

3rd International Shared Decision Making Conference 2005

June 14-16

Ottawa, Canada

Implementing Shared Decision Making In Diverse Health Care Systems And Cultures

Program and Abstracts



**University of Ottawa
Ottawa, Ontario, Canada**

3rd International Shared Decision Making Conference

June 14 – 16, 2005

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Program and Abstracts



University of Ottawa

Ottawa, Ontario Canada

ISDM2005 PROGRAM
University of Ottawa
Café 216 (2nd floor), Jock Turcott University Centre,
85 University

	Tuesday, June 14th	Wednesday, June 15th	Thursday, June 16th
7:30		Breakfast Café 216	Breakfast Café 216
8:30		Plenary Keynote Speaker: J.A. Muir Gray Room A	Plenary Keynote Speaker: Cathy Charles Room A
9:30		Plenary: IPDAS Collaboration Chair: Angela Coulter Room A	Plenary: Debate Chair: Angela Coulter Room A
10:30		Poster Session 1 (Refreshments) Café 216/Terminus	Poster Session 3 (Refreshments) Café 216/Terminus
11:30		Parallel Session 2 Rooms A to D	Parallel Session 4 Rooms A to D
12:30	Registration (Refreshments) Café 216	Lunch University Centre Cafeteria (1 st floor)	Lunch University Centre Cafeteria (1 st floor)
14:00	Opening Plenary Keynote Speaker: Jonathan Lomas Room A	Parallel Session 3 Rooms A to D	Parallel Session 5 Rooms A to D
15:00	Guest Speaker: Donald Kemper	Poster Session 2 (Refreshments) Café 216/Terminus	Refreshments Café 216
15:30	Refreshments Café 216		Parallel Session 6 Rooms A to D
16:00	Parallel Session 1 Rooms A to D	Open Forum TBD	
16:30			Conference Closes
17:00			
18:00	Reception/Welcome BBQ Jock Turcott University Centre Outdoor Patio	Gala Dinner Museum of Civilization Transport via buses Pianist: Lila Arancze	
21:00			
22:00			

MONTPETIT HALL Room A = MNT 202, Room B = MNT 203, Room C = MNT 201, Room D = MNT 207

UNIVERSITY OF OTTAWA MAP



PLANNING COMMITTEES

Organizing Committee:

Annette O'Connor (Chair)	University of Ottawa, OHRI, Canada
Alexandra Barratt	University of Sydney, Australia
Cathy Charles	McMaster University, Canada
Angela Coulter	Picker Institute, UK
Ian Graham	University of Ottawa, OHRI, Canada
Margaret Holmes-Rovner	Michigan State University, USA
France Légaré	University of Laval, Canada
Hilary Llewellyn-Thomas	Dartmouth College, USA
Nora Moumjid	GRESAC, CNRS, Centre Léon Bérard, France
Albert Mulley	Harvard Medical School, USA
Michael Pignone	University of North Carolina, USA

Scientific Committee:

Alexandra Barratt	University of Sydney, Australia	Jessie McGowan	University of Ottawa, Canada
Jamie Brehaut	University of Ottawa, OHRI, Canada	Nora Moumjid	GRESAC, CNRS, Centre Léon Bérard, France
Helen Bunn	University of Ottawa, Canada	Albert Mulley	Harvard Medical School, USA
Phyllis Butow	University of Sydney, Australia	Madeleine Murtagh	University of Newcastle, UK
Adrian Edwards	Cardiff University, UK	Natasha Nassar	University of Sydney, Australia
Glyn Elywn	Cardiff University, UK	Mary Ann O'Connor	Dartmouth Medical School, USA
Vikki Entwistle	University of Aberdeen, UK	Michael Pignone	University of North Carolina, USA
Deb Feldman-Stewart	Queen's University, Canada	Cornelia Ruland	Rikshospitalet - Radiumhospitalet HF, Norway
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William Godolphin	University of British Columbia, Canada	Karen Sepucha	Massachusetts General Hospital, USA
Ian Graham (Chair)	University of Ottawa, OHRI, Canada	Dawn Stacey	University of Ottawa, OHRI, Canada
Pierrette Guimond	Université d'Ottawa, Canada	Lyndall Trevena	University of Sydney, Australia
Martin Härter	Universitätsklinikum Freiburg, Germany	Trudy Van der Weijden	Maastricht University, The Netherlands
Margaret Holmes-Rovner	Michigan State University, USA	Adriaan Visser	Helen Dowling Institute: Centre for Psycho-oncology, The Netherlands
France Légaré	Université Laval, Canada	Celia Wills	Michigan State University, USA

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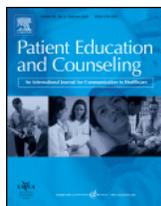
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THANKS ALSO TO



Patient Education and Counseling
Official Journal of the European Association for Communication
in Healthcare and the American Academy on Physician and Patient



Society for Medical Decision Making

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Welcome Message

We offer you a warm welcome to the University of Ottawa and the 3rd International Shared Decision Making Conference. Our program builds on earlier conferences in the UK; the first was held at St. Catherine's College, Oxford England and the second was at Swansea Clinical School, University of Wales, Swansea.

The conference theme is: **Implementing shared decision making in diverse health care systems and cultures.**

Associated themes include:

- *Basic science of shared decision making*
- *Measuring process and outcomes*
- *Designing interventions and implementation strategies*

To welcome members of the conference, there will be a Reception/Welcome BBQ on Tuesday evening. On Wednesday evening we invite everyone to a Gala Dinner at the Museum of Civilization.

We would like to thank the members of the organizing and scientific committees, guest speakers and many presenters for contributing to the conference.

A special thanks is extended to Liz Drake who coordinated the conference along with Anton Saarimaki, Debbie Morris, Laura Hopkins and our enthusiastic team of volunteers.

Annette O'Connor and Ian Graham on behalf of the Organizing and Scientific Committees.



Annette M. O'Connor, PhD
Chair, Organizing Committee



Ian D. Graham, PhD
Chair, Scientific Committee

KEYNOTE SPEAKER

Tuesday June 14, 2005

2:00 – 3:00 p.m.

Room A

*Research Implementation as Politics, or
What Happened when Machiavelli met Archie Cochrane*

Biography

Jonathan Lomas

Jonathan Lomas is the inaugural Chief Executive Officer of the Canadian Health Services Research Foundation, a nationally endowed organization founded in 1997 to improve the relevance and use of health services research in health system decision-making.

He grew up in Britain and did his undergraduate training in experimental psychology at Oxford University before coming to Canada as a Commonwealth Scholar. His background includes work or training in psychology, health economics, epidemiology, political science, and management.

From 1982-1997 he was a Professor of Health Policy Analysis at McMaster University in Hamilton, Canada, where he co-founded the Centre for Health Economics and Policy Analysis - an applied research group with a strong emphasis on research dissemination and uptake. He has published two books and numerous articles and chapters in the area of health policy and health services research. His main interest, and the area in which he has an international reputation, is the role and impact of research evidence in health systems decision-making.

He has been a consultant to national and provincial governments, as well as providing research and advice to various non-governmental organizations, task forces and inquiries. He is currently on a number of boards including, in the US: AcademyHealth and *Health Affairs*; in the UK: *Journal of Health Services Research and Policy* and the *Journal of Evidence-based Policy and Management*; in Australia: the Institute of Health Research; and in Canada: *Healthcare Quarterly*. In Canada he has also been an Associate of the Population Health Programme of the Canadian Institute for Advanced Research (1988-2004), a member of the Federal/Provincial/Territorial Advisory Committee to Deputy Ministers on Health Services (1994-96), a member of the Ontario Premier's Council on Health, Well-being and Social Justice (1991-94), and a member of the Interim Governing Council of the Canadian Institutes of Health Research (1999-2000) as well as a member of the Institute Advisory Board for its Institute of Health Services and Policy Research (2000-2004).

His interest in international health issues is strong and reflected in consultancies for the World Health Organization, the World Bank, the International Development Research Centre and the Rockefeller Foundation in Indonesia, Sri Lanka, The Philippines, South Korea, Myanmar (Burma), Thailand and Australia. He has been a Visiting Professor or Scientist at the University of Gadjah Mada in Indonesia (1990), the University of Sydney, Australia (where he was also a Visiting Scholar in the Department of Health of the New South Wales Government) (1996/97), and the Dutch national research and development agency ZonMw (2004).

GUEST SPEAKER
Tuesday June 14, 2005
3:00 – 3:30 p.m.
Room A

***Information Therapy: A Strategy for Delivering Patient Decision Aids
(to Every Patient Who Needs One)***

Biography

Donald Kemper

As Chairman and CEO of Healthwise and founding chairman of the Center for Information Therapy and the Information Therapy Commission, Mr. Kemper is a passionate advocate for improving patient physician partnerships through prescription information. By offering every patient the right information prescription as part of the process of care, the health care system can achieve measurable improvements in medical outcomes, patient safety, the overall cost-effectiveness of care, and patient satisfaction.

Mr. Kemper's educational background includes master's degrees in Health Systems Engineering from Georgia Institute of Technology and in Public Health from the University of California, Berkeley.

Mr. Kemper co-authored *Information Therapy: Prescribed Information as a Reimbursable Medical Service* with Molly Mettler. The Ix® book lays out both the concept and the practical details of how information prescriptions will become a core and expected part of health care. Kemper and Mettler spearhead the annual Information Therapy Conferences held in Park City, Utah.

Articles on Mr. Kemper and information therapy have appeared in *The Wall Street Journal*, *The LA Times*, and *Health Forum Journal*, and other health industry and consumer publications. He and Mettler have presented information therapy at conferences organized by the Harvard Conference on American Healthcare, Robert Wood Johnson Foundation, American Association of Health Plans (AAHP), Healthcare Information and Management Systems Society (HIMSS), Foundation for Accountability (FACCT), eHealth Initiative, International Society for Quality in Health Care (ISQua), and others.

Recognized for his visionary approach to self-care and medical consumerism, Mr. Kemper has helped to define and promote what people can do to improve their own health problems and their health. He has coauthored five medical self-care and health promotion handbooks that together have sold more than 26 million copies. He created the vision for the Healthwise® Knowledgebase, a comprehensive electronic health information and decision-support tool that supports Ix programs.

Mr. Kemper is a member of the AMA-sponsored Health Sector Assembly and treasurer of the Foundation for the eHealth Initiative. He has been part of the U.S. delegation at both the second and third World Health Organization Conferences on Health Promotion. He has served on the board of the American Society on Aging and the board of trustees for the National Wellness Institute and is founding chairman of Hi-Ethics, Inc.

KEYNOTE SPEAKER
Wednesday June 15, 2005
8:30 – 9:30 a.m.
Room A

Biography

J. A. Muir Gray

Muir Gray has worked in public health for 25 years. For the last ten years his principal interests have been screening and knowledge management, and as Director of R&D for Anglia and Oxford he was in a position to support the UK Cochrane Centre in its early days and in addition develop a number of initiatives designed to promote evidence-based decision-making.

As the Programmes Director of the UK National Screening Committee he has identified informed choice as one of the most important issues for people involved in screening in the 21st century and is fortunate in being able to work with groups in Oxford with an interest in many different aspects of communication with patients and informed decision-making. Dr. Gray is also Director of the National Electronic Library for Health Project, soon to become the National Library for Health.

As the new Director of Clinical Knowledge Process and Safety for the National Programme for Information Technology in the UK he is responsible for ensuring that the Programme is ready for the world of 2010 which requires both stimulating change in the patient's role, the clinician's practice, and healthcare organization on one side and, on the other, changing the specifications for the National Programme in anticipation of the evolutionary changes in the role of the patient and clinician.

He is the author of the book *Evidence-Based Healthcare*, the second edition of which was published in 2001. He is also joint author of *The Oxford Handbook of Public Health Practice*. His most recent book is *The Resourceful Patient*, published in April 2002.

He is the author of the book *Evidence-Based Healthcare*, the second edition of which was published in 2001. He is also joint author of *The Oxford Handbook of Public Health Practice*. His most recent book is *The Resourceful Patient*, published in April 2002.

KEYNOTE SPEAKER
Thursday June 16, 2005
8:30 – 9:30 a.m.
Room A

Cultural Influences on the Physician - Patient Encounter: The Case of Treatment Decision-Making

Cathy Charles, PhD, Amiram Gafni, PhD, and Timothy Whelan BM,BCh,MSc

Biography

Cathy Charles

Cathy Charles is an Associate Professor in the Department of Clinical Epidemiology & Biostatistics and a Member of CHEPA at McMaster University. She is also an Investigator in the Supportive Cancer Care Research Unit which is co-sponsored by the Hamilton Regional Cancer Centre and McMaster University. Cathy received a B.A. and M.A. in Sociology at the University of Toronto and a M.Phil. and Ph.D. in Socio-Medical Sciences from Columbia University.

Cathy's research interests include: public and patient participation in health care and treatment decision-making, shared treatment decision-making, the use of research information in health decision-making and the social construction of meanings in health policy analysis. She is currently undertaking a collaborative study on shared treatment decision-making among women with early stage breast cancer and among physicians who specialize in this area. She is also PI on a funded research project on the role of patient values in evidence-based medicine. Cathy's teaching interests include medical sociology, health policy analysis, and qualitative research methods. Cathy has been a health policy consultant to several provincial governments as well as to the federal government.

IPDAS Collaboration
Wednesday, June 15, 2005
9:30-10:30 a.m.
Room A

International Patient Decision Aid Standards Collaboration

For the past two years an international team of 122 researchers, practitioner, policy makers and consumers from 14 countries have been working towards reaching agreement about standards for the development and evaluation of patient decision aids. This session will describe the process and outcome of the collaboration and provide a forum for a discussion of where we go from here.

CHAIR:

Angela Coulter Chief Executive of Picker Institute Europe, UK

INTRODUCTION:

Annette O'Connor Professor and Tier 1 Canada Research Chair, University of Ottawa and Senior Scientist, Ottawa Health Research Institute, Canada

RESULTS:

Glyn Elwyn Research Professor Primary Medical Care, Centre for Health Sciences Research, Cardiff University, UK

PANEL DISCUSSION:

Alexandra Barratt	University of Sydney, Australia
Margaret Holmes-Rovner	Michigan State University, USA
Hilary Llewellyn-Thomas	Dartmouth Medical School, USA
Nora Mounjid	GRESAC, CNRS, Centre Léon Bérard, France
Ann Qualman	Canadian Arthritis Patient Alliance, Canada
Richard Thomson	University of Newcastle, UK
Dawn Stacey	Ottawa Health Research Institute, Canada
Tim Whelan	Juravinski Cancer Centre, Canada

CONTRIBUTORS:

Steering Committee: A O'Connor (CA) & Glyn Elwyn (UK) (co-leaders) with A Barratt (AU), M Barry (US), A Coulter (UK), M Holmes-Rovner (US), N Mounjid (FR), H Llewellyn-Thomas (US), M O'Kane (US), R Thomson (UK), D Stacey (CA), T Whelan (CA)

Quality Criteria Panels: A O'Connor (CA) & Hilary Llewellyn-Thomas (US) (editors) with J Austoker (UK), A Barratt (AU), M Barry (US), H Bekker (UK), J Belkora (US), C Braddock (US), P Butow (AU), E Chan (US), A Charvet (Switz), A Clarke (UK), J Davison (CA), J Dolan (US), A Edwards (UK), V Entwistle (UK), A Fagerlin (US), D Feldman-Stewart (CA), J Fowler (US), D Frosch (US), P Hewitson (UK), M Holmes-Rovner (US), T Hope (UK), MJ Jacobsen (CA), A Kennedy (Switz), S Knight (US), M Kupperman (US), B Ling (US), T Marteau (UK), K McCaffery (AU), N Mounjid (FR), A Mulley (US), M O'Connor (US), E Ozanne (US), M Pignone (US), A Raffle (UK), C Ruland (NO), L Schwartz (US), K Sepucha (US), S Sheridan (US), S Stableford (US), D Stacey (CA), D Stilwell (US), V Tait (CA), D Timmermans (NL), L Trevena (AU), T Whelan (CA), C Wills (US), S Woloshin (US), S Ziebland (UK)

Methods Group: G Elwyn (leader, UK) with S Bernstein (US), P Shekelle (US), R Thomson (UK), R Volk (US)

DEBATE PLENARY SESSION

Thursday June 16, 2005

9:30 to 10:30 a.m.

Room A

Resolution: Shared Decision Making is Only Relevant for Privileged Groups

Join us for a light-hearted debate about a serious topic on the final morning of the conference.

