund, 2012

Summary:
Many doctors aspire to excellence in diagnosing disease. Far fewer, unfortunately, aspire to the same standards of excellence in diagnosing patients’ preferences for their care. Because doctors are rarely made aware of an erroneous preference diagnosis, it could be called ‘the silent misdiagnosis’. Misdiagnosing patients’ preferences may be less obvious than misdiagnosing disease, but the consequences for the patient can be just as severe.

Patients’ preferences matter: stop the silent misdiagnosis outlines the scale of the problem, showing that:
- When they are well informed, patients make different choices about treatment
- What patients want often differs from what doctors think they want
- There are significant variations in care across geographic regions.

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Shared Decision-Making: Enhancing the Clinical Relevance
Vikki A Entwistle, BA, MSc, PhD, MA, Alan Cribb, BA, PhD and Ian S Watt, BSc, MB, ChB. MPH, FFPH

Summary:
Shared decision-making is increasingly advocated to enable patients to participate in decisions that affect them, to protect patients from insufficiently individualized supply driven care, and to reduce health care costs and waste by avoiding the provision of unwanted interventions. The concept of shared decision-making can be understood in several ways. A number of definitions and descriptive models have been offered, emphasizing different aspects of clinician patient interaction and decision-making. Most definitions and models can be variously interpreted when considered in relation to the complex realities of health care provision. Clinicians’ understandings of shared decision-making can have important implications for clinical practice. They can diverge, for example, over questions of whether, when and how it is appropriate to recommend a particular treatment or challenge a patient’s expressed preferences.

This paper considers the practical and ethical implications of, ‘narrow’ and ‘broader’ ways of thinking about shared decision-making. It illustrates how narrow understandings of shared decision-making, which focus on informing patients so they can choose between options, can make it hard for many patients to share meaningfully in decision-making that affects them. It then outlines how broader understandings, which allow for more clinician influence and extend the relevance of shared decision-making to diverse situations, can be justified in principle and appraised for appropriateness.

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Shared Mind: Communication, Decision Making, and Autonomy in Serious Illness
Ronald M. Epstein, MD, Richard L. Street, Jr, PhD
Annals of Family Medicine, Vol. 9, No. 5, 2011

Abstract:
In the context of serious illness, individuals usually rely on others to help them think and feel their way through difficult decisions. To help us to understand why, when, and how individuals involve trusted others in sharing information, deliberation, and decision making, we offer the concept of shared mind—ways in which new ideas and perspectives can emerge through the sharing of thoughts, feelings, perceptions, meanings, and intentions among 2 or more people. We consider how shared mind manifests in relationships and organizations in general, building on studies of collaborative cognition, attunement, and sensemaking.

Then, we explore how shared mind might be promoted through communication, when appropriate, and the implications of shared mind for decision making and patient autonomy. Next, we consider a continuum of patient-centered approaches to patient-clinician interactions. At one end of the continuum, an interactional approach promotes knowing the patient as a person, tailoring information, constructing preferences, achieving consensus, and promoting relational autonomy. At the other end, a transactional approach focuses on knowledge about the patient, information-as-commodity, negotiation, consent, and individual autonomy. Finally, we propose that autonomy and decision making should consider not only the individual perspectives of patients, their families, and members of the health care team, but also the perspectives that emerge from the interactions among them. By drawing attention to shared mind, clinicians can observe in what ways they can promote it through bidirectional sharing of information and engaging in shared deliberation.

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**Decision Aids for People Facing Health Treatment or Screening Decisions (Review)**
Dawn Stacey, PhD, MScN, Carol L Bennett, Michael J Barry, MD, Nananda F Col, MD, MPP, MPH, FACP, Karen B Eden, PhD, Margaret Holmes-Rovner, PhD, Hilary Llewellyn-Thomas, BSc, MSc, PhD, Anne Lyddiatt, France Légaré, PhD, MD, Richard Thomson, MD
*The Cochrane Library*, Issue 10, 2011

**Summary:**
Decision aids to help people who are facing health treatment or screening decisions identifying and making a decision on the best health treatment or screening option can be difficult for patients. Decision aids can be used when there is more than one reasonable option, when no option that has a clear advantage in terms of health outcomes, and when each option has benefits and harms that patients may value differently. Decision aids may be pamphlets, videos, or web-based tools. They describe the options available and help people to understand these options as well as the possible benefits and harms. This allows patients to consider the options from a personal view (e.g. how important the possible benefits and harms are to them) and prepares them to participate with their health practitioner in making a decision.

The updated review of 86 studies found that when patients use decision aids they: a) improve their knowledge of the options; b) are helped to have more accurate expectations of possible benefits and harms; c) reach choices that are more consistent with their informed values; and d) participate more in decision making. Decision aids have a variable effect on actual choices, but they reduce the choice of elective surgery when patients consider other options. When patients use decision aids, there appears to be a positive effect on communication with their health practitioner, and a variable effect on the time required for this consultation. Decision aids with more detail compared to simpler decision aids showed smaller improvements. There are no apparent adverse effects on health outcomes or satisfaction. More research is needed to evaluate adherence with the chosen option, patient-practitioner communication, and the associated costs.

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**The Meaning of Patient Involvement and Participation in Health Care Consultations: A Taxonomy**
Andrew G.H. Thompson, University of Edinburgh

**Abstract:**
A number of trends, pressures and policy shifts can be identified that are promoting greater patient involvement in health care delivery through consultations, treatments and continuing care. However, while the literature is growing fast on different methods of involvement, little attention has been given so far to the role which patients themselves wish to play, nor even of the conceptual meanings behind involvement or participation. This article reviews the current models of involvement in health care delivery as derived from studies of professional views of current and potential practice, prior to examining the empirical evidence from a large-scale qualitative study of the views and preferences of citizens, as patients, members of voluntary groups, or neither. Individual domiciliary interviews were carried out with 44 people recruited from GP practices in northern England. These respondents were then included in a second phase of 34 focus groups in 6 different localities in northern and southern England, of which 22 were with individuals unaffiliated to any voluntary/community groups, 6 related to local voluntary/community groups with specific interests in health or health care, and 6 related to groups without such specific interests. A final set of 12 workshops with the same samples helped to confirm emergent themes.

The qualitative data enabled a taxonomy of patient-desired involvement to be derived, which is contrasted with professional-determined levels of involvement identified from the literature. Participation is seen as being co-determined by patients and professionals, and occurring only through the reciprocal relationships of
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dialogue and shared decision-making. Not everyone wanted to be involved and the extent to which involvement was desired depended on the contexts of type and seriousness of illness, various personal characteristics and patients’ relationships with professionals. These levels are seen to provide basic building blocks for a more sophisticated understanding of involvement within and between these contexts for use by professionals, managers, policy-makers and researchers.

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The Minnesota Shared Decision-Making Collaborative is a multi-stakeholder community learning collaborative working to remove barriers to adoption and promote the routine use of shared decision-making in clinical practice throughout Minnesota. www.msdmc.org

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