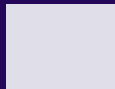


Annual Accomplishments



FOUNDATION FOR
INFORMED MEDICAL
DECISION MAKING

July 1, 2007- June 30, 2008



Dear Friend of the Foundation,

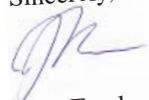
For the first 15 years of its existence, the Foundation focused almost exclusively on making balanced, accurate audiovisual programs to help patients faced with decisions about medical treatments. With our partners at Health Dialog, the development and updating of decision aids continues to be a core part of what we do. However, in the last couple of years, our Board has asked us to expand our agenda to include three additional kinds of activities:

1. Research into how best to provide information and support to patients who are faced with complex decisions.
2. Supporting clinical sites interested in trying to integrate decision aids into routine medical care in order to learn how best to implement such programs and to provide models for provider groups who want to inform and involve their patients in their medical care.
3. Communicating to interest groups, those making policy and especially to journalists so that there is a more general understanding of key messages such as more care is not always better care and having informed and involved patients is both an ethical requirement and helps to protect patients from medical treatments that do not serve their interests, and results in better medical care.

This brief document provides an overview of the Foundation's activities in each of these areas. More information is available on the Foundation's web site (www.InformedMedicalDecisions.org) and by contacting the Foundation.

We thank all the many people who work with the Foundation to help move us toward the goal of having patients routinely informed and fully involved in the decisions that affect their health and well-being.

Sincerely,



Jack Fowler

Focus of the Foundation

The Foundation for Informed Medical Decision Making is a non-profit organization based in Boston, MA, dedicated to assuring that people understand their choices and have the information they need to make sound decisions affecting their health and well being. We concentrate on four main areas of work, and this report will describe the highlights of our efforts over the past 12 months.

Decision Support

From its inception, the Foundation has built a state-of-the-art portfolio of decision support tools in various formats to help patients make informed choices. All materials provide an organized summary of the current evidence and clearly explain all related risks and benefits.

Research

Funding research to expand our knowledge of medical decision making reinforces our understanding of the best ways to support patients and providers in the medical encounter

Outreach

To accomplish our mission and advance the goal of informed medical decision making, the Foundation reaches out to share its vision with individuals and organizations across the spectrum of health and medicine.

Demonstrations

By supporting demonstrations in primary and specialty care, we learn how to integrate shared decision-making and the use of decision aids into day-to-day patient care.

Supporting Patients' Decisions

Since 1989, the Foundation has produced decision support materials for patients facing choices in medical care and treatment. All materials are high quality, up-to-date, unbiased and evidence-based.

As our portfolio of programs expands, our commitment to keep all materials current becomes vital to the value of each decision aid. Over 30 decision topics are covered in the Foundation library including most all the major medical decisions made by patients in the US.

Shared Decision-Making® Programs New or Under Development

- Living with Diabetes: Making lifestyle changes to last a lifetime (English & Spanish)
- Geriatrics
- Looking Ahead: Choices for Medical Care When You're Seriously Ill
- Coronary Heart Disease Testing Choices
- Herniated Disc
- Spinal Stenosis

Shared Decision-Making® Programs Reviewed and Updated this Year

- Acute low back pain
- Benign prostatic hyperplasia
- Breast cancer reconstruction
- Breast cancer surgery
- Chronic Low Back Pain
- DCIS
- Hip osteoarthritis
- Menopause
- Knee osteoarthritis
- Colorectal cancer screening
- Depression
- Metastatic breast cancer

Chronic Condition Guide

Conducted annual review and update of content that supports coaching for people with chronic diseases including heart disease, heart failure, diabetes, and COPD.

Focused Evidence Reviews for Health Dialog Health Coaching

- Allergies and anxiety
- Breast cancer prevention
- Carotid endarterectomy
- Chronic kidney disease
- Morphine pain pumps
- Osteoporosis
- Spinal cord stimulators

The Perspective of Patients

A unique aspect of the Foundation's approach to developing decision support tools is the way we systematically gather the perspective of patients. In preparation for each topic covered, we conduct focus groups and interview patients to identify the role of preferences and values in each decision. Patient input is then thoughtfully incorporated into the production process.

Over the past year, 23 focus groups were conducted in 8 cities involving over 100 patients to examine patient perspectives in four clinical areas.

Research

The goals of the Foundation's research agenda are to strengthen the growing knowledge of the value and effectiveness associated with informed medical decision-making and to learn how best to support patients making decisions.

