



Annual Report for Fiscal Year 2004  
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## **The Foundation for Informed Medical Decision Making, Inc. Annual Report for Fiscal Year 2004**

### **Foreword**

The Foundation for Informed Medical Decision Making, Inc. (FIMDM) 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 (SDM) programs (more generally called decision aids) 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, NH. In 2002, recognizing the expanding scope of FIMDM's work, the Foundation moved to 40 Court Street in Boston.

## **I. New Program/Content Development**

As of 2004, eighteen SDM programs are currently available in videotape form. Each year we revise some of the current programs and add new programs. In FY 2004, the following program development took place:

### New programs completed

- ♦ Treatment Choices for DCIS: Choosing Your Treatment (September 2003)
- ♦ Chronic Low Back Pain: Managing Your Pain and Your Life (January 2004)

### Revised programs completed

- ♦ Treatment Choices for Abnormal Uterine Bleeding (January 2004)
- ♦ Treatment Choices for Uterine Fibroids (January 2004)
- ♦ Early Breast Cancer Hormone Therapy and Chemotherapy: Are they Right for You? (April 2004)
- ♦ Early Stage Breast Cancer: Choosing Your Surgery (April 2004)

### Existing programs currently undergoing revision (to be completed by Fall 2004)

- ♦ Benign Prostatic Hyperplasia
- ♦ Treatment Choices for Coronary Artery Disease
- ♦ Living with Coronary Artery Disease: Doing Your Part
- ♦ Treatment Choices for Back Pain: Herniated Disc
- ♦ Treatment Choices for Back Pain: Spinal Stenosis

### Programs on which we have begun production

- ♦ Osteoarthritis of the Hip (Fall 2004)
- ♦ Colon Cancer Screening (Fall 2004)
- ♦ Treatment of Metastatic Breast Cancer (Winter 2005)
- ♦ Depression (Spring 2005)
- ♦ Managing Menopause (Spring 2005)
- ♦ Spanish translation of the program, Is a PSA Test Right for You? (Winter 2005)

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. (see Table 1.1 below)

Content development for new programs also draws on focus group discussions with patients, and separate focus groups are sometimes held with providers. (see Table 1.2)

(Table 1.1) Reviews to Evaluate Programs in “Rough Cut” Stage

Program	Release Date	# Patients	# Providers
DCIS Treatment	September 2003	46	7
Hormone Therapy & Chemotherapy for Breast Cancer	April 2004	31	6
Chronic Low Back Pain	January 2004	26	7
<b>TOTAL</b>		<b>103</b>	<b>20</b>

(Table 1.2) Focus Groups - Patient Perspectives on Medical Topics by Location

Topic	Expected Release Date	# Patients
Colon Cancer Screening	Fall 2004	
<i>Atlanta, GA</i>		23
<i>Boston, MA</i>		17
Metastatic Breast Cancer	Winter 2005	
<i>Boston, MA</i>		4
<i>Hanover, NH</i>		4
Depression	Spring 2005	
<i>Hanover, NH</i>		18
<i>Durham, NC</i>		24
Managing Menopause	Spring 2005	
<i>Boston, MA</i>		8
<i>Hanover, NH</i>		14
Renal Disease	NA	
<i>Hanover, NH</i>		5
<i>Lancaster, NH</i>		7
<b>TOTAL</b>		<b>124</b>

## II. Ongoing Evaluation of Existing Programs

Our Shared Decision Making programs, which include a video tape and a booklet, present the latest clinical evidence about the risks and benefits of treatment options in ways that patients can understand. In the past, these programs were reviewed and updated as needed. In May 2002, a systematic evaluation calendar was established in agreement with Health Dialog. 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. Updates may occur at any time if warranted by substantial advancements in clinical knowledge. Every two years, we conduct an extensive review that involves outside clinical advisors, experts and patients. A Senior Research Assistant for Program Evaluation coordinates these evaluation activities and integrates the results from evaluations into reports.

Evaluations are also done for the online information in the HealthDialog.com Crossroads, a collection of Web-based tools available to those receiving patient support services from Health Dialog through their employers, insurers or special programs.

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).

## III. Use and Distribution of SDM materials

**SDM programs** are distributed in three ways:

- ♦ The primary method is through Health Dialog Health Coaches providing patient support services. In FY 04, Health Dialog sent out over 20,000 tapes. The program most often distributed was Secondary Prevention of CAD (over 4,000) while the combined total for all of the Orthopedic programs came to over 10,000.
- ♦ 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 now planning strategies to integrate SDM programs into primary care practice.

