Decision making is fundamental to all aspects of cancer care—prevention, detection, treatment, survivorship, and end of life—and yet researchers and clinicians have limited knowledge of the ways in which patients and their health care providers make critical health decisions. Recognizing how important it is to understand how patients and their providers make potentially life-altering decisions, the National Cancer Institute developed a decision making in cancer control initiative. The goal of this initiative is to enhance understanding of human decision-making processes so that individuals can make more informed and satisfying choices regarding their health. This article describes the multidisciplinary meeting that provided the scientific foundation for this initiative.

**Keywords:** cancer, decision making, judgment and decision making

Nothing is more difficult, and therefore more precious, than to be able to decide.

—Napoleon Bonaparte

Decision making is fundamental to all aspects of cancer care—prevention, detection, treatment, survivorship, and end of life—and yet researchers and clinicians have limited knowledge of the ways in which patients and their health care providers make critical health decisions. Advances in cancer care, coupled with advances in bioinformatics, have created a staggering array of health care options and sources of medical information. Individuals at risk, patients, and providers face a multitude of decisions across the cancer continuum that may profoundly affect outcomes in a number of domains: life expectancy, treatment outcomes, and overall quality of life.

Sophisticated decision-analytic modeling techniques and high-technology decision support tools have been designed to help patients and providers manage the uncertainty inherent in prevention, screening, or treatment decisions. While judgment and decision-making science has given researchers the tools to arrive at rational decisions, they know that in-the-moment, real-world decisions are frequently not based on the rational utilities and normative models that underlie these tools (Siminoff & Fetting, 1991). Moreover, it is well recognized that competent patients often make seemingly irrational health decisions, such as delaying or declining necessary treatment, or make choices that conflict with their stated values and preferences (Brock, 1990). Researchers have only recently begun to appreciate fully the roles that intuition, affect, and cognitive biases play in decision making (Redelmeier, Rozin, & Kahneman, 1993; Slovic, Finucane, Peters, & MacGregor, 2002; Ubel & Loewenstein, 1997).

Cancer patients, individuals at risk, and health care providers often make critical health decisions with only limited awareness of how or why they make the choices they do. Consider the following hypothetical scenarios.

A teenager ignores warnings about the dangers of smoking because she believes that only old people develop lung cancer.

A healthy 30-year-old woman worryingly schedules a colonoscopy after watching Katie Couric’s report on colon cancer on TV, despite assurances from her physician that this procedure is not indicated.

A physician does not encourage his patient to enroll in a cancer clinical trial because the patient has a history of substance abuse.

A patient with early-stage prostate cancer and his physician must decide on a course of treatment: observation, hormone therapy, surgery, or radiotherapy. Each of these options is associated with potential benefits and risks.
In each of these examples, suboptimal decisions could result from mental shortcuts that are often used in everyday life. For example, the teenager’s stereotype of the older bronchitic smoker prevents her from recognizing that she too is at risk for smoking-related diseases. The young adult’s extreme worry about colon cancer generated by Katie Couric’s report overrides her physician’s assurances that colonoscopy is not indicated.

Recognizing how critical it is to understand how cancer patients and their health care providers make potentially life-altering decisions, the National Cancer Institute (NCI) developed a decision making in cancer control initiative. The overarching goal of the Basic and Applied Decision Making in Cancer Control initiative is to enhance understanding of human decision-making processes so that individuals can make more informed and satisfying choices regarding their health. However, in order to achieve this aim, we realized that it was necessary to draw equally upon research in both basic judgment and decision-making science and applied behavioral science. To this end, we convened a meeting of experts in these two historically separate research domains in an effort to encourage the integration of basic and applied decision research and to advance the science of decision making in cancer control. Such translational research is a reciprocal process whereby basic scientists provide applied/clinical researchers with new tools to test and potentially use in the clinical arena, and applied/clinical researchers make observations about patients and diseases that stimulate basic investigations.

On February 19 and 20, 2004, the Behavioral Research Program, Division of Cancer Control and Population Sciences at the NCI sponsored a multidisciplinary scientific meeting that brought together leaders in basic judgment and decision-making science, behavioral science in cancer control, health psychology, and bioinformatics. Also present at this meeting were invited scientists from the NCI; the Office of Behavioral and Social Sciences Research at the National Institutes of Health; the Federation of Behavioral, Psychological, and Cognitive Sciences; the American Psychological Society; the Agency for Healthcare Research and Quality; and the National Science Foundation (see Appendix A).