The Foundation seeks to change the way medicine is practiced so that patients are routinely informed about decisions that affect their care and their lives. To do this, the Foundation supports research which will:

1. Improve decision support materials;
2. Facilitate use of decision support materials in clinical practice; and
3. Promote systematic reform in the environment in which medicine is practiced.

The DECISIONS Survey

A national survey of medical decisions has been conducted by investigators from the Survey Research Center and the Center for Behavioral and Decision Sciences in Medicine at the University of Michigan. The purpose of the project is to understand how medical decisions are made. Specifically, to describe the extent to which patients who have made decisions had basic information about their options and the implications of those options, and to understand how patients' perceive the decision-making process. The survey includes a probability sample of 3,010 adults, age 40 or older who have recently made medical decisions, selected based on random digit dialing.

Several publications are in various stages of development based on the data collected through this national survey.

Decision Quality

The objective of the Decision Quality initiative is to develop instruments that provide an assessment of the quality of medical decisions across populations of patients. This past year, the medical editors have approved draft instruments for ten conditions, including: benign prostate hyperplasia, PSA, prostate cancer, knee OA, hip OA, spinal stenosis and herniated disc, breast cancer surgery, breast cancer reconstruction, and adjuvant therapy for breast cancer.

A Mock Trial Experiment

To test potential juror's reactions to a PSA malpractice case, the Foundation conducted six focus groups with a total of 47 potential jurors. Focus groups were presented with up to three scenarios in a hypothetical malpractice case involving an allegation of failure by a primary care physician to order a PSA test for the plaintiff, a patient who later presented with incurable prostate cancer. The conclusion of this experiment is that better documentation that a patient made an informed decision to decline a PSA test appears to provide higher medical-legal protection for physicians following national guidelines, with the greatest protection conferred by the use of a decision aid. The findings of this study have been published in the Journal of Law, Medicine and Ethics.



Research (continued)

Investigator Initiated Grants

Grants awarded in this initiative are intended to support basic and applied research that will advance the field of shared decision-making. In FY2008, 7 grants were funded.

George Bennett Dissertation Fellowships & Post Doctoral Grants

To attract scholars to the field of shared decision-making in clinical care, the Foundation awards dissertation and postdoctoral grants. This past year 2 George Bennett Fellow manuscripts were published and 8 projects were funded.

Conference Presentations and Publications

14 manuscripts published in peer reviewed journals

30 posters presented at national and international scientific meetings

77 oral presentations delivered at national and international scientific meetings

Pending Publications

Several manuscripts reporting results of Foundation-funded research are in development including:

- 17 from the DECISIONS Survey
- 13 from the Demonstration Sites
- 8 from the Decision Quality Initiative
- 6 from the Investigator Initiated Grants
- 9 from the Communications/Strategic Initiatives

Demonstration Sites

The Foundation funds primary care and specialty care practices across the U.S. to learn how to integrate shared decision-making and the use of decision aids into day-to-day patient care. These practices differ in size, location, institutional affiliation and the patient population served.

All participating practices share the goal of providing high quality, patient-centered care and support the concept that shared decision-making can and should be a fundamental component care delivery. Physicians and other clinicians find that decision aids save time and enrich their practice by preparing patients with accurate and balanced information which can then personalized to meet the unique needs and preferences of an individual patient during a visit.

Aligning Incentives

The Foundation and its practice partners have learned that the process of distributing decision aids to the right people at the right time and supporting their use requires the enthusiastic endorsement of providers and staff, processes which integrate well with existing work flows, and a modest amount of infrastructure support.

While current provider reimbursement models usually do not support the cost to implement provider-based decision support programs, we believe that demonstrating the practicality and value of these programs will facilitate reimbursement redesign, encouraging broad adoption of shared decision-making.

Demonstration Sites (continued)

Primary care practices and the patient-centered medical home are particularly well suited for adopting the shared decision-making approach and are well represented amongst the Foundation's funded sites. They afford the opportunity for patients to be informed and actively involved in making decisions about screening tests, living with chronic conditions, and referrals for sub-specialty care. To date, our specialty sites are supporting shared decision-making related to breast cancer, prostate cancer and back pain.