CHAIR:

Angela Coulter

Chief Executive of Picker Institute Europe, UK

AFFIRMATIVE TEAM:

Alexandra Barratt

Associate Professor, Epidemiology, Screening and Test Evaluation Program School of Public Health, University of Sydney, Australia

Michael Pignone

Associate Chief, UNC Division of General Internal Medicine, University of North Carolina Hospital, USA

NEGATIVE TEAM:

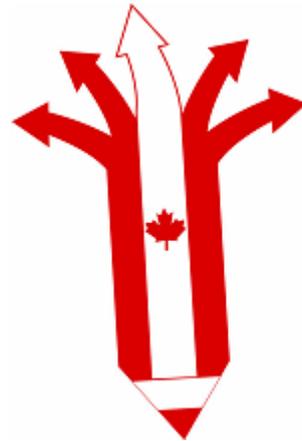
Vikki Entwistle

Reader and Programme Director, Delivery of Care Programme, Health Services Research Unit, University of Aberdeen, UK

Adrian Edwards

Research Professor, General Practice Centre for Health Sciences Research, Cardiff University, UK

ORAL SESSION SCHEDULE



Session 1 – 16:00-17:00 Tuesday, June 14, 2005

Parallel Oral Session Schedule

Time	Room A (MNT 202)	Room B (MNT 203)	Room C (MNT 201)	Room D (MNT 207)
	Risk Presentation I Chair: Elwyn G	Effectiveness of decision aids I Chair: Brehaut J	Decision making in mental health Chair: Härter M	Assessing decision making needs Chair: Murtagh M
16:00	1A1 Evaluating different formats to represent medical risks in online information for people with Diabetes – a randomised controlled trial Edwards A , Thomas I, Williams DRR, Elwyn G	1B1 MENTIP – Menorrhagia, Treatment; Information and Preferences. Enhancing decision making in menorrhagia in primary care using computerised decision analysis: randomised trial and qualitative evaluation Protheroe J	1C1 Adherence therapy a new intervention for enhancing collaboration and choice for people with schizophrenia Gray R , Robson D, David A, Bindman J, Thornicroft G, Tansella M, Schene A, Becker T	1D1 Web-based decision making – mso© a German case study Hoeldke B
16:15	1A2 Mismatch between the actual cardiovascular risk and the patient's risk perception van der Weijden T , van Steenkiste B, Coenen J, Stoffers H, Grol R	1B2 Randomised controlled trial of a patient decision aid in stroke prevention in patients with atrial fibrillation Thomson RG , Eccles M, Graham R, Greenaway J, Heaven B, Kaner E, May C, Murtagh M, Rapley T, Steen N, Stobbart L	1C2 Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial Henderson C , Flood C, Leese M, Thornicroft G, Sutherby K, Szmukler G	1D2 Patient involvement in therapeutic decision-making for low rectal cancers Zenasni F , Sideris L, Dauchy S, Di Palma M, Vernerey D, Pocard M
16:30	1A3 Information men want about PSA testing: a qualitative study Hewitson P , Bukach C, Watson E, Austoker J	1B3 Evaluation of a decision aid for pregnant women with a breech-presenting baby: a randomised controlled trial Nassar N , Roberts CL, Raynes-Greenow CH, Barratt A on behalf of the ECV Decision Aid collaborative group	1C3 Relationships Between Mental Health Status and Decision-Making Variables: Implications for the Design of Treatment Decision Aids Wills CE	1D3 What do patients consider when making decisions about treatment for Hepatitis C? Fraenkel L , McGraw S, Wongcharatrawee S, Garcia-Tsao G
16:45	1A4 Effect of Extended Balance Sheet with Graphic Absolute Probabilities on Prostate Cancer Screening Beliefs, Intentions, and Behavior Hamm RM , Scheid DC, Volk RJ, Bard DE, Patrick RD, Weidman, K	1B4 A general practice-based randomised trial of a decision aid for colorectal cancer screening Trevena L , Barratt A, Irwig L	1C4 The impact of shared decision making on patients' treatment acceptance, compliance and clinical outcome in primary care of depression Loh A , Simon D, Wills CE, Bermejo I, Haerter M	1D4 Different Information Needs by Gender During Colorectal Cancer Screening Decision-Making Friedemann-Sanchez G , Griffin JM, Partin MR

Session 2 – 11:30-12:30 Wednesday, June 15, 2005

Parallel Oral Session Schedule

Time	Room A (MNT 202)	Room B (MNT 203)	Room C (MNT 201)	Room D (MNT 207)
	Physician attitudes towards shared decision making Chair: Edwards A	Standards in the development of patient information and decision aids (presented in French with English simultaneous translation) Chair: Legaré F	Effectiveness of decision aids II (prostate) Chair: Frosch D	Decision making in prostate cancer Chair: Barratt A
11:30	2A1 Informed decision making regarding Prostate-Specific Antigen (PSA) screening: findings from the 2000 National Health Interview Survey Han PK , Coates RJ, Uhler RJ, Breen N	2B1 Outil d'aide à la décision en matière de stérilisation masculine: étude de besoin Baldé A , Labrecque M, Légaré F, Desmartis M, Thabet M	2C1 Effect of prostate cancer screening decision aids on shared decision making process outcomes: results from a randomized trial Partin MR , Nelson D, Nugent S, Holtzman J, Wilt TJ	2D1 The PSA test: narratives about an uncertain investigation Evans R , Edwards A, Elwyn G
11:45	2A2 Orthopaedic Surgeons' Opinions About Patients' Decision Aids For Elective Surgery For Herniated Disc / Spinal Stenosis: A National Survey Llewellyn-Thomas HA , Mimnaugh D, Weinstein J	2B2 Évaluation d'un outil d'aide à la décision et d'un profil de risque personnalisé en pharmacies communautaires sur les options de traitement pour améliorer la santé cardiovasculaire : Étude pilote OPTIONS Lalonde L , O'Connor AM, Duguay P, Brassard J, Kayal A, Drake E, Grover SA	2C2 Do Decision Aids Promote Shared Decision-Making? A Randomized Trial among Men Eligible for Prostate Cancer Screening Krist AH , Woolf SH, Johnson RE	2D2 Decisional Conflict Concerning Prostate Cancer Screening Among Low Income Men Weinrich S
12:00	2A3 A survey of Australian oncologists' views about shared decision making (SDM) Shepherd H , Tattersall MHN, Butow P, Charles C	2B3 Développement et mise en œuvre du programme national SOR SAVOIR PATIENT d'information et d'éducation thérapeutique des personnes atteintes de cancer et de leurs proches Leichtnam-Dugarin L , Carretier J , Fervers B, Brusco S, Delavigne V, Philip T	2C3 Informed decision making and PSA testing for prostate cancer: a randomized trial of a mailed decision aid in the UK Watson E , Hewitson P, Bukach C, Brett J, Edwards A, Elwyn G, Love S, Austoker J	2D3 Persistence of men's theories about BPH and prostate cancer following a decision aid Holmes-Rovner M , Price C, Rovner DR, Kelly-Blake K, Lillie JA, Wills CE, Bonham B
12:15	2A4 Women's decision making regarding pain relief in labour Lally J , Murtagh, M, Thomson, RG, MacPhail, S	2B4 Description du processus de soutien décisionnel des infirmières en centre de traitement des agressions sexuelles Guimond P , O'Connor AM, Siedlikowski H		2D4 Understanding African American Men's Beliefs about Prostate Cancer Screening: Formative Research Findings and Implications for Intervention Allen J, Wilson-Glover A, Kennedy M, Kantoff P, Emmons K, Gilligan T

Session 3 – 14:00-15:00 Wednesday, June 15, 2005

Parallel Oral Session Schedule

Time	Room A (MNT 202)	Room B (MNT 203)	Room C (MNT 201)	Room D (MNT 207)
	Patient involvement in decision making Chair: Butow P	Physicians point of view on patient information needs and shared decision making (presented in French with English simultaneous translation) Chair: Moumjid N	Values and value consistency Chair: Llewellyn-Thomas HA	System and health service perspectives Chair: Stacey D
14:00	3A1 Shared decision making with chronic pain patients. A quantitative and qualitative one year follow-up Eich W , Bieber C, Mueller KG, Richter A, Hochlehnert A, Blumenstiel K, Wilke S	3B1 Perception des médecins de famille quant aux facteurs contrecarrant et ceux favorisant l'implantation du Modèle d'Aide à la Décision d'Ottawa (MADÉO) dans leur pratique Légaré F, Cauchon M , O'Connor AM, Graham ID, Côté L, Saucier D, Blais J, Paré L	3C1 The need to facilitate informed choice equitably Dormandy E , Marteau TM	3D1 Integration of a shared decision making model into the clinical care of patients with advanced osteoarthritis of the knee Carlson L, Clay K, Kantor S, Tomek I
14:15	3A2 Do cancer patients' preferred roles for participation in treatment decision making change during the treatment experience? Ruland CM	3B2 Barrières et facteurs favorables à l'implantation de la prise de décision partagée dans les pratiques professionnelles en santé : revue de la littérature Gravel K , Légaré F	3C2 Measuring Decision Quality: Lessons from Pilot Testing Sepucha KR , Farrelly KA, Hughes KS, Partridge AH, Mulley AG	3D2 Patients' opinion of shared decision making and informed consent in situations of medical risk and uncertainty Charvet A , Cleopas A, Kolly V, Chopard P, Perneger TV
14:30	3A3 Patients with prostate cancer want to choose their own radiation treatment van Tol-Geerdink JJ , Stalmeier PFM, van Lin EJNTh, Schimmel EC, Huizenga H, van Daal WAJ, Leer JW	3B3 Les besoins d'information des patients du point de vue des médecins d'un réseau français de soins en cancérologie Camhi B , Farsi F, Bremond A	3C3 Explicit Value Clarification: Validation of a new technique Feldman-Stewart D , Brennenstuhl S, Brundage M, Zoltov V, Roques T, Siemens R, Campbell H, Pickles T, Hack T	3D3 Cancer-Related News Coverage and Information Seeking: Results from a National Survey Frosch D , Niederdeppe J, Hornik R
14:45	3A4 Preferred participation in treatment decision making of Patients with End Stage Renal Disease: Results on Control Preference of patients Kuch C , Scheibler F, Stoffel MP, Pfaff H		3C4 Are pregnant women making informed choices about prenatal screening? Van den Berg M, Timmermans DRM , Ten Kate LP, Van Vugt JMG, Van der Wal G	3D4 Initiatives and developments on patient participation in German health care Härter M and the members of the German Research Consortium

Session 4 – 11:30-12:30 Thursday, June 16, 2005

Parallel Oral Session Schedule

Time	Room A (MNT 202)	Room B (MNT 203)	Room C (MNT 201)	Room D (MNT 207)
	Implementing decision support Chair: Holmes-Rovner M	Seniors' decision making Chair: Ruland C	Decision support in primary care Chair: Trevena L	Fundamentals Chair: Sepucha KR
11:30	4A1 Improving the quality of decision support by call centre nurses for callers facing values-sensitive health decisions: A randomized controlled trial Stacey D , O'Connor AM, Graham ID, Pomey MP	4B1 Evaluation of two mammography decision aids for women outside the target age for screening: deciding to start (40-49) or stop (70+) mammography screening Mathieu E , Barratt A, Davey H, Page A, Houssami N, Butow P, Higginson R	4C1 A Theory-based process evaluation of a multifaceted intervention to implement the Ottawa Decision Support Framework (ODSF) in clinical practice Légaré F , Graham ID, O'Connor AM, Wells G, Turcot-Lemay L, Aubin M, Baillargeon L, Leduc J, Maziade J	4D1 Patients' Time Trade-off preferences predict smoking cessation Wiggers LCW, Stalmeier PFM , Oort FJ, Smets EMA, Legemate DA, de Haes JCJM
11:45	4A2 Integration of Decision Support and Computerized Assessment for Women Newly Diagnosed with Early Stage Breast Cancer Collins ED , O'Connor AM, Clay K, Kearing S, Llewellyn-Thomas HA, Moore C, Sepucha KR, Maheu L, Gallagher S, Chambers K, Aman D	4B2 Can you have agency and not choose? Older people's involvement in decision making about prevention and treatment of falls and fractures Murtagh M , Stobbart L, Newton J, Fay M, Thomson RG	4C2 The teaching and learning of informed and shared decision making Godolphin W , Towle A, Kline C, Grams G	4D2 Patients and Consumers of Health Care Engaged in Shared Decision-Making Processes: A Canadian Story Kovacs Burns K
12:00	4A3 Introducing patient decision aids into treatment pathways – lessons learnt from a pilot implementation of decision aids in England Wirrmann E , Askham J	4B3 Shared Information Improves Elders' Recovery After Major Abdominal Surgery Lawrence VA , Cornell JE, Hazuda HP	4C3 Impartial Evidence: An oxymoron or just difficult to find? An examination of the discursive construction of risk, agency and evidence Robertson M , Dowell J, Cowan S, Sullivan F, Moir J	4D3 'Rhetorical' styles of communication in everyday decision-making: an ethnographic observation study in heart failure Sanders T , Harrison S
12:15		4B4 Patient preferences for participation in decision making Flynn KE , Smith MA, Vanness D	4C4 Guidelines for GP referrals to elective surgical specialties and the role of patient involvement in the referral decision: A systematic review Clarke A, Le Maistre N , Van der Meulen J, Rashidian A	

Session 5 – 14:00-15:00 Thursday, June 16, 2005

Parallel Oral Session Schedule

Time	Room A (MNT 202)	Room B (MNT 203)	Room C (MNT 201)	Room D (MNT 207)
	Decision making in primary care Chair: Pignone M	Risk presentation II Chair: Godolphin W	Measurement and methods Chair: Wills CE	Effectiveness of decision aids III (breast cancer) Chair: Guimond P
14:00	5A1 Chronic Illness Care Management (CICM): A Patient Centered Team Approach to Managing Chronic Illness to Improve Quality of Care. A Progress Report Hogg W , Lemelin J	5B1 Using patients to evaluate decisions aids about the risk of breast cancer: a focus group study Elwyn G , Rapport F, Edwards A, Jones W, Iredale R, Gray J	5C1 Patients' preferences vs. oncologists' perceptions of treatment decisions: are there predictors of better agreement? Gabrijel S , Herrmann R, Wernli M, Rochlitz C, Bargetzi M, Pless M, Betschart P, Kiss A	5D1 A randomised controlled trial of shared decision making in primary breast cancer patients – effects on patients' perceptions and psychological outcome Vodermaier A , Caspari C, Koehm J, Untch M
14:15	5A2 Measuring client's involvement in decision making: An evaluation of WHO's Decision-Making Tool for Family Planning Clients and Providers in Mexico Kim YM , Kols A, Rinehart W	5B2 Screening mammography: presenting evidence to support informed choices by women Barratt A , Howard K, Irwig L, Salkeld G, Houssami N	5C2 Evaluating Uptake of Cancer Genetic Testing As An Outcome for Shared Decision Making: All That Glitters Isn't Real! Ropka M , Phillips E, Wenzel J, Philbrick J	5D2 Effects of an American decision aid for surgical options in primary breast cancer in Germany: a feasibility study with German medical students Scheibler F , Schloer B, Jessie M, Kuch C, Pfaff H
14:30	5A3 Decision support for patients to enhance GPs' implementation of a national cholesterol guideline in primary care: a randomized cluster controlled trial van Steenkiste B, van der Weijden T , Schouten B, Stoffers H, Grol R	5B3 Examining the acceptability of a Decision Aid developed for HRT among consumers from multiethnic backgrounds and health practitioners McCaffery K , Trevena L, Barratt A, Clarke J, O'Connor AM, Armstrong B	5C3 Measuring the Physician-Parent Relationship in Pediatric Care Cox E , Smith MA, Brown R, Fitzpatrick M	5D3 Development of and pilot evaluation of a decision aid for advanced breast cancer patients considering chemotherapy Shepherd H , Tattersall MHN, Leigh N, Butow P, Sullivan A, Hamilton A, Beith J, Vardy J, Chiew K
14:45	5A4 The use of the OPTION scale as a measure for patient involvement in a sample of General Practitioners in Italy Goss C , Fontanesi S, Mazzi MA, Del Piccolo L, Rimondini M, Zimmermann C	5B4 What does order have to do with it?: The role of risk/benefit order in shaping risk perception Fagerlin A , Zikmund-Fisher BJ, Derry HA, Sarr BJ, Smith D, Ubel PA	5C3 Development and validation of a new questionnaire to measure process and outcome of shared decision making Simon D , Loh A, Härter M	

Session 6 – 15:30-16:30 Thursday, June 16, 2005

Parallel Oral Session Schedule

Time	Room A (MNT 202)	Room B (MNT 203)	Room C (MNT 201)	Room D (MNT 207)
	Models and frameworks of shared decision making Chair: Feldman-Stewart D	Shared decision making in cancer Chair: Visser A	Effectiveness of decision aids IV Chair: Scheibler F	Decision aids development process Chair: van der Weijden T
15:30	6A1 Definitions of “shared decision making” evident in the medical literature: Back to basics Makoul G, Clayman M	6B1 How do elements of the decision-making process for localized prostate cancer impact long-term decision regret? Gurmankin AD, Ubel PA, Badler A, Dean LT, Coyne J, Armstrong A	6C1 An Entertainment-Education Approach to the Development of Decision Aids for Lower Literate and Naïve Computer Users Jibaja-Weiss ML, Volk RJ, Granchi TS, Neff NE, Spann SJ, Beck JR, Aoki N	6D1 Creation of Lung Cancer Caregiver Planning Aids Within an Online Support System Kopetsky DJ, Bernard LL, Gustafson DH, Cleary JF, McTavish FM
15:45	6A2 Pediatric cancer choices: decisions both shared and not Whitney S, Volk RJ, Ethier A, Barrera P, Hockenberry M	6B2 Shared Decision Making and Posttraumatic Growth in Early-Stage Breast Cancer Survivors Farrelly KA, Hughes KS, Mulley AG, Partridge AH, Sepucha KR	6C2 Development and pilot testing of two decision aids for genetic testing for hereditary cancer Wakefield C, Meiser B , Homewood J, Kirk J, Peate M, Tucker K et al.	6D2 Demonstration of the Adjuvant Survival Presentation for breast cancer patients Byers A, Belkora J
16:00	6A3 Shared decision-making in the medical encounter : are we all talking about the same thing? Moumjid N, Gafni A, Brémond A, Carrère MO	6B3 Impact of Cancer-related Decision Aids: A Systematic Review O'Brien, MA, Whelan TJ, Villasis M, Gafni A, Charles C, Willan A	6C3 Pilot Study of a Decision Aid for Patients with Metastatic Colorectal Cancer Leighl N, Butow P, Tattersall MHN, McJannett M, Clarke S, Boyer MJ, Barratt A, Glare P, Princess Margaret Hospital GI Medical Oncology Site Group	6D3 Using an innovation process to develop a decision aid Weymiller A, Whitt I, Montori VM
16:15	6A4 It's more than talk about treatment options: a broader conceptualisation of patient involvement in decision making Entwistle VA, Watt IS	6B4 Patients with incurable cancer: discussions and decision making about medical treatment in the last phase of life Visser AP, Voogt E, van der Heide A, van Leeuwen AF, van der Rijt CCD, van der Maas PJ	6C4 A decision aid for patients with metastatic colorectal cancer deciding between supportive care and supportive care plus chemotherapy Butow P, Leighl N, Tattersall MHN, Shepherd H, Clarke S, Beale P, Wilkin N, Horvath L	6D4 Criteria for assessing the quality of decision aids Kasper J, Lenz M