- ◆ In FY04, the Foundation began working with several additional clinical sites to collect data about patient experiences and means to integrate decision support into practice. The Breast Cancer Initiative (a joint effort of the Foundation and Health Dialog) has developed a network involving 9 sites around the country and 16 additional sites in Massachusetts. In Fiscal Year 2004, an estimated 1,000 breast cancer patients used relevant decision aids through one of these sites. In the coming year, patients using our materials will fill out questionnaires about them. Their experience will provide input for the ongoing evaluation of our programs.

**Web-based materials** are also available through Health Dialog; they currently address over 70 decision points (crossroads) for 6 health conditions. In FY04, the Foundation's medical editors reviewed all of the material and some of the revisions were completed by July 1. In the Spring of 2004, Health Dialog launched a pilot program to offer its web-based materials to WebMD subscribers. The Foundation and Health Dialog are currently designing ways to reorganize this material. Another new initiative is the development of a Coronary Artery Disease Risk calculator to be available to the Health Coaches or via the Internet. The calculator, as currently planned, will not only calculate Coronary Artery Risks but also highlight changes patients might make to reduce their risks.

#### IV. 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 in FY04 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. Products have included a web-based auto-tutorial (which is currently being tested for use in routine training) and a simulated caller training program which will be applied to chronic condition management in FY05.
- ◆ The Foundation's clinical 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. Some recent topics included: virtual colonoscopy, intensive statin therapy and heart disease risk, off-label use of drugs for weight loss, minimally invasive surgery for hip replacement and knee replacement, and epidural injections for back pain.

- ♦ 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. We participate in the annual review and update of chronic condition management materials by reviewing new guidelines and literature and recommending revisions as appropriate.
- ♦ 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.

## V. Research

- ♦ The Foundation has launched pilot projects at several cooperating clinical sites to engage them in routine use of SDM programs. Cooperating sites include the University of California at San Diego and a small orthopedic practice in Scarborough, Maine.
- ♦ A potentially ground-breaking project at Dartmouth involves a collaboration between the SDM Center and the Comprehensive Breast Care Program at DHMC to determine whether decision support using counseling and videos on the treatment of early breast cancer can be successfully integrated into the usual process of clinical care and determine its impact on physical, social and emotional distress and decision conflict.
- ♦ In FY04, the Foundation received a grant from the Commonwealth Fund to evaluate issues affecting the value of SDM programs for potentially underserved groups. Focus groups were held in San Diego, Atlanta and Maine with patients who had previously made breast cancer surgery decisions and agreed to evaluate our Early Stage Breast Cancer Surgery program. Participants included African American, Latina and rural women. An additional Latina group will be convened in October by the Latino American Health Institute in Boston.
- ♦ We are participating in evaluation studies of SDM programs in Norway and Germany.
- ♦ A grant proposal has been submitted to the National Cancer Institute (NCI) to develop and evaluate measures of decision quality in breast cancer treatment decisions.

## VI. Dissemination, Teaching and Training

One of the Foundation's missions is to educate patients and physicians about how Shared Decision Making is accomplished. This year's 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.
- ♦ Meetings in the United Kingdom about pilot programs to integrate the Foundation's work into urology and primary care practices there.
- ♦ A Continuing Medical Education course on Shared Decision Making has been developed by Al Mulley, Karen Sepucha, John Wong and Michael Barry. They have written case studies on decision quality and pitfalls in medical decision making and prepared abstracts and references for use in a CME course.
- ♦ Two of our programs received national media recognition. *Treatment Choices for Knee Osteoarthritis* won a Freddie Award from the International Health and Medical Awards in the Arthritis and Inflammatory Diseases category. This competition's goal is to encourage and celebrate excellence, and it attracts documentaries, series, shorts, videos, Web sites and CD-ROMs from around the world. The Freddie is often considered the Oscar of Medical Media. In addition the SDM program *DCIS: Choosing Your Treatment* received an American Medical Writer's Award.

## VII. Administration: Major Highlights

To continue to refine the Foundation's infrastructure, we undertook the following activities in FY04:

- ♦ A new contract-tracking system was developed and implemented.
- ♦ An online database is now used to coordinate and track periodic program reviews and new program development.
- ♦ Additional professional staff members have been hired to strengthen our core capabilities. We now have four research associates compiling clinical evidence, two research associates analyzing patient perspectives as well as appropriate evaluation and administrative staff are in place.



## VIII. Future Directions

Priorities for the coming year include:

- ♦ Expanding our portfolio of programs for use in primary care settings.
- ♦ Developing several new test sites where Shared Decision Making will be integrated into primary care practice.
- ♦ Establishing several model specialty practices where Shared Decision Making will be integrated into the treatment of breast cancer and, possibly, urological conditions.
- ♦ Working with Health Dialog to further develop the value of the material available via the Internet.
- ♦ Enhance our knowledge about chronic condition management.
- ♦ 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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