



Report for Fiscal Years 2005-2006

FY05: July 1, 2004 – June 30, 2005

FY06: July 1, 2005 – June 30, 2006

40 Court Street
Suite 200
Boston, MA 02108

www.fimdm.org
617-367-2000 tel
617-367-0315 fax

Organizational Profile

The Foundation for Informed Medical Decision Making, Inc. is a not-for-profit organization dedicated to improving the quality of decisions made by patients in collaboration with their physicians. The Foundation creates Shared Decision-Making® programs in video tape and other forms that combine the best medical evidence with a clear appreciation of patients' attitudes and preferences regarding treatment alternatives.

Since 1997, the Foundation has worked in partnership with Health Dialog to expand the distribution of Shared Decision-Making® programs and other material developed by the Foundation. Health Dialog is a for-profit company that provides patient support services, including a health-coaching network involving nurses, for employers and health plans that are interested in providing excellent care to their employees or members. Among the services that Health Dialog provides to its clients are access to the Foundation's decision aids and decision support material. A portion of Health Dialog's revenues go to the Foundation in the form of royalties to support the development of new decision aids and research on how best to help patients make decisions. The Foundation does not accept funding from any source that has a financial interest in any particular approach to medical testing or treatment.

At its inception in 1989, the Foundation was housed at Dartmouth Medical School in Hanover, New Hampshire. In 2002, recognizing the expanding scope of the Foundation's work, the Foundation moved to 40 Court Street in Boston, Massachusetts.

Our Mission

The Foundation for Informed Medical Decision Making is a not-for-profit organization dedicated to ensuring that people understand their choices and have the information they need to make sound decisions affecting their health and well being.

Accomplishing our mission:

- ❖ We promote understanding and adoption of informed medical decision-making.
- ❖ We organize and frame medical evidence in an unbiased manner to help people evaluate their options, particularly in instances where differences in individual preferences and perspectives are likely to affect personal choice.
- ❖ We sponsor research to expand knowledge of how to improve decision quality in health care.

Medical Evidence + Patient Perspective = Informed Medical Decisions

Medical Evidence

The science of medical care is advancing at a rate that makes the delivery of quality patient-focused care an enormous challenge. New information about disease biology and genetics, rapid development of new tests and treatments, and the shift in disease from largely acute to largely chronic are all important contributing factors.

Patient Perspective

Medical research on practice variation indicates that patient perspectives are often less important in treatment decisions than factors having little to do with patients or their illnesses, such as geography, economics or supplier-induced demands.

The Foundation brings the patient perspective into focus by interviewing real patients who can talk about the choices they made and why. Without the perspective of the patient, we cannot achieve a quality medical decision.

Informed Medical Decisions

The Foundation believes that it is the convergence of the two concepts: medical evidence and patient perspectives that create a truly informed decision in medical care.

The Foundation for Informed Medical Decision Making, Inc.
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I. New Program and Content Development

As of 2006, 26 Shared Decision-Making® programs are currently available in videotape and DVD form. Each year we revise some of the current programs and add new programs. In the past two fiscal years, the following program development took place:

FY 05

New programs completed

- ❖ Acute Low Back Pain: Managing Your Pain Through Self-Care
- ❖ Treatment Choices for Hip Osteoarthritis
- ❖ Living with Metastatic Breast Cancer: Making the Journey Your Own
- ❖ Colon Cancer Screening

Revised programs completed

- ❖ Treatment Choices for Benign Prostatic Hyperplasia: Choosing Surgical or Nonsurgical Treatment
- ❖ Treatment Choices for Knee Osteoarthritis
- ❖ Treatment Choices for Prostate Cancer
- ❖ Ovarian Cancer: Reducing Your Risks

FY06

New programs completed

- ❖ Advanced Prostate Cancer: Is Hormone Therapy Right for You? (Androgen Deprivation Therapy)
- ❖ Coping with Symptoms of Depression
- ❖ Managing Menopause: Choosing Treatments for Menopause Symptoms
- ❖ Weight Loss Surgery: Is it Right for You?