POSTER SESSION SCHEDULE



POSTER SESSION SCHEDULE

Session 1 10:30 – 11:30 Wednesday June 15

Terminus

101	Stability and Change in Men's Benign Prostatic Hyperplasia (BPH) Treatment Preferences in Response to a Videotape Decision Aid	Wills CE , Holmes-Rovner M, Rovner DR, Lillie JA, Kelly-Blake K, Bonham V
102	Using Information Technology to Enhance Patient Decision Support	Jacobsen MJ , Saarimaki A, O'Connor AM, Tait V, Drake E, Khangura S
103	CHAIN Canada – Contact, Help, Advice & Information, Network	McGowan J , Santesso N, Grimshaw G
104	MMR vaccination decisions - a case of message framing	Abhyankar P , O'Connor DB, Lawton RJ
105	Using Information Technology to Evaluate Shared Decision Making in a Clinical Setting	Kearing S , Clay K, Maheu L, Collins ED, Moore C, Llewellyn-Thomas HA, O'Connor AM, Gallagher S, Chambers K, and Aman D
106	Patient decision-making in clinical depression and reported satisfaction with practitioners	Bunn H , Jacobsen MJ, Whitelaw C, Ritchie L, McIntosh A, Fox J
107	Early work on the CReDITED decision aid development process	Byers A, Belkora J
108	Rules-of-Thumb Used for Statin Decision Making: Eliciting Patients' Decision Heuristics	Crouch M , Whitney S
109	Prevention of cardiovascular diseases by means of a decision support tool for sharing the medical evidence with patients, a clustered randomized controlled trial in primary care	van Steenkiste B , van der Weijden T, Stoffers H, Kester A, Timmermans D, Rinkens P, Grol R
110	Women's decision making needs related to treatment decision for recurrent ovarian cancer	Jolicoeur L , O'Connor AM, Graham ID, Hopkins L
111	Measuring the usability and usefulness of online patient decision aids: A demonstration of methods	Brehaut JC , O'Connor AM, Tugwell P, Lindgaard G, Santesso N, Cranney A, Graham I
112	The assessment of depressive patients' involvement in decision making in audiotaped primary care consultations	Loh A , Simon D, Hennig K, Härter M
113	Who utilizes decision aids? Findings from a randomized trial of two patient directed prostate cancer screening decision support interventions.	Partin MR , Nelson D, Flood AB, Wilt TJ
114	Assisting Physicians with Decision Making for Children with Motor Coordination Problems	Gaines BR , Egan M, Missiuna C, McLean J, De Laat D
115	Choice of Risk Representation to Enable Diabetes Decision-Making	Whitt I , Chung JA, Noble K, Vallena A, Alam F, Adams A, Weymiller A, Montori VM
116	Models for Integrating Decision Support into Clinical Care: The Dartmouth Experience	Clay K , Brooks WB, Cochran N, Collins ED, Fowler FJ, Mimnaugh D, O'Connor AM, O'Connor MA, Tomek I, Weinstein J, Abdu W, Wennberg J, Llewellyn-Thomas H
117	Methods for Integrating Decision Support into Clinical Care: The Dartmouth Experience	Clay K , Collins ED, Moore C, Weinstein J, O'Connor AM, Jacobsen MJ, Llewellyn-Thomas H

Session 2 15:00 – 16:00 Wednesday June 15**Terminus**

201	Breast Cancer Treatment Decision Making: Does the Sisterhood of Breast Cancer Transcend Culture?	Wescott P , Reifler E, Sepucha K, Park E
202	Information and shared decision making in Dutch prostate cancer patients	Visser AP , Fischer F, Voerman B, Garssen B, Van Anandel G, Bensing J
203	Sexual Health Decision Making: Listening to Thai Youth	Doull M , O'Connor AM, Chuemchit M, Jacobsen MJ, Robinson V, Tugwell P, Sitti-Amorn C
204	What information do patients select from an interactive CD-Rom on treatment options in breast cancer?	Molenaar S , Sprangers M, Oort FJ, Rutgers E, Luiten E, Mulder J, de Haes H,
205	Gaps and opportunities in the maternal decision-making needs of HIV-positive women in Africa	Doull M , Robinson V, Cook L, O'Connor AM, Jacobsen MJ, Tugwell P
206	Conflicts of decision making on prenatal testing in Japan	Arimori N , Aoki M, Horiuchi S, Arita M
207	Perceptions des participants à l'Université du 3e âge face au Modèle d'Aide à la Décision d'Ottawa (MADÉO)	Blais J , Desmartis M, Légaré F, Turcot-Lemay L
208	Parents' perceived vulnerability and control in preventing an infectious child disease: A large-scale interview study about vaccination	Timmermans DRM , Henneman L, Hirasing R, Van der Wal G
209	Implementing Nurse-Mediated Telephone Support for Chronic Conditions in Primary Care Centers Situated in Low Income Communities: Needs of People with Type 2 Diabetes	Lange I , Bustamante C, Vial B, Maturana C, Ferrer L, Sapag J, Araya S, Rojas M, del Mazo I, Mena I, Clavero C, Pantoja T, Urrutia M, Jaimovich S, et al.
210	Involving patients into clinical practice guidelines (CPGs) process: a study by French guidelines developers in the field of oncology	Carretier J , Bataillard A, Kelson M, Fervers B
211	Evaluating the need for a decision support tool for immigrant and refugee women from HIV-endemic countries regarding voluntary testing and counselling (VCT)	Mitra D, Tugwell P, Jacobsen MJ , Pottie K
212	Feasibility of organisational development strategies to implement shared decision making in German health care organisations	Kuch C , Scheibler F, Pfaff H
213	Themes and Persuasive Devices in US Television Advertising of Prescription Pharmaceuticals	Frosch D
214	Assessment of breast cancer patient's information needs in France : first step before the implementation of shared decision-making in the medical encounter	Moumjid N , Morelle M, Brémond A, Farsi F, Carrère MO
215	Shared-decision-making in the medical encounter: French physicians' point of view in breast cancer	Nguyen F, Moumjid N , Brémond A, Carrère MO
216	Décision informée dans le dépistage du cancer du sein au sein de la Francophonie	Brémond A, Moumjid N , Soler P, Légaré F, Major D, Brisson J, Lepage C
217	Participation des patientes à la décision thérapeutique dans la prise en charge initiale du cancer du sein : Développement et évaluation préliminaire d'un protocole d'aide au partage de la décision médicale	Meunier A, Moumjid N , Brémond A, Mignotte H, Faure C, Carrère MO

Session 3 10:30 – 11:30 Thursday June 16

Terminus

301	Decision Making for Stage I Seminoma: A 15-Year Review	Samant R , Alomary I, Gallant V
302	Developing Patient Competencies Through the Use of Health Coaching Methodology	Powers A , Rapp L, Erramuzpe K
303	Evaluation of an Education Program to Enhance Decision Support at a Health Call Center	Powers A , Rapp L, O'Connor AM, Stacey D, Jacobsen MJ, Kearing S, Erramuzpe K
304	What Do Patients Think of Video-Based Decision Aids “Downstream”? A Telephone Debriefing Process	O'Connor MA , Kearing S, Maheu L, Fowler FJ
305	Predicting Downstream Effects of High Decisional Conflict: Meta-analyses of the Decisional Conflict Scale	O'Connor AM, Sun Q , Laupacis A, Man Son Hing M, Dodin S, Feldman-Stewart D, Siminoff L, Morgan, M, Murray E
306	Supporting informed parental decision-making in relation to the MMR vaccine: A systematic review	Jackson C , Cheater FM
307	Patient involvement in treatment choices for End Stage Renal Failure: a systematic review.	Winterbottom A , Bekker H, Conner M, Mooney A
308	Decision Making about Joining a Prostate Cancer Chemoprevention Trial	Myers R , Delmoor E, Iacono R, Lang C, Chelnik K, Kash K, Hubert C, Keenan K, Hirsch I
309	Training mental health workers in adherence therapy: a cluster randomised controlled trial	Gray R , Robson D
310	Ethical stakes in screening workers exposed to beryllium: usefulness of a risk management framework	Poulin M
311	Prototyping a User Interface for Collaborative Intelligence-Based Ethical Decision Support in NICU	Yang L, Ou Y , Walker CR, Frize M
312	A Clinical Center For Shared Decision Making: The First Five Years	Llewellyn-Thomas H , Clay K, Mimnaugh D
313	Development of a Decision Support Tool for Malaria Chemoprophylaxis: Needs Assessment and Validation Study	McCarthy AE , Daniel VJ, Jacobsen MJ, O Connor AM
314	Women’s Perspectives on Genetics: Understanding, Expectations, and Values	Potter B , Boland I, Chorny Y, O'Reilly N, Graham I, Cappelli M, Coyle D, Walker M, Wilson BJ
315	Patient Willingness to Take Teriparatide	Fraenkel L , Gulanski B, Wittink D
316	The Ottawa Panel Evidence-Based Clinical Practice Guidelines (EBCPGs) for Post-Stroke Physical Rehabilitation Interventions - A Decision Aid for clinicians	Brosseau L , Laferrière L, Wells GA, The Ottawa Expert Panel Members

**ABSTRACTS
ORAL PRESENTATIONS**



1A1**Evaluating different formats to represent medical risks in online information for people with Diabetes – a randomised controlled trial**

Edwards A (1), Thomas I (2), Williams DRR (2), Elwyn G (1)

(1) Centre for Health Science Research, Cardiff University, Wales; (2) Swansea Clinical School, Swansea University, Wales

Background: Information must be communicated effectively to enhance peoples' understanding of their condition and treatment options. There have been few randomised trials of risk presentation formats, such as graphs and narrative descriptions, for patients with real conditions or in actual health care contexts. We evaluated risk presentation formats addressing the pros and cons of tight control versus usual treatment approaches for diabetes.

Design: randomised controlled trial.

Setting: online. Publicity disseminated via Diabetes UK (patients' organisation).

Participants: People in the UK with diabetes or their carers.

Interventions: Control group received information based on BMJ 'Best Treatments'. Four intervention groups received enhanced information resources:- 1: detailed Numerical information (absolute / relative risk, numbers-needed-to-treat); 2: 'Anchoring' to familiar or everyday risks; 3: Graphical (bar charts, thermometer scales, crowd figure formats); 4: combination.

Outcomes: Decision Conflict Scale (principal outcome); DCS sub-scales; satisfaction with information; further free text responses.

Quantitative results: 710 people visited the website and were randomised. 508 completed the questionnaire (quantitative analysis: ANOVA, Dunnett's test, multiple regression; >90% power). There were no statistically significant effects of the interventions on DCS, its sub-scales, or satisfaction with information.

Qualitative results: 256 participants provided responses for qualitative 'content analysis'. Most found graphical representations helpful, specifically bar chart formats. Many found other graphic formats (thermometer type and crowd figures) and 'anchoring' information unhelpful, and indicated information overload. Many negative experiences with care indicate a challenging context for effective information provision and decision support.

Conclusions: Online evaluation of different risk representation formats was feasible. The lack of intervention effects on quantitative outcomes may reflect already well-informed participants from the Diabetes UK patient organisation. The large qualitative dataset indicated many helpful formats for communicating risk information. The challenge is to strike a balance between providing more information, in appropriate and clear formats, but without risking information overload. Interactive web designs hold much promise to achieve this.

1A2**Mismatch between the actual cardiovascular risk and the patient's risk perception.**

van der Weijden T, van Steenkiste B, Coenen J, Stoffers H, Grol R

Centre for Quality of Care Research (WOK), Department of General Practice, Maastricht University, Maastricht, The Netherlands

Background: Prevention of cardiovascular disease (CVD) is embedded in the so-called high-risk approach that is expressed in risk tables. In designing decision aids, it is important to have insight in the type of patients with whom general practitioners (GPs) discuss cardiovascular risks. How adequate is the risk perception of these patients, and what determines an appropriate risk perception?

Methods: The data stem from the baseline measurements of a RCT with 34 participating GPs on implementation of a CVD risk table. Patients aged 40-75 with whom cardiovascular risk was discussed during the consultation, either on the GP's or patient's initiative, were included in the study. After the consultation the GP completed a registration form and the patient a questionnaire. The patients are described on demographic characteristics (age, sex, SES), their cardiovascular risk profile, and risk perception. Risk perception is defined in three aspects: absolute and comparative

probability perception and anxiety. Determinants of appropriate risk perception (perceived risk related to actual risk) are explored by multivariate analysis.

Results: 490 patient contacts were registered. In 17% of the consultations the patient was actually having high risk. The overall proportion of anxious patients was 15%. 56% of the patients had appropriate risk perception on all three aspects. Perceived risk was not related to the actual risk level. Absolute and comparative probability perception were significantly related to anxiety (CC 0.38* and 0.24* respectively). The results of the multivariate analysis will be presented at the conference.

Conclusions: In daily practice GPs need to explain both high and low risk of CVD to patients. Nearly half of the patients do not perceive risk appropriate on all aspects. Influencing the probability perception seems a vehicle for influencing inappropriate anxiety.

1A3

Information men want about PSA testing: a qualitative study

Hewitson P, Bukach C, Watson E, Austoker J

University of Oxford

Background: In the UK, the Prostate Cancer Risk Management Programme (PCRMP) was implemented to ensure that men who requested the PSA test from their GP received clear and balanced information about the advantages and disadvantages of the PSA test and the treatments for prostate cancer. As part of a larger randomised study to learn more about men's preferences for the content and presentation of information and to explore men's views on making a decision about the PSA test.

Methods: 37 men participated in the semi-structured interview series. Participants received four information leaflets/booklets (ranging from general information to a well-designed decision-aid) before the interview. These leaflets/booklets were provided to allow men to view a range of presentation styles and as a visual aid during the interviews. Men were asked about their views and preferences for the content, format and communication of risks in the information materials. Further, men were also asked about how they preferred to make a decision, the role of significant others and how important information materials were for making a decision about screening.

Results: There was a great diversity in men's preferences for the length, content and presentation of risk information. Several prominent themes emerged from the interviews concerning the decision whether or not to have the test including, 'GP's decision dictating man's decision', 'all screening is good', 'treatment more important than screening' and 'uncertainty about the utility of the test'.

Conclusions: In general, men wanted to receive information about PSA testing, however, their GPs recommendation was viewed as far more significant to their decision than the information materials. Although men felt that all screening was worthwhile, information materials were viewed as more important for treatment decisions, than for the decision to have the PSA test. The study has important implications for the role of prostate cancer screening information materials and men's decision-making about the PSA test.

1A4

Effect of Extended Balance Sheet with Graphic Absolute Probabilities on Prostate Cancer Screening Beliefs, Intentions, and Behavior

Hamm RM, Scheid DC, Volk RJ, Bard DE, Patrick RD, Weidman, K

Department of Family and Preventive Medicine, University of Oklahoma Health Sciences Center, Oklahoma City; Department of Family and Community Medicine, Baylor College of Medicine, Houston

Background: Many prostate cancer (PC) screening educational materials omit numerical probabilities. We tested whether graphical display of absolute frequencies affected knowledge, beliefs, intentions, and actual screening behavior.

Methods: A 12-page Extended Balance Sheet (EBS) presented PC prevalence, screening accuracy (FN and FP rates), treatment efficacy, and side effect rates (impotence and incontinence), all in terms of an initial population of 1000 “men like you,” represented as smiley and frowny faces. The numbers and graphs were customized by age (decade) and race (African American, Hispanic, White), based on a Markov analysis. Men were randomized to read a control booklet, read the EBS, or have a research assistant explain the EBS.