**Model sites distributed over
13,000 decision aids to patients**

Demonstration Sites

Primary Care Demonstration Sites

- Dartmouth Hitchcock - General Internal Medicine; Lebanon, NH
- Massachusetts General Hospital (MGH) - General Medicine & John D. Stoeckle Center for Primary Care Innovation; Boston, MA
- University of California, Los Angeles - Division of General Internal Medicine & Health Services Research, Department of Medicine; Los Angeles, CA
- University of California, San Diego - Division of Family Medicine; San Diego County, CA
- University of North Carolina - General Internal Medicine; Chapel Hill, NC
- White River Junction VA Hospital - Primary Care Clinic; White River Junction, VT

Specialty Care Demonstration Sites

- Allegheny General Hospital Breast Care Center - Pittsburgh, PA
- Dartmouth Hitchcock Medical Center Prostate Cancer Program - Lebanon, NH
- Dartmouth Hitchcock Medical Center Comprehensive Breast Program - Lebanon, NH
- Group Health Shared Decision-Making Demonstration Project - Seattle, WA
- University of California at San Francisco Breast Care Center - San Francisco, CA

**324 health care providers participated
in the distribution of decision aids**

Breast Cancer Initiative

77 academic and community-based breast cancer centers participate in the Foundation's Breast Cancer Initiative distributing the portfolio of Breast Cancer Shared Decision-Making Programs. These sites receive no funding, but are provided the decision aids at no cost. Data collection involving both patients and health care providers at these sites is providing important insight into the value of decision support in breast cancer.

Outreach

The Foundation supports a number of outreach initiatives to advance the understanding of the importance and value of balanced patient-focused information in medical decision-making. This past year, these efforts included a variety of targeted activities designed to inform and heighten awareness.

Research Forum

The Foundation hosted its first Research Forum in January, 2008 bringing research and policy professionals together to learn and dialog. The meeting brought together over 100 participants and featured the results from many of the Foundation-funded research and demonstration projects. A second Forum is planned for February, 2009 in Washington, DC.

Journalist Collaboration

The media's portrayal of medical interventions and treatments has great influence on how patients view their options in medical decision-making. For this reason, the Foundation has set as one of its priorities an effort to collaborate and educate key journalists in the field of medicine and health. This past year, several successful relationships were initiated in this outreach and continue to grow.

HealthNewsReview.org

In its second year of operation, this web site has systematically reviewed over 600 health news stories in mainstream media for balance and accuracy. The first paper analyzing the results of these evaluations was published in the Public Library of Science Medicine Journal in May 2008.

Patient Centered Primary Care Collaborative

The patient-centered medical home is an ambitious initiative where decision support has been recognized as one of the ingredients of quality primary care. As several stakeholders meet at the various tables to discuss making this concept a reality, it became evident the Foundation's voice was an important one. Our involvement has improved the likelihood that shared decision-making will be included in the "home" and our efforts to support this element of the larger initiative will continue into FY2009.

Conference Sponsorship

In addition to hosting our own meeting, the Foundation was one of the sponsors of several conferences including:

Association for Health Care Journalists
Center for Information Therapy
International Shared Decision Making Conference
Society for Medical Decision Making
Society of General Internal Medicine

Outreach (continued)

National Patient Safety Foundation

The Foundation was invited to present a plenary address at the annual meeting of the National Patient Safety Foundation in May 2008. The recognition that medical safety includes a patient's involvement as an informed participant in medical decisions is an important step to enhance the understanding of shared decision-making.

Milbank Memorial Fund

An informational seminar was conducted by the Foundation for 21 members (representing 16 states) of the Reforming States Group sponsored by the Milbank Memorial Fund. This seminar was held in response to interest in shared decision-making as a national policy item for the group to consider.

IOM Evidence Based Medicine Communications Collaborative

The Institute of Medicine Evidence Based Medicine Roundtable established a Communications Collaborative to address the importance of a patient's understanding of the role of evidence in medical decisions. Much of the Foundation's work can make an important contribution to help this group meet its objectives. The Foundation has, and will continue to support the work of this Collaborative.

A Partnership for Progress



Much of our funding is derived from a unique partnership with Health Dialog, a company that provides patient support services to providers and health plans. Our portfolio of programs helps Health Dialog to provide comprehensive decision support materials. In exchange, we receive a portion of Health Dialog's revenues as royalties.