Revised programs completed

- ❖ Breast Reconstruction - Is It Right for You? (booklet)
- ❖ Early Stage Breast Cancer: Choosing Your Surgery
- ❖ Chronic Low Back Pain: Managing Your Pain and Your Life (booklet)
- ❖ DCIS: Choosing Your Treatment
- ❖ Peace of Mind: Personal Stories about Advance Directives
- ❖ Treatment Choices for Hip Osteoarthritis
- ❖ Is a PSA Test Right for You?
- ❖ Treatment Choices for Low Back Pain: Spinal Stenosis

Existing programs currently undergoing revision

- ❖ Treatment Choices for Abnormal Uterine Bleeding
- ❖ Treatment Choices for Uterine Fibroids
- ❖ Living with Coronary Artery Disease: Doing Your Part

- ❖ Early Breast Cancer: Hormone Therapy and Chemotherapy - Are They Right for You?
- ❖ Treatment Choices for Low Back Pain: Herniated Disc

Programs in production or content development phase

- ❖ Heart failure
- ❖ Informed Healthcare Consumer
- ❖ Chronic Pain
- ❖ Diabetes

Content development for new programs also draws on focus group discussions with patients, and separate focus groups are sometimes held with providers.

The development process for both new and revised programs includes review by patients and providers of “rough cuts,” the first video version of the script with the evidence (including risks and benefits of treatment choices) and clips from patient and provider interviews.

II. Ongoing Evaluation of Existing Programs

The Evaluation Process

Our Shared Decision-Making® programs include a video tape or DVD and a booklet which present the latest clinical evidence about the risks and benefits of treatment options and patients’ testimonials about their reasons for choosing different treatments. The evaluation process includes both six month and two year reviews which can result in program revisions:

- ❖ Every six months, the medical editor for each program reviews the current version and all related products to ensure that they are up to date and reflect current clinical practice.
- ❖ Every two years, we conduct an extensive review that involves outside clinical advisors, experts and patient focus groups recruited from at least two different evaluation sites.
- ❖ In addition, updates may occur at any time if warranted by substantial advancements in clinical knowledge
- ❖ Finally, the results from these evaluations are integrated into reports for Health Dialog.

In addition, we receive ongoing feedback from patients who use our programs to help make decisions at the Shared Decision-Making Center at Dartmouth Hitchcock Medical Center (DHMC). Efforts are underway to analyze this quantitative and qualitative data from DHMC to determine patterns in responses from different patient viewer populations.

III. Technical Assistance to Health Dialog

The Foundation serves as a resource to Health Dialog in a variety of ways. Activities undertaken to support Health Dialog included:

- ❖ DHMC is working with the Health Coach leadership at Health Dialog to refine training protocols and monitor strategies for supervising and improving the quality of decision support provided by the Health Coaches.
- ❖ The Foundation's clinical evidence staff is available as a resource to Health Coaches when new clinical studies are released and the media raises issues of interest to patients. The Foundation staff helps to put the results into perspective and answer patients' questions.
- ❖ FIMDM provides clinical support for all of Health Dialog's activities relating to chronic condition management, particularly for the Health Coaches providing patient assistance over the phone. In FY 2006, we completed a large-scale review and update of the chronic condition guide (CCG), including review and update of all content by Medical Editors. This was in addition to the annual review of new guidelines and literature.
- ❖ Drs. Mulley and Wennberg frequently make presentations and meet with those potentially interested in working with Health Dialog to help elaborate the scientific underpinnings of the Foundation's work.

IV. Use and Distribution of Shared Decision-Making materials

Shared Decision-Making® programs are distributed in three ways:

- ❖ As founding partners, the Massachusetts General Hospital (MGH) and Dartmouth Hitchcock Medical Center (DHMC) have had the right to use all of the Foundation's materials. Both institutions are integrating SDM programs into primary care practice.
- ❖ In FY05 and FY06, the Foundation has worked with additional clinical sites to collect data about patient experiences and device methods to integrate decision support into practice. Please see the information on demonstration sites described in the Research section below for more information on these programs.