Results: 160 Whites, 159 African Americans, and 70 Hispanics were interviewed, with 85% follow-up after 6 months. EBS increased participant score on multiple choice PC knowledge test more than control. All scores returned toward baseline at 6 months. EBS and control had similar effects on each of 7 judgments of probabilities of PC screening or treatment events. The impact of the educational materials upon a Health Belief Model subscale, susceptibility, and upon an overall HBM measure, was influenced by participant race but not by EBS versus control: they increased African Americans’ impression of PC screening but decreased Whites’. Both EBS and control materials decreased participants’ Decision Conflict subscales concerning “decision making”, “feeling uninformed”, and “feeling unsupported.” EBS had no effect on participants’ intention to get screened, self reported discussions of PC with physicians, nor self reported screening behavior in the subsequent 6 months, compared to control, though it produced fewer screenings verified from medical records (EBS: 13%, control: 20%). EBS was rated better on graphics, text, and pro-con balance.

Conclusions: Though patients liked the EBS better than the control booklet, its graphic absolute probabilities had little effect on beliefs, intentions, or PC screening behavior.

1B1

MENTIP – Menorrhagia, Treatment; Information and Preferences. Enhancing decision making in menorrhagia in primary care using computerised decision analysis: randomised trial and qualitative evaluation

Protheroe J

National Primary Care Research and Development Centre, University of Manchester, UK

Background: Menorrhagia is a common problem, and current clinical guidelines recommend that it should be primarily managed in primary care. As menorrhagia has many equally effective treatments, patient preference is important, which in turn requires that patients be active participants in decision-making.

Achieving such shared decision-making can be difficult. Computerised decision aids based on decision analysis have the potential to provide information and assist patients to become active in the decision-making process. However, the available literature on the effectiveness of such aids is limited, and often derives from secondary care, where the issues may differ. The role of technologies such as computerised decision analysis requires urgent evaluation

The aim of the present study was to evaluate whether the addition of computerised decision analysis to written information reduces decisional conflict in women consulting their GP with menorrhagia. In addition, qualitative methods were used in line with the recommendations of the Medical Research Council Complex Interventions Framework. These methods were used to examine the mechanisms by which computerised decision analysis influences outcomes such as decisional conflict, and to investigate the role of decision analysis in the wider context of decision making in primary care.

Methods: Women consulting their GP with menorrhagia were randomised into one of two groups. Group 1 received an information leaflet alone. Group 2 received the leaflet and access to a computerised decision aid (Clinical Guidance Tree), which included formal decision analysis. Outcome measures included decision conflict, anxiety, symptom severity, and knowledge, completed at 2 weeks and 6 months. In addition, women from the intervention group were purposively sampled for n=20 qualitative interviews, using a semi-structured schedule.

Results: 145 patients were randomised to the study, and 73 patients completed the decision analysis. The main intention to treat analysis of the effect of the intervention on the primary outcome (decision conflict) will be presented, together with analysis of secondary outcomes including anxiety, and knowledge. Initial analysis of the qualitative data has revealed the following emerging theme: that this computerised decision aid has been effective in

improving shared decision-making in less well educated, lower socio-economic groups. This data will be explored further and presented.

Conclusions: The quantitative results will be considered in the light of previous data from similar interventions in published systematic reviews. In combination with insights from the qualitative research, this will enable a comprehensive assessment of the value of this technology in the primary care setting.

1B2

Randomised controlled trial of a patient decision aid in stroke prevention in patients with atrial fibrillation

Thomson RG, Eccles M, Graham R, Greenaway J, Heaven B, Kaner E, May C, Murtagh M, Rapley T, Steen N, Stobbart L

School of Population and Health Sciences, Newcastle upon Tyne Medical School

Background: Patients with non-valvular atrial fibrillation (NVAf) are at increased stroke risk, which can be reduced by aspirin or warfarin - treatments with different harm and benefit profiles. We undertook a trial of a computerised decision aid for use in the clinical consultation which presents the benefits of, and potential harm from, warfarin compared to standard practice using guidelines.

Methods: Patients over 60 with NVAf, recruited from general practice settings in North East England, were randomised to one of two clinics: the first (intervention, N=53), using the decision support tool within a shared decision making consultation, the second (control, N=56) giving a doctor-led recommendation using paper based guidelines. The primary outcome measure was the decision conflict scale. Secondary outcome measures included the state trait anxiety inventory, knowledge, decision making preference and the treatment decision.

Results: Decision conflict was lower at the first post clinic assessment in the intervention arm than the control arm (1.89, SD 0.43 compared to 2.07, SD 0.43, mean difference -0.18 95% CI -0.34 to -0.01). In patients not already on warfarin, the proportion of subjects who made a definite decision to start warfarin therapy was significantly lower in the intervention arm (4/16, 25% compared to control 15/16, 93.8%, RR 0.27, 95% CI 0.11 – 0.63). In patients already on warfarin there was no difference in the treatment decision between intervention and control groups.

Conclusions: A computerised decision aid applied in a shared decision making context produces lower post-intervention decision conflict than use of doctor-led guidelines advice, consistent with studies of similar aids. The differences in actual decisions made, although not a primary outcome measure, was marked in those who were not already on therapy. This suggests that patients' decisions, where the treatment has marked potential for harm, may be more conservative with balanced presentation of harm and benefits.

1B3

Evaluation of a decision aid for pregnant women with a breech-presenting baby: a randomised controlled trial

Nassar N, Roberts CL, Raynes-Greenow CH, Barratt A on behalf of the ECV Decision Aid collaborative group
Centre for Perinatal Health Services Research, University of Sydney, NSW, Australia

Background: Recent findings from a large international trial dramatically altered the options for women with a breech-presenting baby (buttocks or feet rather than head-first) in late pregnancy. To inform women of evidence-based safe and effective management options for breech presentation we developed a decision aid comprising an audio guided (CD) workbook and worksheet – a format that could be taken home and discussed with a partner. The effectiveness of the decision aid compared with usual care was evaluated in a randomised controlled trial.

Methods: Clinically eligible women were randomised to either the study group and received the decision aid in addition to usual care or to the control group and received usual care with standard counselling from their usual pregnancy care provider. Primary outcomes included decisional conflict, knowledge, anxiety and preparation for decision-making, and were assessed using self-administered questionnaires. Data were collected at baseline and at one week after randomisation and intervention, for primary outcomes.

Results: Approximately 200 women were randomised to the study with no significant differences in maternal characteristics between the groups. Baseline measures of knowledge, decisional conflict and anxiety were also comparable. Compared with usual care, women reviewing the decision aid experienced significantly lower decisional conflict ($p < 0.01$) and increased knowledge ($p < 0.001$), and were more likely to feel they had enough information to make a decision ($p < 0.01$). There was no significant difference in the level of anxiety between the two groups.

Conclusions: Findings demonstrate that our decision aid is an effective tool that provides an important adjunct to usual care and standard counselling for pregnant women about the management of breech presentation. These results suggest that decision aids may be applied to improve consumer information and participation in clinical decisions across a wide spectrum of pregnancy care.

1B4

A general practice-based randomised trial of a decision aid for colorectal cancer screening

Trevena L, Barratt A, Irwig L

University of Sydney

Background: Making informed decisions about participating in a screening program requires the healthy consumer to weigh up the harms and benefits with their individual risk and personal preferences. We have designed a suite of six age, gender and family history-specific decision aids that present the potential benefits and harms of screening over a ten year period.

Methods: This paper will report on the results of a general practice-based randomised controlled trial of the six tailored decision aids on 314 people aged between 50-74 years who were eligible for colorectal cancer screening by faecal occult blood testing. Patients were randomised to receive either the appropriate evidence-based decision aid for their age and gender or standard consumer guideline information. The decision aid is designed to be used at home by well consumers who might be considering a 'check-up' for bowel cancer.

Results: Interim analysis has shown no difference in overall participation in screening despite evidence-based and balanced information about the risks as well as the benefits of screening. Understanding of what screening means, of risk factors for colorectal cancer, of benefits and harms of screening was significantly greater in the decision aid group. At interim analysis stage, there was no difference in psychological outcomes such as decisional conflict, anxiety, satisfaction or self-efficacy between groups despite this knowledge 'gap'.

Conclusions: We have found a difference when changes in screening decisions are explored by age-gender (i.e. risk) subgroups. People in younger age groups (i.e. higher risk to benefit ratio) are more likely to switch away from screening after using the decision aid. Similarly, people in the older age group (at higher absolute risk of colorectal cancer) were more likely to switch toward colorectal cancer screening with the decision aid compared with their guideline counterparts. Implications for screening programs will be further discussed in light of these results.

1C1

Adherence therapy a new intervention for enhancing collaboration and choice for people with schizophrenia

Gray R (1), Robson D (1), David A (1), Bindman J (1), Thornicroft G (1), Tansella M (2), Schene A (3), Becker T (4)

(1) Institute of Psychiatry, Kings College, London (2) Verona, Italy (3) Academic Centre, Amsterdam The Netherlands (4) University of Ulm, Gunzburg, Germany

Background: Adherence therapy is a structured pragmatic intervention that aims to promote shared decision making between clinician and people prescribed antipsychotic medication. The therapy is based on motivational interviewing and cognitive behaviour therapy and has evolved from compliance therapy. The key therapeutic techniques therapists' use are exchanging information, developing discrepancy and effectively dealing with resistance. There are five key interventions to adherence therapy: problem solving; a medication timeline, exploring

ambivalence, discussing beliefs about medication and using medication in the future. The aim of the therapy is to achieve concordance about medication between the patient and clinician

Methods: We will present two case studies and the results from three randomised controlled trials evaluating adherence therapy involving over 400 patients in six countries.

Results: Preliminary results will be presented and discussed.

Conclusions: Patients report a high degree of satisfaction with adherence therapy.

1C2

Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial

Henderson C, Flood C, Leese M, Thornicroft G, Sutherby K, Szmukler G

Health Services Research Department, Institute of Psychiatry, Kings College London

Background: We evaluated the effectiveness of joint crisis plans at reducing use of inpatient services and objective coercion at and during admission.

Methods: Design: Single blind randomised controlled trial, with randomisation of individual patients. The investigator was blind to allocation.

Setting: Eight community mental health teams in southern England.

Participants: 160 people with an operational diagnosis of psychotic illness or non-psychotic bipolar disorder who had experienced a hospital admission within the previous two years.

Intervention: The joint crisis plan was formulated by the patient, care coordinator, psychiatrist, and project worker and contained contact information, details of mental and physical illnesses, treatments, indicators for relapse, and advance statements of preferences for care in the event of future relapse.

Main outcome measures: Admission to hospital, bed days, and use of the Mental Health Act over 15 month follow up.

Results: Use of the Mental Health Act was significantly reduced for the intervention group, 13% (10/80) of whom experienced compulsory admission or treatment compared with 27% (21/80) of the control group (risk ratio 0.48, 95% confidence interval 0.24 to 0.95, $P = 0.028$). As a consequence, the mean number of days of detention (days spent as an inpatient while under a section of the Mental Health Act) for the whole intervention group was 14 compared with 31 for the control group (difference 16, 0 to 36, $P = 0.04$). For those admitted under a section of the Mental Health Act, the number of days of detention was similar in the two groups (means 114 and 117, difference 3, -61 to 67, $P = 0.98$). The intervention group had fewer admissions (risk ratio 0.69, 0.45 to 1.04, $P = 0.07$). There was no evidence for differences in bed days (total number of days spent as an inpatient) (means 32 and 36, difference 4, -18 to 26, $P = 0.15$ for the whole sample; means 107 and 83, difference -24, -72 to 24, $P = 0.39$ for those admitted).

Conclusions: Use of joint crisis plans reduced compulsory admissions and treatment in patients with severe mental illness. The reduction in overall admission was less. This is the first structured clinical intervention that seems to reduce compulsory admission and treatment in mental health services.

1C3

Relationships Between Mental Health Status and Decision-Making Variables: Implications for the Design of Treatment Decision Aids

Wills CE

Michigan State University

Background: Little published information is available regarding relationships between mental health status and the decision-making variables that are the targets of treatment decision aids (DAs).

Methods: Mental health characteristics of primary care patients who screened positive for depression and who met (N=72) and did not meet (N=61) migraine headache diagnostic criteria were examined in relation to decision-making variables. Decision-making measures included the Decisional Conflict Scale, Satisfaction With Decision Scale, and an in-depth semi-structured interview about decision support needs and preferences regarding depression treatment. Mental health status measures included the PRIME-MD depression and anxiety modules.

Results: 43% of the sample was currently making a depression treatment decision, and “Deciders” were significantly more depressed compared to those not making decisions. Deciders with migraine headaches were more likely to report feeling physically stressed about their decision-making compared to those without migraines (69.2% versus 38%, $p < .05$). Deciders who met diagnostic criteria for a non-panic type of anxiety disorder tended to report more distress in decision-making compared to those without the diagnosis (feeling distressed/upset, constantly thinking about it, wavering/changing mind; p -values $< .05 - .06$). There was also a trend for Deciders with a non-panic anxiety disorder to be more likely to report that they were currently making a decision compared to those without the diagnosis (60.4% versus 40.6%; $p < .06$).

Conclusions: These results show that clinically significant levels of depression, anxiety, and migraine headaches may be associated with certain types of decision-making distress. DAs for these patients should address strategies for dealing with specific types of decision-making distress that are likely to co-occur with clinically significant affective disorders and migraine headaches. Although trials of DAs for non-mental health populations most often show little or no effect of DAs on anxiety and depression, additional research is needed for study populations with affective disorders and migraine headaches.

1C4

The impact of shared decision making on patients’ treatment acceptance, compliance and clinical outcome in primary care of depression

Loh A, Simon D, Wills CE, Bermejo I, Härter M

University Hospital, Department of Psychiatry and Psychotherapy

Background: Depression is highly prevalent in primary care. The involvement of patients in the process of shared treatment decision-making is a central element to ensure high quality care that is also consistent with patient preferences. There is little published research to date on the impact of shared decision-making in primary care of depression.

Methods: In a randomised controlled trial evaluating the impact of a shared decision-making intervention for depression, 30 general practitioners documented their clinical management plans. 486 depressed patients rated their own participation in decision-making (Man-Son-Hing’s Scale), acceptance of diagnoses and treatment (5 point Likert-Scales) and mental health status (Brief PHQ). Baseline data for 227 patients were collected twice within 6 weeks. Per random 20 physicians were assigned to the intervention group and received physician training as well as patient information material and patient decision aids. 10 physicians were assigned to control group and performed usual care. Post-intervention data were collected again twice within 6 weeks. 259 new patients with depressive disorders were enrolled. Intervention group physicians treated in sum 347 patients, control group physicians 139 patients.

Results: Patient participation ($p = .000$) and patients’ acceptance of treatment ($p = .02$) were significantly higher in the intervention group. Compliance was also higher in the intervention group but did not reach statistical significance ($p = .08$). Patients with higher participation rates showed more favorable clinical outcomes ($p = .04$). Significant positive correlations occurred between participation and patients’ acceptance of treatment ($p < .05$), compliance ($p < .01$) and clinical outcome ($p < .01$).

Conclusions: Depressed patients who are engaged in shared decision-making show higher acceptance of diagnosis and therapy, perform therapeutic tasks to a higher degree, and gain more clinical effects than patients not involved in decision making. These results support the usefulness of incorporating shared decision-making into treatment of depressed primary care patients.

1D1

Web-based decision making – mso© a German case study

Hoeldke B

University Hamburg

Background: Decision aids are tools designed to help people make specific and deliberate choices. The basis of informed consumer choice should be evidence-based. For that reason we developed online patient information about mammography screening. We evaluated the usefulness of this information for decision making and assessed women's attitude about mammography screening before and after information was provided.

Methods: The target group in this study were laypersons. The presented outcome data includes the complete estimation of the potential benefit-harm relation and further information on the test accuracy of mammography screening. We revised and edited previously published evidence for use on the world-wide-web (<http://www.mammographie-screening-online.de>). The designed information-aid mso© is co-located with a questionnaire, including the German version of the Decisional Conflict Scale (DCS). We evaluated women's difficulty in making a decision, their perceived uncertainty in choosing between options, modifiable factors contributing to uncertainty and quality of choice selected.

Results: The survey is still ongoing. The results after four years of collecting show that a web-based decision aid is an appropriate method for improving the quality of decision making. Our response rate was 4.6%, which was expected and the comprehensibility was evaluated with 'good'. Out of 5139 women who participated in choice predisposition, 47% considered mammography as suitable for them, 44% were uncertain and 12% voted against mammography. 688 women who used mso© as a decision aid regarding mammography, felt well informed and supported. They were content and felt well prepared for better communication with their GP. After using the web-based information-aid the results for the DCS show that 66% of the women were able to make a decision about mammography without decisional conflict (score <2.5).

Conclusions: Our study shows that a web-based decision-aid, presenting evidence based medical information in a format that is understandable for lay-persons, is able to improve decision-making.

1D2

Patient involvement in therapeutic decision-making for low rectal cancers

Zenasni F, Sideris L, Dauchy S, Di Palma M, Vernerey D, Pocard M.