The intent of this meeting was for basic judgment and decision-making researchers to inform applied behavioral science researchers about the state of decision science, and, similarly, for applied cancer control researchers to inform decision-making researchers about applied decision research in health psychology. The articles in this special issue of Health Psychology are based on the scientific presentations and discussions from this meeting. The articles represent one of the first attempts to synthesize basic and applied research in decision making in cancer control.

The contributions of Gretchen Chapman, Terry Connolly, Baruch Fischhoff, Eric Johnson, George Loewenstein, Mary Frances Luce, Paul Slovic, and Peter Ubel introduce important issues in basic judgment and decision-making research. These articles are neither meant to reflect the gamut of judgment and decision-making research nor are they comprehensive reviews; rather, they are intended to provide the unfamiliar reader with an introduction to basic judgment and decision-making theory, research questions, and methodology. (For those readers who would like to learn more about judgment and decision-making research, a brief history of the field of judgment and decision making is provided in Appendix B.) These articles raise a number of compelling questions that have particular relevance to cancer prevention and control. For example, how can an understanding of the psychological processes that underlie how people value future outcomes relative to immediate outcomes help promote self-protective health behaviors (Chapman, 2005)? How might expectations of regret influence decisions about cancer treatment (Connolly & Reb, 2005)? How can an understanding of behavioral decision research strategies improve the informed consent to treatment process (Fischhoff, 2005)? If one believes that preferences are dynamic rather than static, and are often constructed “on the spot,” rather than measured, how can researchers best facilitate the construction of preferences for cancer treatment (Johnson, Steffel, & Goldstein, 2005)? If preferences are influenced by fluctuating affecting states, is it ever possible to give informed consent to treatment (Loewenstein, 2005)? Is information processed differently when a decision entails tradeoffs between highly valued attributes (Luce, 2005)? What role does affect play in assessing the risks and benefits of cancer treatment (Slovic, Peters, Finucane, & MacGregor, 2005)? Is it possible to help people accurately imagine future health states (Ubel, Loewenstein, Schwarz, & Smith, 2005)?

The contributions of Peter Ditto, Arthur Elstein, Ronald Myers, Tracey Revenson, Marc Schwartz, and Laura Siminoff represent a more applied research approach to decision making in cancer control. Their articles span the cancer continuum: from prevention to screening to treatment to survivorship and end of life. These authors address a number of critical issues in cancer care. For example, how can basic judgment and decision-making research inform end-of-life decision making and advance directives policy (Ditto & Hawkins, 2005)? What accounts for the low correlation between patients’ and clinicians’ utilities for health states (Elstein, Chapman, & Knight, 2005)? How can researchers promote value-based decision making in cancer prevention and control (Myers, 2005)? How can a social ecological framework help researchers understand and improve cancer treatment decision making (Revenson & Pranikoff, 2005)? What elements factor into a decision to undergo genetic testing for cancer susceptibility (M. D. Schwartz, Peshkin, Tercyak, Taylor, & Valdimarsdottir, 2005)? What factors influence communication in physician–patient interactions (Siminoff & Step, 2005)?
We hope that this special issue will serve as a catalyst for motivating researchers to consider how basic and applied decision science can advance researchers’ knowledge of decision making in cancer control.

References


(Appendices follow)
Appendix A

Basic and Applied Decision Making in Cancer Control Initiative

Inaugural Scientific Meeting
February 19–20, 2004, Washington, DC

Invited Speakers

Gretchen Chapman, PhD, Department of Psychology, Rutgers University
Terry Connolly, PhD, Department of Management and Policy, University of Arizona
Peter Ditto, PhD, Department of Psychology and Social Behavior, University of California, Irvine
Arthur Elstein, PhD, Department of Medical Education, University of Illinois College of Medicine, Chicago
Baruch Fischhoff, PhD, Department of Social and Decision Sciences, Department of Engineering and Public Policy, Carnegie Mellon University
Eric Johnson, PhD, Columbia Business School, Columbia University
David Kaufman, PhD, Department of Biomedical Informatics, Columbia University
George Loewenstein, PhD, Department of Social and Decision Sciences, Carnegie Mellon University
Mary Frances Luce, PhD, Fuqua School of Business, Duke University
Ronald Myers, PhD, Department of Medicine, Thomas Jefferson University
Don Redelmeier, MD, Department of Medicine, University of Toronto
Tracey Revenson, PhD, Department of Psychology, The Graduate Center of the City University of New York
Marc Schwartz, PhD, Lombardi Comprehensive Cancer Center, Georgetown University
Laura Siminoff, PhD, Department of Bioethics, Case Western Reserve University School of Medicine
Paul Slovic, PhD, Decision Research
Peter Ubel, MD, Department of Internal Medicine, University of Michigan Medical School