- ❖ The *Breast Cancer Initiative* (a joint effort of the Foundation and Health Dialog) has developed a network involving 24 sites around the country and an additional 23 sites in Massachusetts. In Fiscal Years 2005 and 2006, an estimated 1,200 breast cancer patients used decision aids through one of these sites.

Cardiovascular Risk Calculator

The Foundation has been working on the development of a web-based risk calculator to help patients put their individual risks of heart events and the value of interventions into perspective. The Cardiovascular Risk Calculator will estimate an individual's chance of a cardiac event, dying from heart disease, and overall chance of dying in the next 10 years.

It is not designed for individuals who have had a heart event or a diagnosis of heart disease; and it is not for diabetics or people over the age of 75. Those subroutines will be added once the Foundation completes an appropriate and successful method to communicate these complex ideas.

V. Research

The Foundation has launched pilot projects at several clinical sites to engage them in routine use of Shared Decision-Making® programs. These demonstration sites include:

Primary Care Demonstration Sites

- ❖ *Massachusetts General Hospital, General Medicine Unit:* This project uses a pilot group of primary care physicians to demonstrate how “e-prescribing” videos affect clinician workflow and time; identifies barriers faced by clinicians; gathers feedback from patients about their perceptions and satisfaction with receiving videos; explores and documents effective strategies for achieving physician buy-in; and “closes the loop” to make shared decision making an integral part of routine clinical practice. The electronic medical record allows decision aids to be mailed or picked up by patient.
- ❖ *Dartmouth Hitchcock Medical Center (DHMC), Department of General Internal Medicine:* Shared decision-making is tied into a larger “re-engineering” initiative in primary care to implement an electronic Health History Questionnaire (HHQ) to be completed by patients. This project evaluates the best method to: persuade patients eligible for PSA and colon cancer screening to complete the HHQ pre-visit at home or at the clinic; view a Shared Decision-Making® program; and complete a post-visit questionnaire.

- ❖ ***White River Junction Veterans Administration, Primary Care Medicine:*** This project aims to fully integrate one preventive medicine decision aid, the Foundation's PSA screening program, into the process of care throughout the section of Primary Care Medicine at the White River Junction VA.
- ❖ ***University of California at Los Angeles, Department of Medicine:*** The goals of this project are to recruit 10 community-based primary care practices; collect qualitative data on barriers and solutions to decision aid integration using focus groups, in-depth interviews and participant observation; collect quantitative data to describe psychological determinants of shared decision-making; and examine the impact of using decision aids with diverse low-income patients.
- ❖ ***University of California at San Diego, Division of Family Medicine:*** The focus of this project is to examine factors that predict response to Shared Decision-Making® decision aids. It will investigate whether particular health conditions predict satisfaction with decision aids; to use electronic medical record prompts to facilitate shared decision-making; and assess the feasibility of using a web-enabled video viewing and data capture system to measure satisfaction and rate of patient-physician interactions resulting from video viewing.
- ❖ ***University of North Carolina (UNC) at Chapel Hill, Division of General Internal Medicine:*** The project aims to determine the effectiveness, acceptability and feasibility of mass mailing of the Colon Cancer Screening decision aid.

Specialty Care Demonstration Sites

- ❖ ***University of California at San Francisco, Cancer Center (Breast and Prostate Cancer):*** This project aims to achieve routine integration of shared decision-making into the breast care center; validate and integrate the Foundation's decision quality surveys into clinical outcome measures; and move toward integrating shared decision-making into prostate cancer care via a small randomized controlled trial with 20 patients in each arm. The trial will compare viewing the Treatment choices for Prostate Cancer video with usual care.
- ❖ ***University of AZ, Arizona Cancer Center (Breast Cancer):*** The study focuses on the responses of Latina women to the Foundation breast cancer decision aids to determine the feasibility and acceptability of their use in this population. This study will determine: the salient issues; whether the materials will prove useful for all or only a portion of the patient population; and when, how, and under what circumstances the decision aids should be presented.