Gustave Roussy Institute

Background: Low rectal cancer often requires a mutilating surgery (permanent stoma) to hope for a cure, and the involvement of patients in therapeutic decision-making may depend on both seriousness and misunderstanding of their disease. Previous studies reported that when compared to patients treated for breast cancer, colorectal cancer patients were less willing to be active in the choice of their treatment. These results mean that the nature and degree of patient implication in the choice of treatment may be disease-specific

Methods: We conducted a study on patients sustaining low rectal cancer exclusively to assess their preference level for an active participation in therapeutic decision-making. Eighty-five patients operated at the Gustave Roussy Institute between 1986 and 2002 were accrued. A surgeon and a psychologist explored what has been considered by the patients as the most important element(s) guiding their decision during preoperative surgeon-patient consultation. We also assessed the discrepancy between patients' preference and real involvement in the decision-making process. Finally, we examined patients' satisfaction about the decision-making process, surgery, post-operative course and whether they had any regret about it. The French adaptation of both Control Preference Scale (Degner et al. 1997) and Decisional Conflict Scale (O'Connor, 1995) were used.

Results: Results indicate that even though 61.2 % of patients did not want to be involved in the choice of their treatment, 38.8 % wished to be more or less active. When considering elements that may guide patients' decisions, quality of life criteria were not taken into account (14.2 %), contrarily to survival criteria (69.5 %). This means that patients do not wish to trade a better quality of life for a diminished survival by having a less mutilating treatment.

Conclusions: The concept of shared decision-making is thus difficult to apply to patients sustaining low rectal cancer since their main criterion for accepting a treatment is overall survival, not quality of life.

1D3**What do patients consider when making decisions about treatment for Hepatitis C?**

Fraenkel L, McGraw S, Wongcharatrawee S, Garcia-Tsao G.

Yale University School of Medicine, VA Connecticut Healthcare System

Background: Given the complexity of the decision that patients face when considering treatment for hepatitis C (HCV), and the lack of studies addressing decision-making in HCV from the patient's perspective, we sought to investigate the factors that influence patients' treatment decisions for HCV.

Methods: We chose to use a qualitative study using focus groups to obtain a thorough understanding of the factors related to decision-making about HCV from the patients' perspective. Purposeful sampling was employed to include both patients who were currently being treated or had recently been treated for HCV as well as patients who had refused therapy. Focus groups were conducted until thematic saturation was reached. We used constant comparative methods to analyze the data. Two analysts independently read the transcripts, jointly developing an initial list of codes. This list was modified and the codes refined with sub-headings on a second reading of the transcripts.

Results: A total of 40 patients (80% male) participated in eight focus groups. The mean age (SD) was 51.5 (5.2); 82% Caucasian; 59% greater than a high school education; and 55% were employed. At the time of the session, 32.5% were in treatment, 50% had completed treatment and 17.5% had refused treatment.

The determinants of patients' decision-making that emerged most frequently during the focus groups were: consideration of risk benefit tradeoffs, protected values, heuristics, patients' conceptualization of HCV, social issues, and physicians' recommendations. Interestingly, the same factors influenced patients in opposite ways. For example, some participants felt obliged to undergo treatment so that they would be able to care for their children in the future, whereas others refused treatment because they feared that the adverse effects would interfere with their familial responsibilities.

Conclusions: Improved awareness of these factors might improve physicians' abilities to help patients make informed decisions about treatment for HCV.

1D4**Different Information Needs by Gender During Colorectal Cancer Screening Decision-Making**

Friedemann-Sanchez G, Griffin JM, Partin MR

Center for Chronic Disease Outcomes Research, Minneapolis VA Medical Center

Background: Four screening modalities have been found to be efficacious at reducing colorectal (CRC) mortality: Fecal Occult Blood Test, sigmoidoscopy, Double Contrast Barium Enema, and colonoscopy. Given the number of choices and the varying complexity, risks, and efficacy across modes, shared decision making may be essential to patients adhering to CRC screening guidelines. Key to shared decision-making is patient's preference. There is a gender gap in CRC screening rates. We sought to determine whether women and men have different preferences, barriers and facilitators to CRC screening and, if so, how knowledge shaped their decision-making regarding mode preference.

Methods: Six focus groups were conducted with male and four with female U.S. veterans to elicit information about barriers and facilitators to four screening modes. The groups were stratified by screening status (screened/unscreened). Six to eight individuals participated per group. A semi-structured interview guide was developed to assess perceptions, attitudes, and beliefs about CRC screening options. Discussions were recorded, transcribed and coded according to themes.

Results: Previous studies on CRC screening preferences have found that patient's prefer colonoscopy and FOBT at nearly equal rates. Our findings indicate colonoscopy as the preferred screening modality over all other modes among both women and men. But only women who had a prior endoscopic procedure viewed the required preparation as a major barrier to screening. Women and men expressed significantly different fears (affective and physical respectively) and information preferences regarding endoscopic procedures.

Conclusions: Tailoring by gender the type of knowledge may facilitate mode choice in a shared decision context, and it may be warranted given the gendered barriers by mode and reasoning behind the preferred mode. Providing specific information addressing type of discomfort (physical and affective) may also affect individual's mode preference. Subtle differences in languages may make significant differences in the decision-making process and ultimately in patient's preferences.

2A1**Informed decision making regarding Prostate-Specific Antigen (PSA) screening: findings from the 2000 National Health Interview Survey**

Han PK, Coates RJ, Uhler RJ, Breen N

(1) National Cancer Institute, National Institutes of Health, (2) Centers for Disease Control

Background: The net benefits and harms of prostate cancer screening with the Prostate-Specific Antigen (PSA) test are uncertain, and major professional organizations recommend that physicians inform patients about these uncertainties before initiating PSA screening. However, little is known about the practice of informed decision making regarding PSA screening in the United States.

Methods: Cross-sectional analysis of data from the 2000 National Health Interview Survey (NHIS) was performed to determine the extent to which PSA screening is 1) initiated by physicians, and 2) preceded by informed physician-patient discussions of the test's advantages and disadvantages, and to explore sociodemographic and health-related factors associated with these outcomes.

Results: Overall, 74% (95% C.I., 71.8-76.0) of screening PSA recipients reported that screening was initiated by the physician, and the proportion increased with advancing age, declining health status, lack of family history of prostate cancer, presence of a usual source of medical care, and non-Hispanic ethnicity. 65% (95% C.I., 63.1-67.1) of all screening recipients reported that pre-screening discussions with their physicians occurred. Discussions were more common when the physician initiated PSA screening, and for patients who reported a usual source of medical care, non-blue collar occupation, and black race.

Conclusions: PSA screening in the United States is usually initiated by physicians, and often without pre-screening discussions about the test. Physician initiation of PSA screening is greatest in men least likely to benefit from it, and pre-screening discussions are more common when physicians initiate screening than when patients do. PSA screening falls short of ideals of informed decision making, and further examination of the factors influencing the decision-making process is warranted.

2A2**Orthopaedic Surgeons' Opinions About Patients' Decision Aids For Elective Surgery For Herniated Disc / Spinal Stenosis: A National Survey**

Llewellyn-Thomas HA, Mimnaugh D, Weinstein J

Center for the Evaluative Clinical Sciences, Dartmouth Medical School, Dartmouth College, Hanover, NH; Department of Orthopaedic Surgery, Dartmouth-Hitchcock Medical Center, Lebanon, NH

Background: Video-based patients' decision aids (PtDAs) for individuals considering elective back surgery for herniated disc / spinal stenosis have been successfully tested in RCT studies. However, their implementation in "real time" could be handicapped by failing to understand orthopaedic surgeons' opinions about whether back surgery PtDAs could be useful in actual clinical practice, and, if so, in what particular ways.

Methods: We contacted, by e-mail, fax, and surface mail, all 2430 available members of the American Academy of Orthopaedic Surgeons (AAOS) who perform elective back surgery for herniated disc / spinal stenosis. Decision support with PtDAs was outlined, then a questionnaire assessed their opinions; responses were obtained by e-mail (7%), fax (29%), surface mail (32%), and on a designated website (32%).

Results: Among 629 respondents (target sample was 520): 89% indicated decision support using PtDAs was a "good/excellent" idea; 51% favoured booklets + audiotapes over other media; and 85% favoured providing the PtDA at the 1st consultation for the patient to view at home followed by discussion of the options and decision making at the 2nd consultation. Majorities considered PtDAs most helpful if they increase patients' understanding of options, benefits, and risks (88-91%); help with use of time in the clinic (88%); ensure "matches" between preferences and actual treatment (79%); improve patient-MD communication and relationships ((79% & 73%, respectively); as well as positively affect patients' anxiety (80%), depression (53%), quality of life (65%), adherence to treatment (75%), and satisfaction with care (85%). Respondents also wanted PtDAs to reduce malpractice

insurance and local litigation rates (87-88%), think that health insurers should reimburse surgeons for using PtDas (83%), and advocate that PtDA use serve as a Quality Assurance indicator (79%).

Conclusions: These observations will help the AAOS to devise effective Continuing Medical Education curricula and feasible dissemination strategies for decision support/PtDAs in this surgical context.

2A3

A survey of Australian oncologists' views about shared decision making (SDM)

Shepherd H (1), Tattersall MHN (2), Butow P (3), Charles C (4)

(1) Medical Psychology Research Unit, Department of Medicine, University of Sydney, (2) Department of Cancer Medicine, University of Sydney, (3) Medical Psychology Research Unit, School of Psychology, University of Sydney, (4) Centre for Health Economics and Policy Analysis, McMaster University

Background: Shared decision making is now regarded as the gold standard in clinical care; however, little is known about doctor attitudes to SDM or the barriers to its implementation.

Methods: A shortened version of the survey instrument reported by Charles et al (2003) was sent to a national sample of: a) breast surgeons, and medical and radiation oncologists with an interest in breast cancer, similar to the group reported from Canada; b) haematologists; and c) oncologists and surgeons with interests other than breast cancer, grouped according to organ sites. The survey gathered information concerning usual approach to decision making, use of methods to encourage SDM and barriers to SDM were elicited. Demographic data, location, clinic setting patient load were obtained.

Results: An interim analysis of breast cancer doctors and haematologists has been conducted. 227 breast doctors, comprising 125 surgeons, 64 medical oncologists, 38 radiation oncologists and 50 haematologists have responded to date. 64% of breast cancer doctors report using SDM as their usual approach versus 42% of haematologists.

Most common barriers reported by breast cancer doctors were misconceptions about treatment or disease, insufficient time, high patient anxiety levels, patient indecision and patients not wanting to participate in the process. Haematologists reported insufficient information and time and co-morbidity as most often being barriers to SDM. Breast cancer doctors and haematologists reported trust and the patient being accompanied in the consultation as the most facilitative to SDM.

Significant predictors of SDM as the usual approach were identified in the breast cancer doctor sample. Female doctors compared to their male colleagues ($p < 0.018$), breast surgeons compared to medical and radiation oncologist ($p < 0.01$) doctors in urban communities compared to doctors in communities of $< 100,000$ ($p < 0.042$) were more likely to use a SDM approach. Data from the full data set will be available by June and an updated analysis will be presented.

Conclusions: Preliminary results among breast cancer doctors are similar to those reported in Ontario. In both environments (80%) of oncologists reported they were comfortable with SDM. However Australian and Canadian breast surgeons report they practice SDM as their usual approach significantly more often than their medical and radiation oncology colleagues treating breast cancer. We believe this may reflect professional views about the existence of realistic clinical options regarding treatment in breast cancer management.

2A4

Women's decision making regarding pain relief in labour

Lally J, Murtagh M, Thomson RG, MacPhail S

School of Population and Health Sciences, The Medical School, University of Newcastle upon Tyne, Newcastle, England

Background: The study examines the views and expectations of women and professionals about their experience and information needs to support decision making about pain relief in labour. It will determine what information is

currently provided and what information women and professionals require; when this information should be provided; and which media are the most appropriate.

Methods: A systematic literature review explored methods of pain relief, women's expectations and experiences and decision making in the field of obstetrics.

Interviews and focus groups were also conducted with the professional groups involved in the care of pregnant women. Discourse analysis will be drawn upon to understand how women draw on their social context to make decisions

Results: The literature review identified three areas of interest. First there is evidence of the effectiveness but little on the acceptability of pain relief in labour. Secondly, the focus in obstetrics has been on decisions regarding ante-natal testing, with little on decisions where there is a time lag between decision and action, as happens in pain relief. Finally, whilst there are many narratives of women's experience of labour, few explore the impact of social context and social constructs of labour

Preliminary results from focus groups, which give the professional perception, suggest that firstly; women are not well prepared for the pain of labour, hence a gap between their expectations and actual experience. Also many professionals raised the issue that as a society women no longer need to feel pain, as we have the methods available to relieve it. Finally professionals feel that although women are in control of making the decisions, often their choices are guided.

Conclusions: Results of this qualitative study will support the subsequent development of risk communication and decision aid(s) to support evidence-based choice in pain relief in labour.

2B1

Outil d'aide à la décision en matière de stérilisation masculine: étude de besoin

Baldé A, Labrecque M, Légaré F, Desmartis M, Thabet M

Unité de recherche évaluative Hôpital Saint-François d'Assise, Québec Canada

Contexte : Jusqu'à 10% des hommes éprouvent du regret suite à la vasectomie. Ce regret est souvent associé à un changement matrimonial ou familial. Toutefois, un conflit décisionnel élevé non résolu pourrait être déterminant. Notre étude visait à évaluer le besoin d'un outil d'aide à la décision en matière de stérilisation masculine.

Méthodes : Le jour de la vasectomie, 209 hommes ont complété l'Échelle de conflit décisionnel (ECD) à 16 items (1 = conflit faible à 5 = conflit élevé) et un questionnaire auto administré de 13 items portant sur les connaissances en matière de vasectomie. L'opinion de 42 hommes qui envisageaient la stérilisation et de 11 médecins qui la pratiquaient concernant le besoin d'un outil d'aide à la décision a été recueillie à l'aide d'interviews individuelles semi-structurées.

Résultats : Le score moyen sur l'ECD (n=207) a été de $1,5 \pm 0,4$ (médiane 1,4, étendue 1,0 - 2,8). Au total, 4 hommes (1,9%, IC 95% = 0,5% - 4,8%) avaient un score de 2,5 ou plus (conflit décisionnel élevé). Le score moyen de connaissances fut de $58,2\% \pm 13,5\%$ (médiane 60%, étendue de 30,7%-100%). Il n'y avait pas de corrélation entre le score de connaissances et celui de conflit décisionnel (r Spearman = -0,06, $p = 0,3$). Les hommes et les médecins interviewés ont jugé que cette décision n'est pas toujours facile à prendre et que des renseignements sur les « meilleures » sources d'information accompagnées de matériel visuel pourraient aider à la prise de décision.

Conclusions : Les hommes qui optent pour la stérilisation masculine semblent confortables avec leur décision le jour de leur vasectomie. Cependant, leur niveau de connaissances pourrait être insuffisant pour qualifier cette décision d'informée. Le besoin d'un outil d'aide à la prise de décision est pressenti par les médecins et les hommes qui envisagent la vasectomie.

2B2

Évaluation d'un outil d'aide à la décision et d'un profil de risque personnalisé en pharmacies communautaires sur les options de traitement pour améliorer la santé cardiovasculaire : Étude pilote OPTIONS

Lalonde L, O'Connor AM, Duguay P, Brassard J, Kayal A, Drake E, Grover SA

Faculté de Pharmacie, Université de Montréal, Québec, Canada ; Chaire Avantis Pharma en soins pharmaceutiques ambulatoires, Faculté de Pharmacie, Université de Montréal, Québec, Canada ; Équipe de recherche en soins de première ligne, Cité de la Santé de Laval, Québec, Canada ; Facultés des Sciences de la santé et de Médecine, Université d'Ottawa et Institut de recherche en santé d'Ottawa, Ontario, Canada ; Division of Clinical Epidemiology, Centre for the analysis of cost-effective care and Division of general internal medicine, Centre universitaire de Santé McGill et Université McGill, Québec, Canada

Objectif : Évaluer la faisabilité d'offrir aux patients prenant une médication hypolipémiante ou antihypertensive, dans les pharmacies communautaires, une consultation pharmaceutique assistée d'un outil d'aide à la décision (OA) ou d'un simple profil de risque personnel (PRP).

Méthodologie : Les patients ont été assignés aléatoirement au groupe OA ou PRP et ont été évalués avant, deux semaines après et trois mois après une consultation avec un pharmacien. Les résultats sont rapportés pour tous les patients combinés.

Résultats : 26 patients ont été recrutés dans 8 pharmacies communautaires. Les patients ont rapporté comme excellente ou très bien la façon dont l'information était présentée (79%) dans l'OA et le PRP ainsi que la quantité d'information (88%) et l'utilité de ces outils (100%). La moyenne des scores de satisfaction pour l'implication dans la prise de décision, la quantité d'information fournie et la perception de la qualité des soins prodigués par les pharmaciens étaient de 69%, 81% et 85%, respectivement. Après l'intervention, la proportion de patients avec des scores élevés de conflit décisionnel (score > 2,5) a diminué (58%-25% ; p=0,01) et une plus grande proportion de patients pouvait évaluer leur risque cardiovasculaire (35%-54% ; p=0,80) ainsi que les bénéfices escomptés de traitement (29%-58% ; p=0,06). Le degré de connaissance des facteurs de risque de maladie cardiovasculaire ne s'est pas amélioré. Une progression des stades de changement pour l'activité physique, une diète faible en gras et en cholestérol et la perte de poids a été observée.