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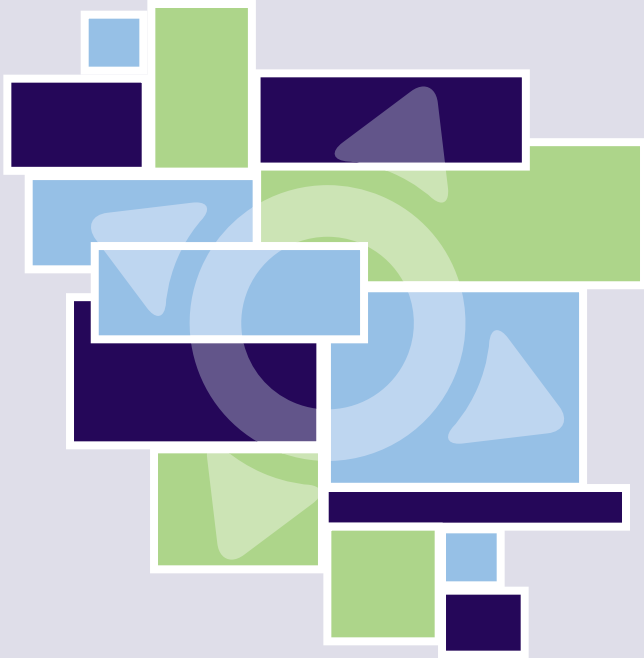
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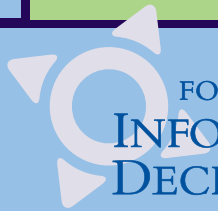
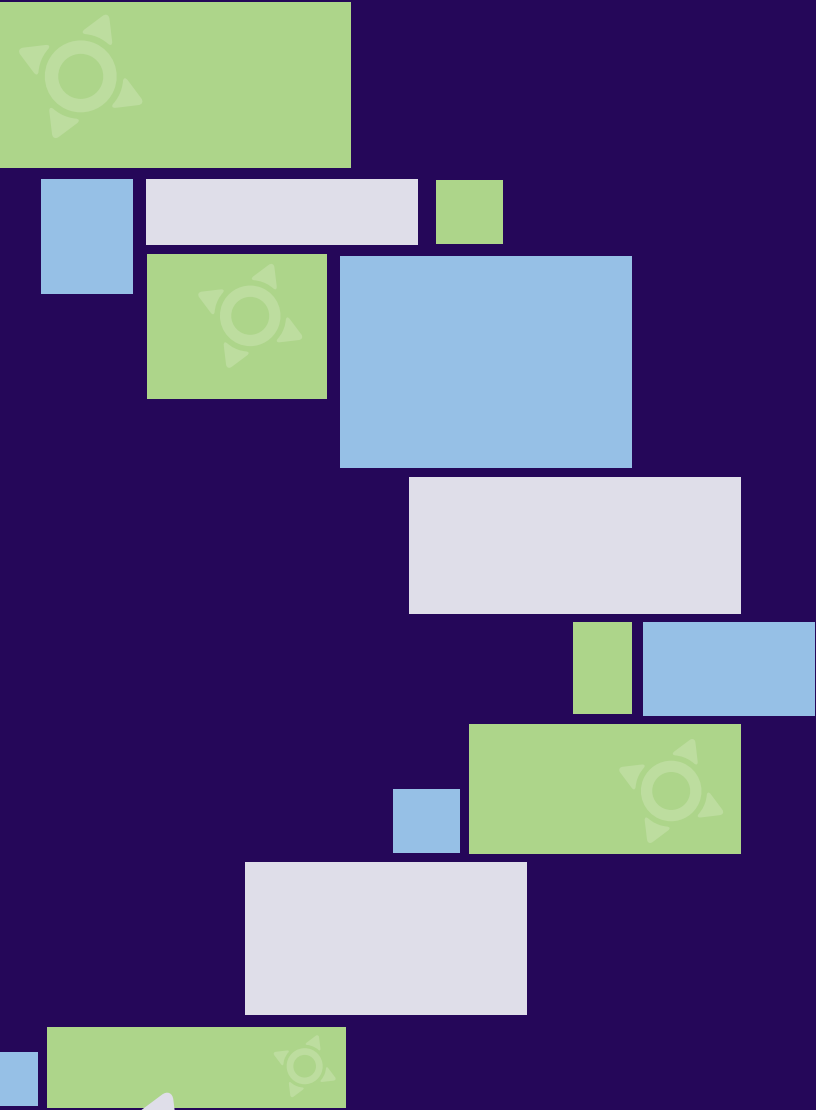
**The care you need and no less.
The care you want and no more.**



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