- ❖ ***University of Cincinnati, Division of General Internal Medicine*** (Coronary Artery Disease, Advance Directives): This project will study the implementation and effectiveness of two Shared Decision-Making® programs (Treatment Choices for Coronary Artery Disease and Peace of Mind: Personal Stories About Advance Directives) in a hospital-based ambulatory practice. The project tests the hypothesis that the video version of the program is “superior” to the printed material alone in patients with poor health literacy.
- ❖ ***Comprehensive Breast Care Program and Center for Shared Decision-Making at DHMC*** (Breast Cancer): This project aims to improve quality of clinical care by incorporating information technology to screen patients, inform physicians, prompt the use of the decision aid, assess naïve and informed preferences, flag emotional distress, and assess decision quality.
- ❖ ***Allegheny General Hospital Breast Care Center*** (Breast Cancer): This is a collaboratively funded project (the Foundation and Highmark) to incorporate decision aids into routine breast cancer care at Allegheny General Hospital with an emphasis on working with a diverse minority population. The program is being modeled on the Breast Program at DHMC.

National Institutes of Health Research Project Grant (RO1): Principal investigators from each of the Primary Care Demonstration Sites are working together to submit an RO1 proposal to respond to the Request For Proposal from NIH titled, “Dissemination and Implementation Research in Health.” This proposal will focus on integrating cancer-related decision aids into primary care practice.

Decision Quality

- ❖ ***United Kingdom Urology***: Drs. Mulley, Barry, Sepucha and O’Connor are working closely with colleagues in the UK on implementation of urological decision aids and decision quality measures in five sites across England.
- ❖ ***Patient and Provider Perspectives on Decision Quality for Key Decisions***: This is a pilot project to develop decision quality instrument for assessing the quality of medical decisions across populations of patients. The instruments developed will be used to evaluate the extent to which patients are informed and make decisions that are consistent with their values. Measures are being piloted with 20 patients and 20 providers across the country.
- ❖ ***Breast Cancer Initiative***: This initiative continues to disseminate the breast cancer programs across the country, focusing on community sites. The Foundation has developed relationships with 35 community-based clinics, Fox

Chase Cancer Center in Philadelphia, and a group of community oncologists affiliated with Wilshire Oncology Group in California.

- ❖ ***National Survey of Medical Decisions:*** Investigators from the Survey Research Center and the Center for Behavioral and Decision Sciences in Medicine at the University of Michigan are conducting a national survey of medical decisions to identify and interview people who have recently made decisions, to describe how decisions are being made and determine which covariates should be measured to understand how these individuals reached their decisions.
- ❖ ***Comparative Analysis of Print and Multimedia Health Materials:*** This is a literature review to examine the evidence on whether multimedia programs improve health communication compared to print materials and whether the benefits of multimedia vary according to patients' level of literacy.

George Bennett Dissertation Fellowship

The George Bennett Dissertation Fellowship supports dissertation research in shared medical decision-making. The grants are designed to support basic and applied research that can advance the field, and to attract scholars to the field of shared decision-making in medical care from divergent fields including psychology, sociology, anthropology, public health, public policy, political science, economics, engineering, business, law, and related fields of study.

- The 2006 George Bennett Fellow is earning his M.D., Ph.D. in the Center for the Evaluative Clinical Sciences at Dartmouth Medical School, researching shared decision making for patients with severe and persistent mental illness.