Discussion : Une consultation pharmaceutique assistée d'un OA ou d'un PRP dans les pharmacies communautaires peut améliorer la qualité de la décision concernant l'initiation ou la poursuite d'un médicament hypocholestérolémiant ou antihypertenseur et pourrait être cliniquement efficace. Conclusion et implications dans la pratique : Les interventions d'un pharmacien, assistées d'un outil éducationnel sont faisables et pertinentes.

2B3

Développement et mise en œuvre du programme national SOR SAVOIR PATIENT d'information et d'éducation thérapeutique des personnes atteintes de cancer et de leurs proches

Leichtnam-Dugarin L (1), Carretier J (1), Fervers B (1,2), Brusco S (1), Delavigne V (1), Philip T (2)

(1) French Federation of Comprehensive Cancer Centre (FNCLCC), Paris, France, (2) Centre Léon Bérard, Lyon, France

Contexte : Face à l'augmentation de la demande d'information des patients et de leur rôle dans la prise de décision médicale, l'accès à une information validée, compréhensible et systématiquement actualisée, en correspondance avec leurs besoins est un enjeu majeur de santé publique. Pour répondre à cette demande, la Fédération Nationale des Centres de Lutte contre le Cancer (FNCLCC) a mis en place en 1998 un programme d'information et d'éducation des patients atteints de cancer et de leurs proches, les SOR SAVOIR PATIENT. Ce programme repose sur une collaboration nationale avec les vingt Centres Régionaux de Lutte Contre le Cancer, la Ligue Nationale contre le Cancer, la Fédération Hospitalière de France, la Fédération Nationale de Cancérologie des Centres Hospitaliers Régionaux et Universitaires, la Fédération Française de Cancérologie des Centres Hospitaliers Généraux, les sociétés savantes concernées ainsi que des patients, anciens patients et proches.

Les objectifs du programme SOR SAVOIR PATIENT sont de permettre aux patients et à leurs proches de mieux comprendre leur maladie et leur traitement, de mieux participer aux choix thérapeutiques, faciliter le dialogue avec le médecin et proposer aux médecins une information synthétique pour mieux communiquer avec le patient dans des termes compréhensibles.

Méthodes : Les SOR SAVOIR PATIENT élaborent des guides d'information et de dialogue selon une démarche systémique participative en 3 étapes complémentaires. 1/ les informations sont développées à partir de recommandations pour la pratique clinique, les Standards, Options : Recommandations (RPC-SOR) qui proposent une revue et analyse critique des données scientifiques actuelles (evidence-based medicine) pour la prise en charge des cancers. Ces RPC-SOR sont d'abord traduits en langage simple par une équipe pluridisciplinaire impliquant des chargés de mission de santé, une linguiste, un psychologue et les spécialistes des disciplines concernées. 2/ Des groupes de patients, d'anciens patients et de proches sont associés tout au long du processus d'élaboration du guide tant pour le recueil de leurs besoins d'informations que pour la rédaction, la formulation et l'adaptation des informations à leurs besoins. Leur participation active repose sur une approche mixte combinant questionnaires, focus groups et entretiens individuels semi-directifs (approche anthropologique). Le contenu scientifique des informations est systématiquement validé par un groupe de travail de spécialistes au cours de cycles de validation successifs. 3/ Une relecture nationale des informations produites réalisée par des experts de la spécialité concernée permet de valider le document final avant sa publication et sa diffusion nationale sur support papier et électronique.

Résultats : Les Centres Régionaux de Lutte Contre le Cancer ont établi un consortium dont l'un des axes a pour objectif d'associer plus largement les personnes malades à la gestion de leurs soins. La diffusion systématique des guides SOR SAVOIR PATIENT répond à cet objectif.

A ce jour, plus d'une centaine de patients ont participé à l'élaboration des guides SOR SAVOIR PATIENT (rédaction, relecture, reformulation, choix de la forme, illustrations, maquette). Plusieurs guides ont été publiés : Comprendre le neuroblastome (2001), Comprendre le cancer du sein (Prix Prescrire 2001, mise à jour en 2002), le cancer de l'ovaire et le risque familial de cancer du sein et/ou de l'ovaire en 2002, le cancer du poumon en 2003, l'ostéosarcome et la chimiothérapie en 2004, la prostate début 2005. Des fiches d'information sur les examens radiologiques en sénologie (mammographie, échographie mammaire, scanner, IRM, etc.) ont également été publiées selon la même méthodologie. D'autres guides vont être publiés courant 2005 sur notamment le cancer du rectum, la douleur, la radiothérapie, etc. Les SOR SAVOIR PATIENT sont publiés sous format papier (la forme étant choisie avec les patients) et sur le site Internet de la FNCLCC (<http://www.fnclcc.fr>). Ils font également l'objet de publication (extraits de guides, méthodologie d'élaboration, etc.) dans des revues scientifiques (Bulletin du cancer, British Journal of Cancer, etc.). La satisfaction des lecteurs est évaluée par questionnaire encarté dans chaque guide. Par exemple, pour le cancer du sein, 87 % des répondeurs jugent que les informations correspondent à leurs besoins.

Conclusions : Les guides SOR SAVOIR PATIENT ne se substituent pas à la relation patient - médecin, mais représentent un complément à cette relation individuelle. Chaque guide représente un outil d'information utilisable dans une démarche d'éducation thérapeutique du patient et de leurs proches. Ces programmes d'éducation thérapeutique doivent être mis en œuvre au niveau local et régional au sein des établissements de santé et des réseaux de soins. L'évaluation de l'impact d'un guide SOR SAVOIR PATIENT sur la relation médecin-patient est en cours. Le contexte culturel dans lequel se situe cette relation doit également faire l'objet de recherches complémentaires.

2B4

Description du processus de soutien décisionnel des infirmières en centre de traitement des agressions sexuelles

Guimond P, O'Connor AM, Siedlikowski H

Université d'Ottawa, Hôpital d'Ottawa.

Contexte : Le programme régional de traitement des agressions sexuelles de l'hôpital d'Ottawa collabore actuellement à un projet qui visent à défrayer les coûts d'un traitement prophylactique au VIH en permettant ainsi aux professionnels de la santé d'offrir cette option aux clientes victimes d'agression sexuelle (Loutfy, M., et al., 2003). Le fait que ce traitement, très coûteux, est offert gratuitement contribue encore plus au conflit décisionnel de ces femmes. En effet, la décision de suivre ou non ce traitement est un choix extrêmement difficile compte tenu

des nombreux effets secondaires que peut occasionner un tel traitement et de l'incertitude que vive ces femmes à l'égard de leur statut de contamination au VHI (National Victim Center, 1992).

Le soutien décisionnel fait partie intégrante du rôle de l'infirmière qui travaille dans un tel Centre de traitement. Malgré le fait que ce programme préconise un modèle de soins centré sur le client, très peu d'infirmières ont été formellement préparées pour répondre de façon efficace aux besoins d'aide à la prise de décision des clientes qui font face à une telle situation conflictuelle (Braddock, et al., 1999). D'autant plus, jusqu'à maintenant aucune étude a décrit le processus de soutien décisionnel des infirmières.

Méthodes : Ainsi, le but de notre étude est de décrire le processus de soutien décisionnel des infirmières qui aident les femmes agressées sexuellement à prendre une décision sur le choix de traitement prophylactique au VIH et ce, à partir du MADÉO (Modèle d'Aide à la Décision de l'Équipe d'Ottawa).

Les entretiens entre les infirmières et les clientes (n=30) en situation de conflits décisionnels font l'objet d'analyse à partir du OAAD (Outil d'Analyse d'Aide à la Décision) afin de dégager le processus de soutien décisionnel des infirmières dans une telle situation.

Résultats : L'étude est cours actuellement et il est trop tôt pour fournir des résultats précis. Par ailleurs, lors de la conférence en juin nous serons en mesure de présenter de tels résultats.

Conclusions : Au terme de la présentation, nous identifions des recommandations pour la formation, la pratique et la recherche.

2C1

Effect of prostate cancer screening decision aids on shared decision making process outcomes: results from a randomized trial

Partin MR, Nelson D, Nugent S, Holtzman J, Wilt TJ

The Center for Chronic Disease Outcomes Research at the Minneapolis VA Medical Center, and the University of Minnesota

Background: This study assessed the effects of mailed video and pamphlet prostate cancer (CaP) screening decision aids on patient decisional involvement, certainty, and satisfaction.

Methods: In this randomized, controlled trial, a sample of 1152 male veterans age 50 and older with no CaP and scheduled appointments at one of four participating Veterans Affairs medical facilities in 2001 was stratified by age (50-69, 70+), PSA in the past year (yes, no), and facility and randomly assigned to one of three study groups: (1) mailed pamphlet, (2) mailed video, or (3) usual care (control). Intervention materials were mailed to patients two weeks prior to their scheduled primary care appointment, and outcomes were assessed by telephone survey one week after the appointment. 42 participants were excluded from the analysis sample (8 deceased, 5 females, 29 CaP diagnoses). 893 (80%) of the remaining 1110 participants completed the survey and were included in analyses. Outcomes examined using adjusted linear regression models included: the Patient Perceptions of Involvement in Care Scale (PICS), O'Connor's Factors Contributing to Decisional Uncertainty Scale, and Holmes-Rovner's Satisfaction with Decision scale.

Results: 56% of video and 50% of pamphlet subjects reported looking at the mailed materials. Video and pamphlet subjects had significantly lower Factors Contributing to Uncertainty scale scores than controls (23.8, 23.8 and 24.5, respectively). Pamphlet subjects were significantly more likely than controls to be involved in CaP decision making (PICS scores 1.73 and 1.20, respectively, $p=.05$) but video subjects were not (PICS score 1.53, $p=.21$). Neither intervention increased satisfaction with decision-making (Satisfaction with Decision scale scores 18.5, 18.3 and 18.3 for video, pamphlet, and control subjects, respectively).

Conclusions: The interventions have modest and comparable effects on decisional uncertainty and involvement, and no affect on satisfaction. The impact of the interventions may be enhanced by increasing patient exposure to the materials.

2C2**Do Decision Aids Promote Shared Decision-Making? A Randomized Trial among Men Eligible for Prostate Cancer Screening**

Krist AH, Woolf SH, Johnson RE

Virginia Commonwealth University

Background: Current guidelines for prostate cancer screening urge physicians to involve patients in shared decision-making, but many physicians lack resources to present pros and cons in a factual and balanced format. We sought to evaluate whether pre-visit educational decision aids facilitate shared decision-making.

Methods: We conducted a randomized controlled comparison of a web-based or paper-based decision aid for prostate cancer screening versus no pre-visit education for men presenting for a health maintenance examination at a single clinic. Outcomes were assessed by patient and physician surveys. The primary outcome was the reported level of control over the screening decision as measured by a single question with response options ranging from A to E: A represented complete patient control, E represented the reverse, and C represented a purely shared decision.

Results: 497 men participated (75 controls, 196 received brochures, 226 received the website). A similar proportion of patients reviewed the material before their visit (brochure, 88%; website, 85%). Patients exposed to either decision aid were no more likely than controls to report a truly shared-decision: 36% of patients in each group reported choice C. Patients randomized to decision aids were more likely to report greater personal control over the decision (comparing the website ($p=0.04$) and brochure ($p=0.03$) to the control group). Patients exposed to a decision aid demonstrated greater knowledge about prostate cancer (correct answers on knowledge test: website, 78%; brochure, 79%; control, 65%; $p < 0.001$) and were less likely to opt for PSA testing (receiving test: website, 86%; brochure, 85%; control, 94%; $p=0.05$).

Conclusions: Pre-visit decision aids appeared to increase patient's knowledge and encouraged active control over decisions but did not promote physician-patient shared decisions like current guidelines advocate. Whether such a decision-making style is indeed ideal and how best to measure its occurrence are subjects for further research.

2C3**Informed decision making and PSA testing for prostate cancer: a randomized trial of a mailed decision aid in the UK**

Watson E (1), Hewitson P (1), Bukach C (1), Brett J (1), Edwards A (2), Elwyn G (2), Love S (3), Austoker J (1)

(1) Cancer Research UK Primary Care Education Research Group, Department of Primary Care, University of Oxford, (2) Department of Primary Care, University of Wales, Swansea, (3) Centre for Statistics in Medicine, University of Oxford

Background: Current UK policy stipulates that any man can have a PSA test provided he has full information about the benefits, limitations and consequences of the test. The main aim of this study was to examine the impact of a written decision aid (DA) on men's knowledge, attitudes and intention to be tested, and to explore the factors which predict intention to be tested.

Methods: 990 men aged 40-75 from 11 General Practices in England and Wales were randomized to receive either a mailed copy of the DA and a questionnaire, or a questionnaire alone. Main outcome measures were knowledge (UK specific 12 item scale developed and validated for this study), attitudes (UK specific 12 item scale developed and validated for this study) intention to be tested within next 12 months (single item 5 point Likert scale) and men's views of content and presentation of the DA (series of 13 questions with multiple response options).

Results: Men who received the DA had significantly higher knowledge scores and less positive attitudes regarding PSA testing than men who did not. Overall, 27.5% men reported positive testing intentions, with those receiving the DA significantly less likely to be in this category (25.6% vs 29.1%, $p < 0.001$). Preliminary analysis has identified age, educational level, the presence of symptoms, perceived risk of developing prostate cancer and degree of concern about the disease as predictors of intention to be tested. The final findings will be presented at the meeting. 87% of men found the DA easy to read, and 94% considered it contained about the right amount of detail. 94% felt the information was presented in a balanced way.

Conclusions: Widespread use of this decision aid in primary care should increase levels of informed decision making amongst men in the UK considering a PSA test.

2D1

The PSA test: narratives about an uncertain investigation

Evans R, Edwards A, Elwyn G

University of Wales Swansea Clinical School, Swansea, Wales, UK

Background: The controversies relating to the Prostate Specific Antigen (PSA) test are well documented. As a screening test for Prostate Cancer it has significant limitations. It is, however, the only simple test available for an increasingly common condition. Unlike the USA, the UK does not promote a screening programme, and advocates informed decision making by men about whether to have the test. Accordingly, we developed a web-based decision aid for men interested in the PSA test. This included enacted, video experiences of men who had contemplated and made decisions on PSA testing, based on interviews from a qualitative study.

Methods: A semi-structured interview technique was used. Men between the ages of 40 and 70 were recruited, via General Practitioners and a Urology department, from different socio-geographic settings in Wales, UK. Theoretical sampling was used to capture a wide range of experiences in men who had decided for and against PSA testing. The interviews were transcribed and subsequently analysed using Atlas.ti software. Using a grounded theory methodology, independent coding and thematic identification was undertaken by two researchers.

Results: 28 men were interviewed. They were all white and only one had declined a PSA test. Of those that received the PSA test, 1 was unaware of being tested; 2 were either unaware or uncertain of the result; 12 had normal PSA levels and 12 had raised PSA levels — 6 of these men were subsequently diagnosed as having prostate cancer. Two groups of themes were identified. The first group, 'Deciding on a PSA test', contained two major themes: information and decision making issues. In the second group, 'After the PSA test', decision making was again a significant theme, particularly in the context of men with raised PSA tests facing further investigations and treatments. The major theme, however, was the uncertainty associated with the whole 'post test period', from the initial PSA result through to considerations of the future.

Conclusions: PSA testing is beset with uncertainty and this needs to be carefully explained to men. The experiences garnered in this study can be integrated as a narrative into a web-based decision aid, to contribute to the evidence base upon which men can make an informed choice about whether or not to have PSA test.

2D2

Decisional Conflict Concerning Prostate Cancer Screening Among Low Income Men

Weinrich S

Medical College of Georgia, School of Nursing, Augusta, Georgia United States

Background: Major discrepancies between the number of men diagnosed with prostate cancer (CaP) (220,900) and the number of men who die from CaP (28,900) raise questions about the efficacy of screening. It is not known whether screening saves lives or causes more harm. Decisional needs, operationalized as knowledge of choices, benefits, and risks, exist in situations in which choices have both desirable and undesirable outcomes, such as prostate cancer screening. However, there has been minimal research on decisional needs with prostate cancer screening. Few studies have evaluated decisional needs related to prostate cancer screening.

Methods: This correlational secondary data analyses research reports on decisional needs measured with an Informed Subscale from O'Connor's Decisional Conflict Scale. O'Connor's decision-support framework provides the overall framework. Men, 214, were recruited from low-income, predominately African American neighborhoods. All of the neighborhoods had mean household incomes lower than the 2000 national average of \$38,453. Similarly, all of the neighborhoods had prostate cancer mortality rates higher than the 2000 national average of 25.6.

Results: The Informed subscale measured the men's awareness of their choices, benefits, and risks. Each man received education on the benefits and limitations of prostate cancer screening based on random assignment to one of two decision aids. Men with lower annual family income and less knowledge were more likely to have lower feelings of being informed, ($F = 6.89$, $df = 2$ and 211 , $p = .001$). Low income men and men with less knowledge need additional education to support decision making with prostate cancer screening.

Conclusions: Low income men and men with less knowledge need additional education to reduce decisional conflict.

2D3**Persistence of men's theories about BPH and prostate cancer following a decision aid**

Holmes-Rovner M, Price C, Rovner DR, Kelly-Blake K, Lillie JA, Wills CE, Bonham B

Michigan State University

Background: As part of a study of men's interpretation of information in a videotape decision aid, we found unexpected patient interpretations of benign prostatic hyperplasia (BPH) in the context of cancer. The purpose of this presentation is to present qualitative and quantitative data that explicate the nature and implications of patient associations of BPH with cancer in our sample.