Karen Emmons, PhD, Department of Society, Human Development, and Health, Dana-Farber Cancer Institute and Harvard School of Public Health
Robert Greens, MD, PhD, Decision Systems Group, Harvard Medical School
Valerie Reyna, PhD, Department of Psychology, University of Texas, Arlington
Barbara Rimer, PhD, University of North Carolina School of Public Health, University of North Carolina at Chapel Hill
Neil Weinstein, PhD, Department of Human Ecology, Rutgers University
Steven Woloshin, MD, MS, Department of Medicine, Dartmouth Medical School

Representatives From Federal Agencies and Professional Organizations

Jill Egeth, PhD, Federation of Behavioral, Psychological, and Cognitive Sciences
Steven Fox, MD, MPH, Agency for Healthcare Research and Quality
Alan Kraut, PhD, American Psychological Society
William Lawrence, MD, Agency for Healthcare Research and Quality
Jonathan Leland, PhD, National Science Foundation
Richard Lempert, PhD, JD, National Science Foundation

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Belinda Borrelli, PhD, Department of Psychiatry and Human Behavior, Brown Medical School
Ann Bostrom, PhD, School of Public Policy, Georgia Institute of Technology
Michael L. DeKay, PhD, H. John Heinz III School of Management, Carnegie Mellon University
Michael Diefenbach, PhD, Department of Urology, The Mount Sinai Hospital
Craig R. Fox, PhD, Fuqua School of Business, Duke University
A Brief History of Modern-Day Decision Making

The field of judgment and decision making is relatively new, having been established in the 1950s and 1960s. Until recently, the prevailing decision-making paradigm was expected utility theory. Expected utility theory, as formulated by von Neumann and Morgenstern in their now classic publication, *Theory of Games and Economic Behavior* (von Neumann & Morgenstern, 1947), is a normative model that prescribes rational decision making through an explicit set of six axioms. Theoretically speaking, if a decision maker does not violate any of the six basic principles of expected utility theory—ordering of alternatives, dominance, cancellation, transitivity, continuity, and invariance—then he or she will select an outcome from an array of outcomes that maximizes expected utility. In the classical model, the so-called “rational actor” first determines the possible outcomes of a given decision. He or she assigns a probability to each outcome, calculates a utility for each outcome, and multiplies these values to arrive at the expected utility for each outcome. He or she then selects the outcome that maximizes expected utility. This model is predicated on the assumption that “rational man” has infinite time, limitless computational ability, and an infallible memory. A number of other theorists subsequently extended expected utility theory. Notable among these variations on expected utility theory are multiattribute utility theory (Edwards & Newman, 1982) and subjective expected utility theory (Edwards, 1961; Savage, 1954).

While the coherence, consistency, and logic of expected utility theories appealed to many, particularly those in the field of economics, others countered that the model of rational choice was an unrealistic standard for human judgment and decision making (Todd & Gigerenzer, 2000). Simon’s theory of “bounded rationality” (Simon, 1955) was one such model that recognized the limits of the mind, time, and the environment on decision making. His notion of “satisficing” (in contrast to optimizing) suggested that people select the first option to satisfy their basic requirements rather than examine all possible options. The extensive literature on heuristics and biases (Gilovich, Griffin, & Kahneman, 2002) further demonstrated that decision makers often rely on cognitive shortcuts. Perhaps the most well-known and widely accepted alternative to expected utility theory is prospect theory (Kahneman & Tversky, 1979). In contrast to expected utility theory, prospect theory provided a more descriptive transformation of utility and probability into value and decision weights. *Value*, for example, was defined in terms of deviations from a reference point. Kahneman and Tversky recognized that, by and large, people do not behave in accordance with the principles of “rational” decision making; rather, they demonstrate patterns of preferences that violate expected utility theory’s basic tenets of...
coherence and consistency. They proposed that the way in which “the acts, outcomes, and contingencies” (p. 453) of a decision problem were framed had a profound effect on peoples’ preferences. Kahneman and Tversky went so far as to say, “When framing influences the experience of consequences, the adoption of a decision frame is an ethically significant act” (Tversky & Kahneman, 1981, p. 458).