Related Research (not directly funded by the Foundation, but uses Foundation decision aids)

- ❖ ***Community Interventions in Non-medical Settings to Increase Informed Decision Making for Prostate Cancer Screening,*** University of Texas Health Science Center at Houston, Center for Health Promotion and Prevention Research (Is a PSA Test Right For You?).
- ❖ ***Patient-Centered Depression Care for African-Americans (the Bridge Study),*** Johns Hopkins University Bloomberg School of Public Health (Coping with Symptoms of Depression).

- ❖ *Assessing the Cultural Competence of the Dartmouth Knee OA Decision Aid*, Center for Health Equity Research and Promotion, VA Pittsburgh Healthcare System (Treatment Choices for Knee Osteoarthritis).
- ❖ *Chronic Pain Program*, Best Doctors Occupational Health Institute (Chronic Low Back Pain).
- ❖ *Improving the Quality of Individual Health Care Decision Making*, Westat. (Breast Cancer)
- ❖ *Treatment choices for Knee Osteoarthritis*, UCLA Rehabilitation Center (Treatment choices for Knee Osteoarthritis)
- ❖ We are consulting on the Prostate Cancer Outreach Program funded by the CDC, *“Reaching Urban African-American Men with Prostate Cancer Screening Information”*.
- ❖ We are participating in evaluation studies of Shared Decision-Making® programs in Norway and Germany.

V. Dissemination, Teaching and Training

One of the Foundation’s missions is to educate patients and physicians about how shared decision-making is accomplished. Our recent efforts included:

- ❖ Presentations by Drs. Mulley and Wennberg at national and international conferences and in a variety of settings with physicians and others who are exploring SDM and decision support.
- ❖ Drs. Barry, Mulley, Sepucha, and Wong gave a short course, *Measuring the Quality of Preference-Sensitive Decisions*, at the annual meeting of the Society of Medical Decision Making.
- ❖ Dr. Mulley developed a template for teaching SDM and collaborative care and used it to make a “see-one-do-one-teach-one” presentation that was presented to the Foundation Medical Editors as well as at multiple presentations in the US, Canada, and the UK. The Medical Editors have since used the template in making presentations in their home institutions and elsewhere.
- ❖ Kate Clay presented the workshop, *Decision Support as a Clinical Skill*, at DHMC and the Foundation. This course teaches providers how to enhance their

interactions with patients who are offered treatment options for a health problem, where there is no clear “best” choice.

- ❖ Professor Annette O’Connor led the International Patient Decision Aids Standards (IPDAS) Collaboration. The IPDAS Collaboration is an international group of researchers, practitioners and stakeholders with the goal of establishing an internationally approved set of criteria to determine the quality of patient decision aids.
- ❖ Drs. O’Connor and Llewellyn-Thomas made presentations at key research and professional meetings such as the International Shared Decision Making Conference and the Society for Medical Decision Making emphasizing systematic evidence about the “best practice” models for implementing decision support in clinical care and the development and performance of decision quality measures in practical applications, in research, and in systematic reviews.

HealthNewsReview.org

In April 2006, the Foundation launched the website HealthNewsReview.org to help journalists achieve excellence in coverage of health news stories. In partnership with Professor Gary Schwitzer of the University of Minnesota School of Journalism & Mass Communication, this website provides the first systematic audit and feedback mechanism for rating US health/medical news coverage. Through this process of standardized rating and documenting the shortcomings in the reporting of new drugs and other health technologies, the Foundation aims to foster improvement in the field of health news reporting, and provide valuable evaluations to consumers and health care professionals.

Outreach and Communications

During FY2006, the Foundation took steps to strategically develop its dissemination plan to include a more aggressive approach to outreach and communication efforts. These planning steps helped to identify appropriate methods to further advance the Foundation’s mission and message. The result of this work was a focus on inspiring influential leaders and stimulating structural change to advance a new standard of informed patient choice.