Methods: Survey and semi-structured interviews of men viewing a videotape decision aid, in a 2 x 2 race by education design. A community sample of college and non-college educated black and white men (age > 50; N=188). **Measurements:** Quantitative measures of knowledge, literacy (S-Tofhla), education (college/non-college), BPH symptoms, occupation, income. **Qualitative analysis** of interview transcripts identified themes among men's comments about BPH and cancer.

Results: For most men, knowledge of BPH and treatment options increased, including cancer-specific items. Health literacy was associated with cancer-specific increase in knowledge. Education and race were not associated with either general or cancer-specific change in knowledge, or with prior associations of BPH and cancer. Cancer concerns centered around theories that any prostate problem may lead to cancer.

Conclusions: Overall knowledge increase with DA use may mask counterfactual theories of disease process in clinical problems. This may produce resistance to new outcome information in decision aids. Further research should identify decision support design strategies and clinical counseling strategies to address persistence of beliefs contrary to new information presented in evidence-based decision aids.

2D4**Understanding African American Men's Beliefs about Prostate Cancer Screening: Formative Research Findings and Implications for Intervention**

Allen J, Wilson-Glover A, Kennedy M, Kantoff P, Emmons K, Gilligan T

Harvard School of Public Health, Harvard Medical School, Dana-Farber Cancer Institute

Background: African American men have the highest prostate cancer incidence and mortality of any racial/ethnic group in the US. Routine screening is controversial and major medical organizations recommend that men be counselled about the risks and benefits prior to making individualized screening decisions. This study explored African American men's views about prostate cancer screening and assessed the acceptability of various strategies and settings for interventions to promote informed decision-making.

Methods: We conducted 4 focus groups among healthy African American men (n= 37 men) and 2 groups among African American prostate cancer survivors (n=14 men) ages 40-75. In addition, we conducted 14 in-depth individual interviews with key community informants. Focus groups and informant interviews were tape-recorded, transcribed and analyzed for emergent themes.

Results: Themes from the focus groups were echoed in key community informant interviews. Respondents cited the following as being major barriers to prostate cancer care for African American men: mistrust of the healthcare system and providers; inadequate access to information and services; perceived threats to male sexuality; and fear of cancer and cancer treatment. Suggested intervention channels included worksites, faith-based organizations, barbershops, athletic facilities, sporting events and health care facilities. Suggested intervention strategies included education for young adult and middle-aged black men about the importance of preventive medicine, one-to-one and small group education sessions about prostate cancer, discussion with prostate cancer survivors, and media campaigns.

Conclusions: African American men in this sample cited numerous barriers to receipt of prostate cancer care. Overall, men felt that providing interventions in settings that are familiar, non-threatening and frequented by African American men was important. Educational strategies should include personalized education and stories reflecting screening experiences of community members. Application of these findings to intervention design will be discussed.

3A1

Shared decision making with chronic pain patients. A quantitative and qualitative one year follow-up

Eich W, Bieber C, Mueller KG, Richter A, Hochlehnert A, Blumenstiel K, Wilke S

University Hospital Heidelberg, Dept. Internal Medicine II

Background: The fibromyalgia syndrome (FMS) is an exemplary condition of chronic widespread pain that is difficult to control and often leads to frustration and resignation on side of the patient and the doctor alike. In the treatment of chronic pain patients - a good doctor patient relationship seems to be crucial. We conducted a prospective randomised controlled study with a one-year follow-up to evaluate the effects of shared decision making on patient satisfaction in patients with chronic pain.

Methods: Intervention group I was treated by physicians trained in shared decision making and had access to a computer-based information tool on fibromyalgia, intervention group II only received treatment (by not specifically communication-trained doctors) and got the information tool, the control group got the standard treatment. Inclusion criteria were ACR-criteria for fibromyalgia and age between 18 and 70. 124 participants were included. Mean age was 50.5(SD=9.4) years, 92.7% were female. Participants completed quantitative questionnaires on physician-patient-interaction and disease-related outcomes. All patients were followed up at 3 and 12 months. In addition patients were interviewed by an independent researcher at t2 and at t3. The qualitative approach focused on subtle components of the treatment process and the doctor patient-relationship.

Results: The differences in patient satisfaction measured directly after the consultation still sustained in the one-year follow-up ($p=.05$, $p<.001$, intervention group I compared to both intervention group II and control group). Although there was no significant difference between the groups regarding disease-related outcome variables, in the qualitative interviews 88% of the patients of IG1 expressed a positive opinion about the SDM they experienced in their treatment and 62% improved their coping strategies with the disease.

Conclusions: In general, hope, high activity, high self-efficacy and a trustful patient-physician-relationship may lead to high satisfaction, irrespective of symptom development. Low activity and high resignation may lead to dissatisfaction as is true for too much activity and too much hope. As to the comparison of the two groups, the patients of IG1 were more content with the treatment than the patients of IG2. Furthermore the patients of IG1 in general gave much more differentiated statements on their condition and the relationship with the physician. A good physician-patient-relationship is obviously fundamental to better coping with the disease.

3A2

Do cancer patients' preferred roles for participation in treatment decision making change during the treatment experience?

Ruland CM

Center for Shared Decision Making, Rikshospitalet- Radiumhospitalet, Oslo, Norway

Background: Over the last decade there has been considerable research on the role patients want to play in treatment decision making. This research has revealed large variations in patients' preferred roles for involvement as well as associated variables such as age, gender, education, seriousness and chronicity of the disease. While this has increased awareness about the importance of assessing patients' preferred participation roles prior to decision making consultations, little is still known about whether role preferences are stable characteristics, or change during patients' treatment experiences over time. For example, it seems plausible that patients with critical illness such as cancer may initially depend strongly on their physician but shift towards a more participatory role preference when they get more knowledgeable about their illness. To investigate changes in role preferences is clinically important, as it would point out whether there is a need to repeat assessments of preferred roles so that clinicians' decision making styles can be adjusted accordingly. The very few studies that have investigated changes in preferred roles are inconclusive, and more research is needed. Therefore, the purpose of this study was to investigate changes in patients' role preferences from the onset of a serious cancer diagnosis to completed treatment.

Methods: To assess patients' preferred role for participation in decision making we asked 60 patients (63% men, 37% women) diagnosed with leukaemia or lymphoma to complete Degner's Control Preference Scale (CPS) twice:

at the time of diagnosis and again at the first outpatient control after completion of their cancer treatment with high-dose chemotherapy and / or stem-cell transplantation 4-6 months later. Patients were presented with five cards laid out in random order where each card depicted a statement and a cartoon that portrayed a different role in treatment decision making. These roles ranged from the individual making a treatment decision, through the individual making decisions jointly with the clinician, to the clinician making decisions (Degner, et al., 1997). Patients were asked to pick the card that corresponded closest to their preferred role in treatment decision making for their current situation; then to pick the next card that was closest. Based on the order of the first and second selected cards, participation roles were classified into active-active, active-collaborative, collaborative-active, collaborative-passive, passive-collaborative and passive-passive roles. The Wilcoxon signed rank test was used to assess changes in preferred participation roles from the time of diagnosis to the post-treatment visit 4-6 months later. The card sorting method has been shown to be a reliable and valid test of treatment control preference in this sample.

Results: On a scale from 1 to 6 (active-active to passive-passive), the most frequently selected preferred participation role at the time of diagnosis was passive-collaborative (Mean 4.8, SD = 1.2; Median = 5.0 Mode= 5.0). Only 8.3 % of the sample chose an active role at diagnosis; 29% chose a collaborative role and 62.7% a passive role. After completion of treatment 4-6 months later the preferred role shifted slightly towards a more collaborative-passive role (Mean = 4.6; Median = 5.0; Mode = 5.0), but this change was not significant ($z = -1.4$; $p > .05$). Role preferences at both time points were highly correlated ($r_s = .62$, $p < .01$).

Conclusions: Patients in this sample had a rather conservative role preference for participation in treatment decision making when faced with a serious cancer diagnosis, and this did not change significantly over time. It is also notable that only so few respondents chose an active role. Given the seriousness of patients' illness, this is however, not surprising and consistent with previous studies. This study confirms that letting patients assume very autonomous roles in the face of a serious cancer diagnosis is not preferred by the majority of patients and may not be the recommended consultation style.

The reason why there were no significant changes in preferred role preferences from diagnosis to end of treatment is not clear. This may also be related to the seriousness of illness and that patients' may have kept a sense of strong dependency on their physicians during the entire treatment. Patients' role preferences may also be relatively stable characteristics that are hard to change. This aspect needs more investigation. For example, it would worthwhile to explore relationships between changes in patients' role preferences and other personality traits, locus of control or trust in the physician, or how changes are related to external factors, such as the amount of information given to the patient or cultural aspects. While this study adds to knowledge about the stability of cancer patients' role preferences over time, generalizations need to be made with caution. As role preferences are known to be associated with the type of illness and the nature of the decision, findings from this study do not necessary apply to other situations. Therefore, it is important to continue research on changes in preferred participation roles with different patient groups and decisions.

3A3

Patients with prostate cancer want to choose their own radiation treatment

van Tol-Geerdink JJ, Stalmeier PFM, van Lin ENJT, Schimmel EC, Huizenga H, van Daa1 WAJ, Leer JW

Radiotherapy and MTA Departments, Radboud University Nijmegen Medical Center, The Netherlands

Background: Patient involvement in treatment choices is still not common in the field of oncology. This may be related to the decline in the desire to participate in decision-making at older age and in more severe disease. This study investigates 1) whether cancer patients want to be involved in treatment-related choices and 2) whether we can predict which patients want to be involved.

Methods: These questions were studied in patients with prostate cancer (T1-3N0M0) treated with radiotherapy. Their treatment decision concerns the choice of the radiation dose; a higher dose leads to a higher chance of disease-free survival but also to a higher risk of severe side effects. In an interview, the effects of two alternative treatment options (70 Gy and 74 Gy) were explained, and the patients were asked whether they wanted to choose one of these two treatments (accept choice), or whether they wanted to leave the decision to the physician (decline choice). Data were collected on socio-demographic, medical, psychological and information-related variables by means of questionnaires. Data were dichotomized and associations were tested by χ^2 tests and multivariate analyses.

Results: Even in this older patient population, a majority of the patients (83%) accepted the option to choose the radiation dose. A lower score on pre-existent Bowel morbidity (OR=0.30, p=.01), Anxiety (OR=0.29, p<.02), Depression (OR=0.25, p<.02), Helpless-/Hopelessness (OR=0.21, p<.03) and a higher score on Numeracy (OR=4.69, p=.002) were associated with an increase in choice acceptance. However, inclusion of these variables hardly improved the prediction of choice acceptance.

Conclusions: Once informed, most patients want to make their own choice of the radiation dose. As choice acceptance is hard to predict and almost all patients consider it useful to be involved in the treatment choice, information on the choice of radiation dose should be provided to all patients with T1-3N0M0 prostate cancer.

3A4

Preferred participation in treatment decision making of Patients with End Stage Renal Disease: Results on Control Preference of patients

Kuch C, Scheibler F, Stoffel MP, Pfaff H

Department for Medical Sociology, University Hospital of Cologne and KfH Kuratorium für Dialyse und Nierentransplantation e.V., Köln/Neu-Isenburg

Background: Decision making preferences of patients with end stage renal disease (ESRD) are unclear. Based on a large database we tested preference for participation in treatment decision making (TDM) of patients with ESRD measured by the Control Preference Scale (CPS). We were interested if age, vintage, educational status or gender are relevant factors associated with preference for participation in TDM

Methods: A cross sectional study conducted every year with patients of the largest German non-profit dialysis provider (KfH) included in 2003 questions about TDM. Results of CPS were categorized under the “active”, “collaborative” and “passive” roles patients want to play in TDM. Univariate analyses and chi square tests were performed to test differences between these groups.

Results: 4117 of 4723 questionnaires could be used for statistical analysis. The “active”, “collaborative” and “passive” groups differ significantly in patient age (F=98,2, df=2, p<0,01), vintage (F=16,34, df=2, p<0,01) and educational status (chi²=123,05, df=10, p<0,01). No significant difference between groups has been found on patients' gender. Descriptive data shows a higher percentage of “active” patients in younger patients and a higher percentage of “passive” patients in older patients (Fig. 1). Higher vintage shows more “active” patients while lower vintage shows more “passive” patients (Fig. 2). Higher educational status shows more “active” patients while lower educational status shows more “passive” patients (Fig. 3).

Conclusions: Age, vintage and educational status are relevant factors for preference for participation in TDM of ESRD. Longitudinal studies are necessary to test if e.g. patient's attitudes changes with increasing age or if the differences found are due to differences between generations.

3B1

Perception des médecins de famille quant aux facteurs contrecarrant et ceux favorisant l'implantation du Modèle d'Aide à la Décision d'Ottawa (MADÉO) dans leur pratique.

Légaré F, Cauchon M, O'Connor AM, Graham ID, Côté L, Saucier D, Blais J, Paré L

Université Laval, Département de médecine familiale

Contexte : Le Modèle d'Aide à la Décision d'Ottawa (MADÉO) favorise la prise de décision partagée. L'objectif principal de cette étude fut l'identification des facteurs contrecarrant et ceux favorisant l'implantation du MADÉO dans les pratiques de médecine familiale.

Méthodes : Les professionnels de la santé de 5 unités de médecine familiale furent invités à participer une étude avant-après visant l'implantation du MADÉO dans leur pratique. Celle-ci incluait des groupes de discussion lors d'ateliers de formation. Une analyse de contenu a été réalisée à l'aide du matériel suivant: observation non participante, notes personnelles, formulaire d'évaluation des ateliers et commentaires recueillis sur les questionnaire de sortie à l'étude. La classification des facteurs contrecarrant et de ceux facilitant l'implantation du MADÉO a été

réalisée à l'aide de la taxonomie de Cabana et al. Le rapport final a été commenté par les co-animateurs de chacun des ateliers.

Résultats : Ce sont 118 professionnels de la santé qui ont participé à 13 groupes de discussion. Les facteurs contraignants identifiés furent : absence de familiarité avec le MADÉO, absence d'accord avec le MADÉO en général ou avec une de ses composantes spécifiques, absence d'impact bénéfiques perçus, sentiment d'efficacité personnelle insuffisant, manque de motivation, facteurs extérieurs en lien avec les patients, le modèle lui-même et l'environnement ainsi que l'oubli. Les facteurs favorisant identifiés furent : sentiment de familiarité avec le MADÉO, accord avec le MADÉO en général ou avec une de ses composantes spécifiques, impact bénéfiques perçus, sentiment d'efficacité personnelle, motivation et facteurs extérieurs en lien avec les patients, le modèle lui-même et l'environnement.

Conclusions : L'implantation du MADÉO dans les pratiques a le potentiel de favoriser la prise de décision partagée. Toutefois, plusieurs facteurs contrecarrant ainsi que plusieurs facteurs favorisant son transfert dans les pratiques devront être pris en considération.

3B2

Barrières et facteurs favorables à l'implantation de la prise de décision partagée dans les pratiques professionnelles en santé : revue de la littérature

Gravel K, Légaré F

Centre de recherche de l'Hôpital Saint-François d'Assise

Contexte : La prise de décision partagée suscite beaucoup d'intérêt. L'objectif de l'étude était l'identification des barrières et des facteurs favorables à l'implantation de la prise de décision partagée dans les pratiques professionnelles.

Méthodes : À l'aide des mots-clés « shared decision making » et « results », une recherche sur PubMed couvrant toutes les années disponibles associée à celle de ressources spécialisées fut réalisée. Seules les publications en langue anglaise ou française de recherches originales sur les barrières et facteurs favorables à l'implantation de la prise de décision partagée dans les pratiques professionnelles ont été retenues. L'extraction des données a été réalisée par deux évaluateurs à l'aide d'une grille d'extraction des données qui incluait une taxonomie inspirée par Cabana et al. (1999). Les divergences furent résolues par discussion. La fréquence des barrières et des facteurs favorables fut établie à l'aide d'une matrice des données (facteurs identifiés en fonction des études). À l'aide du test de Wilcoxon, la distribution des barrières et facteurs favorables fut comparée avec celle retrouvée dans une étude locale.

Résultats : La recherche sur PubMed a généré 292 titres potentiellement intéressants. Avec le recours à des ressources spécialisées, ce sont 18 articles portant sur 17 études distinctes qui furent analysés. Par ordre d'importance, les 3 principales barrières furent: temps, caractéristiques du patient et préférences du patient. Par ordre d'importance, les 3 principaux facteurs favorables furent: motivation, perception d'un impact positif sur le patient et perception d'un impact positif sur le processus. La distribution des barrières et facteurs favorables retrouvés dans la littérature ne se distinguait pas de celle observée dans une étude locale ($p=0,22$ et $0,13$, respectivement).

Conclusions : La distribution des barrières et des facteurs favorables à l'implantation de la prise de décision partagée dans les pratiques professionnelles issus de la littérature est semblable à celle observée dans une étude locale.