Beginning in the late 1980s, a number of decision researchers took issue with the fact that popular decision-making theories did not account for the importance of affect, emotion, motivation, and risk perception in decision making (Epstein, 1994; Loewenstein, 1996; Loewenstein, Weber, Hsee, & Welch, 2001; Schwarz, 2000; Slovic, Finucane, Peters, & MacGregor, 2002; Zajonc, 1980). They argued that feelings needed to be integrated into decision-making models. At the same time, new paradigms, such as naturalistic decision making, emerged in the study of expert decision making (Orasanu & Connolly, 1993; Patel, Kaufman, & Arocha, 2002). Although lacking theoretical grounding, naturalistic decision making offers some advantages over traditional decision-making approaches. Whereas traditional decision-making research tends to focus on the decision event, naturalistic decision-making research “focuses on decisions that are embedded in larger dynamic tasks, made by knowledgeable and experienced decision makers” (Orasanu & Connolly, 1993). In short, expert decision making is envisaged as a dynamic, evolving process that may involve multiple feedback loops rather than a static “single decision event and a fixed set of alternatives in a stable environment” (Patel et al., 2002, p. 65).

The strengths and limitations of traditional decision theory and decision analysis are well recognized today (Elwyn, Edwards, Eccles, & Rovner, 2001; Ranshoff & Feinstein, 1976; W. B. Schwartz, 1979). Traditional decision analysis provides a valuable systematic framework for organizing clinical decisions. Decision trees (Pauker & Kassirer, 1987) are, in one sense, an economical way of structuring a clinical decision: Probabilities are clearly defined, outcomes are clearly enumerated, and patient values are incorporated by utilities (Naglie, Krahm, Naimark, Redelmeier, & Detsky, 1997). In theory, the physician and patient construct the decision tree together, thereby making it a shared decision process. However, this process requires a significant degree of clinical expertise and can be extraordinarily time consuming. There are two important limitations to traditional decision analysis. The first limitation concerns traditional theory’s failure to incorporate “intangible” factors and processes, such as affect, intuition (Slovic et al., 2005; Ubel & Loewenstein, 1997), regret (Bell, 1982; Connolly & Reb, 2005), and conflict (Luce, 2005; Tversky & Shafir, 1992). The second important limitation concerns the difficulty inherent in determining preferences for future health states based on current knowledge and experience (Ditto & Hawkins, 2005; Loewenstein, 2005; Ubel, Loewenstein, Schwarz, & Smith, 2005). In addition to these limitations, some researchers have questioned whether carefully analyzing a decision into its component parts necessarily yields the “best” or most satisfying decision. For example, research suggests that analyzing the reasons for one’s preferences may lead to reductions in postchoice satisfaction (Wilson, Lisle, Schooler, Hodges, Klaaren, & LaFleur, 1993).

Despite these shortcomings, traditional decision theory provides a valuable foundation for studying decision making in cancer control. “However, classical decision theory does not address the question of making correct decisions, it merely addresses the question of making decisions correctly” (Beach & Lipshitz, 1993, p. 28). The challenge researchers face today is how to help cancer patients and their families make the “correct” decision. In other words, how can researchers further understanding of basic decision-making processes in order to help patients and providers make quality decisions—that is, decisions that truly reflect individual preferences, patient autonomy, and sound clinical judgment.

To move the science of decision making in cancer control forward, it is necessary to draw on research in both the basic and applied decision-making domains. For example, applied research that examines the usefulness of decision aids in promoting positive health behaviors should be based on sound basic research that examines such factors and processes as risk perception, heuristics and biases, affect, motivation, and social influence. There is research to suggest that, in some instances, offering too many choices may cause decisional conflict that results in a person making a suboptimal decision (Redelmeier & Shafir, 1995; Ubel, 2002). Providing too much information (e.g., listing all of the possible side effects of surgery) or providing information in a poorly understood format may also result in inconsistent decisions (Ubel, 2002). If researchers are to design useful decision support tools for patients and providers, they must achieve a fuller understanding of human decision-making processes (Kushniruk, 2001). This entails testing existing models and theories, as well as developing and testing new theoretical ideas.