Awards our programs have won

COMPETITION NAME	PROGRAM	AWARD	COMPETITION CATEGORY
National Mature Media Awards (2003)	Knee Osteoarthritis	Silver	
Freddie Award, AMA's International Health and Medical Media Awards (2003)	Knee Osteoarthritis	Winner	Arthritis/Inflammatory Diseases
American Medical Writers Association New England Chapter (2004)	Breast Cancer: DCIS	Will Solimene Award for Excellence	
American Medical Writers Association New England Chapter (2004)	Breast Cancer: DCIS	Neil Duane Award for Distinction	
National Health Information Awards (2004)	Breast Cancer Reconstruction	Merit Award	Consumer Decision-Making, Video
National Health Information Awards (2004)	Chronic Low Back Pain	Merit Award	Patient Education Information, Video
National Mature Media Awards (2004)	PSA	Merit Award	
Freddie Award, AMA's International Health and Medical Media Awards (2004)	PSA	Winner	Men's Health
Freddie Award, AMA's International Health and Medical Media Awards (2004)	Chronic Low Back Pain	Finalist	Coping
Chris Award, Columbus Film and Video Festival (2004)	Breast Cancer Chemotherapy and Hormone Therapy	Honorable Mention	Physical Health
Chris Award, Columbus Film and Video Festival (2004)	Chronic Low Back Pain	Honorable Mention	Physical Health
Chris Award, Columbus Film and Video Festival (2004)	PSA	Honorable Mention	Physical Health

Health Sciences Communications Association (HeSCA Media Festivals) (2005)	Living with CAD	Gold	
Health Sciences Communications Association (HeSCA Media Festivals) (2005)	Breast Cancer Chemotherapy and Hormone Therapy	Bronze	
Health Sciences Communications Association (HeSCA Media Festivals) (2005)	Hip Osteoarthritis	Bronze	
Media Communications Association International (MCA-I) (2005)	Living with CAD	Finalist	
National Mature Media Awards (2005)	Hip Osteoarthritis	Bronze	
National Mature Media Awards (2005)	BPH	Bronze	
National Health Information Awards (2005)	BPH	Gold	Consumer Decision-Making, Video
Freddie Award, AMA's International Health and Medical Media Awards (2005)	Living with CAD	Winner	Stroke and Heart Disease
Freddie Award, AMA's International Health and Medical Media Awards (2005)	Breast Cancer: Metastatic	Finalist	Coping
Freddie Award, AMA's International Health and Medical Media Awards (2005)	Hip Osteoarthritis	Finalist	Arthritis/Inflammatory Diseases
Freddie Award, AMA's International Health and Medical Media Awards (2005)	Chronic Low Back Pain	Finalist	Health Education
Freddie Award, AMA's International Health and Medical Media Awards (2005)	Colon Cancer Screening	Finalist	Prevention

Freddie Award, AMA's International Health and Medical Media Awards (2005)	Health Crossroads	Finalist	Web Sites
American Medical Writers Association New England Chapter (2006)	Breast Cancer Chemotherapy and Hormone Therapy	Will Solimene Award for Excellence	
American Medical Writers Association New England Chapter (2006)	Breast Cancer: Metastatic	Will Solimene Award for Excellence	
National Mature Media Awards (2006)	Knee Osteoarthritis	Bronze	
National Mature Media Awards (2006)	Menopause	Merit Award	

VI. Future Directions

Priorities for the near future include:

- ❖ Expanding our portfolio of programs with special influences on chronic condition management.
- ❖ Expand breast cancer network of sites using decision aids.
- ❖ Establishing several model specialty practices where shared decision making will be integrated into decisions about cardiac care and prostate cancer.
- ❖ Working with Health Dialog to further develop the value of the material available via the Internet.
- ❖ Fund additional basic research to learn more about how best to support patients' decisions.
- ❖ Strengthen dissemination of information about our activities and our goals to our colleagues, the professional community and the public at large.

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Dartmouth Medical School

Albert G. Mulley, MD, MPP

Co-Founder, Senior Medical Advisor

Associate Professor of Medicine and of Health Policy at Harvard Medical School

Chief of the General Medicine Division and Director of the Medical Practices Evaluation
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