3B3

Les besoins d'information des patients du point de vue des médecins d'un réseau français de soins en oncologie

Camhi B (1,2,3), Farsi F (1,4), Bremond A (1,2)

(1) Centre de lutte contre le cancer Léon Bérard, Lyon, France, (2) LASS CNRS FRE 2747, Lyon, France, (3) Faculté de droit, Université Jean Moulin Lyon III, IFROSS, Lyon, France, (4) Réseau de soins en oncologie, ONCORA, Lyon, France

Contexte : La relation médecin-patient a profondément évolué en France lors de la dernière décennie, d'où l'adoption le 4 mars 2002 d'une loi relative aux droits des malades et à la qualité du système de santé. Cette loi cristallise cette évolution et légalise notamment les besoins d'information et de participation du patient à la décision médicale largement revendiqués par les patients et les associations.

Objectifs : Deux mois après la promulgation de cette loi, notre objectif a été d'évaluer l'impact de cette loi sur les patients et les soignants d'un réseau de soins en oncologie (ONCORA, ONCOlogie Rhône-Alpes) et d'analyser, selon les caractéristiques de chacun (âge, genre, spécialité...), les perceptions de chacun, des différents droits du patient et devoirs du médecins.

Méthodes : Après une lecture attentive de la loi et des débats parlementaires préliminaires, nous avons élaboré un questionnaire qui fût prétesté auprès de cinquante patients et trois oncologues dont les remarques et les réactions nous ont suggéré quelques modifications. L'étude fut conduite auprès de 700 patients et 218 médecins d'un réseau de soins en oncologie.

Résultats : Il sera très intéressant de développer les différences statistiquement significatives entre les patients et les médecins mais aussi entre les médecins eux-mêmes selon leur âge, leur genre, leurs spécialités ou le temps hebdomadaire consacré à la prise en charge des patients atteints de cancer.

Conclusions : L'impact premier de la loi est d'engager l'ensemble des professionnels de santé dans une démarche qualité générale sur l'information et la participation du patient à la décision médicale. L'impact attendu de notre étude est d'engager, forts de ces résultats, tous les professionnels de santé, et essentiellement les plus réticents, dans cette démarche qualité afin d'homogénéiser les pratiques professionnelles et la prise en charge du patient au moins dans le cadre de notre réseau de soins en oncologie.

3C1

The need to facilitate informed choice equitably

Dormandy E, Marteau TM

King's College London

Background: The importance for individuals to make healthcare decisions in line with their values is well recognised. In many clinical contexts in which healthcare professionals and patients reach decisions together this is described as shared decision-making. In the context of antenatal screening where the possibility of a termination of pregnancy means that parents' decisions should be in line with their own values, not those of healthcare professionals, this is described as informed choice. Concerns have been raised that acting in line with personal values may be socially patterned, resulting in inequality in rates of shared decision making and informed choice. This study aims to determine if the likelihood of women acting in line with their values varies according to socio-economic status in women offered an antenatal screening test for Down syndrome.

Methods: Design: A descriptive study of 982 women offered antenatal Down syndrome screening.

Outcome measures: Attitudes towards undergoing the screening test (index of values) and screening uptake. Socio-economic status was assessed using a simple classification based on education, housing tenure and car access.

Results: Logistic regression showed no difference in the extent to which women across socio-economic categories acted in line with their attitudes towards undergoing the test when controlling for other demographic variables (OR 1.2, 95%CI 0.8-1.7) Repeating the analysis in women with positive attitudes towards undergoing the test showed that

women with higher socio-economic status were more likely than women with lower socio-economic status to act in line with their attitudes (OR 1.4, 95%CI 1.1-1.9)

Conclusions: Women with higher socio-economic status were more likely to act in line with their positive attitudes than were women with lower socio-economic status. These results suggest that to facilitate shared decision-making and informed choice equitably decision aids should be targeted at women from lower socio-economic groups.

3C2

Measuring Decision Quality: Lessons from Pilot Testing

Sepucha KR, Farrelly KA, Hughes KS, Partridge AH, Mulley AG

Massachusetts General Hospital, Dana Farber Cancer Institute

Background: Recent reviews suggest that the measures used to evaluate the quality of decisions are not adequate. After generating consensus around a definition of a high quality decision, the investigators and colleagues hypothesized that a measure should focus on two main domains, decision-specific knowledge and decision specific-values. Next, they generated items for two decisions in early-stage breast cancer—the surgery decision and the systemic therapy decision.

Methods: The items were subject to testing via cognitive interviewing (n=6), revised and then sent along with several other surveys to a sample of breast cancer survivors (n=62). A second mailing was sent to all non-responders. Responses from 40 survivors (65% response rate) were received and analyzed.

Results: Cognitive interviewing highlighted several misconceptions and misunderstandings of common terms such as “hormone therapy,” “early-stage breast cancer,” and “average risk.” In addition, patients consistently reported difficulty answering questions that assessed quantitative understanding of the benefits or risks of treatments. Median knowledge scores were 40% and 50% (out of 100%) for the surgery and systemic therapy decisions, respectively. Median scores for the Uninformed scale of the Decisional Conflict Scale were 12 (out of 15) for both decisions. There was no correlation between the decision-specific knowledge score and the score of the Uninformed subscale of the Decisional Conflict Scale for surgery (Pearson $r=0.09$, $p=n.s.$) or systemic therapy (Pearson $r=0.10$, $p=n.s.$). Patients disagreed about the importance of preserving a breast and avoiding side effects of treatments, but were fairly uniform in assessing the importance of minimizing recurrence and “doing everything possible to treat the cancer.”

Conclusions: Careful attention must be paid to the wording of items for patient self-reported questionnaires. Patients tended to overestimate their knowledge with the general questions. Decision-specific knowledge questions may provide a better assessment of being “informed” than general questions. Only certain values items discriminated well between treatment choices.

3C3

Explicit Value Clarification: Validation of a new technique

Feldman-Stewart D, Brennenstuhl S, Brundage M, Zoltov V, Roques T, Siemens R, Campbell H, Pickles T, Hack T

Division of Cancer Care and Epidemiology, Cancer Research Institute, Queen's University, Kingston ON

Background: Little is known about the efficacy of Explicit Values Clarification (EVC), a process designed to elicit patients' values related to a decision. This study examines the convergent validity of EVC outcomes in the context of a computerized decision aid for early-stage prostate cancer.

Methods: 69 men from three centres used the decision aid, and later made their actual decision with their doctor. Most men were aged 60-69 (56%), married (89%) and had three or four treatment options (75%). Men identified issues important to their decision three times: before receiving information about treatment options (T1), after the information (T2) and after eliminating their least preferred treatment(s) (T3). At T3 men also did an EVC exercise. For each identified important issue, a horizontal bar anchored with his two most preferred treatment options was presented to the participant. He adjusted each bar to show how much that issue “pushed” his choice toward one

treatment or the other. At each time point men also rated their preference for each treatment option (Treatment Value Assessment, TVA) on a 5-point Likert scale. Decisional conflict and regret were also assessed.

Results: Actual treatment decisions were predicted in 79% of patients by their bar total scores (total of the bars across issues). Those with TVA ties at T1 and T3 had smaller average bar totals ($t=4.37$ and $t=3.74$, respectively, both $p=0.001$). Those tied at T3 were also more likely to have bars pushing in competing directions ($\chi^2=6.51$, $p=0.001$). Of those tied at T3 ($n=16$), 63% had a bar total that predicted their actual decision. Increased decisional conflict was associated with smaller bar totals at T3 ($r=-0.273$, $p=0.031$). Regret was higher, on average, for those with bars pushing in competing directions ($t=-2.107$, $p=0.039$).

Conclusions: An EVC exercise generates data that show convergent validity with treatment choice, decisional conflict and regret. Its helpfulness to patients needs to be investigated.

3C4

Are pregnant women making informed choices about prenatal screening?

Van den Berg M, Timmermans DRM, Ten Kate LP, Van Vugt JMG, Van der Wal G

Institute for Research in Extramural Medicine, Department of Public and Occupational Health, VU University Medical Center, Amsterdam, The Netherlands; Department of Clinical and Human Genetics, VU University Medical Center, The Netherlands; Department of Obstetrics and Gynaecology, VU University Medical Center, The Netherlands

Background: Prenatal screening should enable pregnant women to make informed choices. An informed decision is defined as being based on sufficient, relevant information and consistent with the decision maker's values. This study aims to assess to what extent pregnant women make informed choices about prenatal screening, and to assess the psychological effects of informed decision making.

Methods: The study sample consisted of 1159 pregnant women who were offered the nuchal translucency measurement or the maternal serum screening test. Level of knowledge, value consistency, informed choice, decisional conflict, satisfaction with decision, and anxiety were measured using questionnaires.

Results: Of the participants, 83 % were classified as having sufficient knowledge about prenatal screening, and 82% made a value consistent decision to accept or decline prenatal screening. Sixty-eight percent of the pregnant women made an informed decision. Informed choice was associated with increased satisfaction with decision, less decisional conflict (this applied only to test acceptors), but not with decreased anxiety.

Conclusions: Although the rate of informed choice is relatively high, substantial percentages of women making uninformed choices due to insufficient knowledge, value inconsistency, or both were found. Informed choice appeared to be psychologically beneficial. Present study underlines the importance of achieving informed choice in the context of prenatal screening

3D1

Integration of a shared decision making model into the clinical care of patients with advanced osteoarthritis of the knee

Carlson L, Clay K, Kantor S, Tomek I

Dartmouth Medical School, Dartmouth Hitchcock Medical Center, Lebanon, NH

Background: The benefit of high-quality decision aids has been demonstrated across both medical and surgical disciplines. A shared decision model has yet to be tested in the setting of elective joint reconstruction surgery, where patients must decide whether to proceed with surgery or medical management based on their understanding of the procedure, their assessment of risks and benefits, expected outcomes, and their personal judgments about the tolerability of disease-influenced health states.

Methods: Patients deemed to be candidates for total knee replacement will be randomized into two groups. Group 1 will review a decision aid video describing treatment options for advanced knee osteoarthritis. Group 2, representing

the current care practice, will only be offered a brochure describing knee replacement. Survey measures including SF-36, WOMAC, Knee Society Score, satisfaction with level of preparedness for decision making, decisional regret, comparison of expected and actual outcomes, evaluation of goal attainment, and level of satisfaction will be assessed at baseline and over a two year follow-up.

Results: Several benchmarks will indicate that decision support has successfully been integrated into the osteoarthritis treatment protocol, including enhanced patient comprehension of key points of the surgical procedure, decreased decisional conflict, and minimization of decisional regret at the completion of follow-up. Achievement of all benchmarks will be measured in terms of the relative improvement of patients that received decision support over those who did not.

Conclusions: Anticipated outcomes include an improvement in patient comprehension of available treatment options, resulting in decreased decisional conflict during the decision making process. Increased patient involvement is expected to result in reduction of decisional regret and higher levels of satisfaction with the procedure's eventual outcome. Through the use of high quality decision aids and data collection measures, both clinicians and patients stand to derive significant benefits when faced with total knee replacement as a treatment option for osteoarthritis.

3D2

Patients' opinion of shared decision making and informed consent in situations of medical risk and uncertainty

Charvet A, Cleopas A, Kolly V, Chopard P, Perneger TV

Geneva University Hospitals

Background: It has been proposed that shared decision making (SDM) and informed consent (IC) should be applied to medical situations defined in terms of uncertainty and risk (Whitney SN et al., 2004). Specifically, SDM would be most relevant to situations of uncertainty (more than one therapeutic option); IC, when risk associated with treatment is high. We sought patients' opinion, hypothesizing from previous findings that they would prefer detailed information irrespective of the level of risk.

Methods: As part of a patient satisfaction survey, we designed 4 medical scenarios:

- (1) high risk– certainty (theoretically implying IC and no SDM);
- (2) high risk– uncertainty (IC and SDM);
- (3) low risk– certainty (no IC, no SDM);
- (4) low risk– uncertainty (no IC and SDM).

Recently hospitalised patients received a questionnaire with one of the four versions. They were asked whether the physician should inform the patient in details / in general / not at all; and whether the physician should decide alone / decide with the patient / let the patient decide if the treatment should be implemented.

Results: Of 2,163 eligible patients, 1,465 (68%) returned the survey questionnaire, 1,277 (87%) answered the IC question and 1,285 (88%) the SDM question. Overall, respondents thought physicians should provide detailed (75%) or general (12%) information in all medical situations, and share the decision (61%) or let the patient decide (21%). With respect to treatment options, respondents believed the decision should be shared (certainty: 74% versus uncertainty: 67%) or the patient should decide alone (certainty: 17% versus uncertainty: 32%, $p < 0.001$). Level of risk had no incidence on informed consent (low risk: 87% versus high risk: 84%, $p = 0.31$).

Conclusions: Our findings partially confirm the proposed model. Patients believed physicians should provide detailed information in all medical situations, and medical decisions should generally be shared.

3D3

Cancer-Related News Coverage and Information Seeking: Results from a National Survey

Frosch D, Niederdeppe J, Hornik R

Leonard Davis Institute of Health Economics, Center of Excellence in Cancer Communications Research, University of Pennsylvania

Background: The growing emphasis on shared decision-making occurs within a context of greater public access to health information through the Internet and other media. Some have argued that this has contributed broadly to healthcare consumers taking a more active approach in learning about medical developments and participating in medical decisions. This study empirically tested the hypothesis that health news coverage about cancer prompts Internet health-information seeking in the population.

Methods: The Health Information National Trends Survey (HINTS) is a representative random digit dial survey (N=6,369) that was conducted by the National Cancer Institute. We merged these data with a measure of cancer-focused Associated Press (AP) news stories released during the survey data collection period. Previous studies suggest that AP stories are a useful proxy for broader media news coverage

Results: Using logistic regression we observed no overall relationship between cancer-focused news coverage and cancer information seeking. However, models showed a significant main effect for self-reported attention to health-related news stories in the media (OR=1.17, $p<0.001$) and a significant interaction between attention and news coverage (OR=1.06, $p<0.05$). Controlling for demographics and other covariates, the probability of seeking cancer information in the past week among those in the highest quartile of health news attention varied from 7.9% at the lowest level of news coverage to 13.1% at the highest levels. There was no effect of increased cancer news coverage on information seeking among individuals in the lower three quartiles of health news attention.

Conclusions: Results indicate a substantial segment of the general population monitors news sources for health-related stories and seeks additional information at a higher rate during periods of increased cancer-related news coverage. However, the majority of the population does not appear to seek cancer information at a higher rate during periods of more intense news coverage. Implications will be discussed.

3D4

Initiatives and developments on patient participation in German health care

Härter M and the members of the German Research Consortium

Department of Psychiatry, University Hospital of Freiburg, Germany

Background: In Germany the involvement of patients in medical decision making has recently be claimed by political representatives, by patients as well as by funding agencies and researchers. The developments towards more involvement can be seen on three different levels:

On the macro level a new health law and an information tool on patients' rights have been passed. Furthermore a government's commissioner for patients and a Federal Joint Committee including patient representatives have been nominated. On the meso level health insurance funds are sponsoring patient counseling institutions and self-help institutions. On the micro level the German Ministry of Health and Social Security has funded a research consortium on SDM.

Methods: In this consortium ten model projects have implemented the concept of SDM in different fields of health care such as psychiatry, neurology and internal medicine. Furthermore a comprehensive working group has been established to deal with methods for measuring SDM. Within this group it was agreed that all projects use a core set of instruments. Validation results of these instruments have shown that several improvements are necessary.

Results: As a consequence a new instrument was developed in a theory driven process. Further results from a comprehensive sample of N=1759 patients are available on patients' preferences for information and participation as well as on experiences with SDM trainings and decision aids.

Conclusions: Positive results of implementing SDM have brought the German Ministry of Health and Social Security to fund the transfer of SDM in German health services for another two years. In addition to the developments in Germany a European research program about decisions and risk with eight participating European countries has been proposed.

4A1**Improving the quality of decision support by call centre nurses for callers facing values-sensitive health decisions: A randomized controlled trial**

Stacey D, O'Connor AM, Graham ID, Pomey MP

University of Ottawa

Background: Call centre nurses can link callers to patient decision aids and coach them to address their unresolved needs for information, values clarification, and support. There are no rigorous evaluations of strategies to improve the quality of decision support by nurses' for patients facing multiple options that depend on their values. The objective was to evaluate the effectiveness and acceptability of a multifaceted intervention to improve call centre nurses' decision support skills in coaching callers facing values-sensitive health decisions.

Methods: Randomized controlled trial involving 41 registered nurses working at a province-wide Canadian call centre in December 2003. The multifaceted intervention was a decision support protocol, online autotutorial, skill-building workshop, and performance feedback using simulated calls. Outcome measures included knowledge test, decision support quality audit of simulated calls, length of calls, and acceptability of the autotutorial, workshop, and protocol.

Results: Compared to controls, the intervention group had improved knowledge (74% vs. 60%, $p=0.007$) and provided a higher quality of decision support, particularly in the domains of discussing values and addressing support issues (81% vs. 46%, $p<0.01$), without significantly increasing call duration (18.5 vs. 16.7 min, $p=0.73$). Nurses were satisfied with the autotutorial and workshop. The protocol was rated as having clear steps, compatible with their views on patient decision making, and more advantageous compared to their usual practices.

Conclusions: The intervention enhanced nurses' knowledge and skills in providing decision support to simulated callers without affecting call length. The multifaceted intervention was acceptable to the nurses and feasible for implementing values-sensitive decision support in call centre nursing practice.

4A2**Integration of Decision Support and Computerized Assessment for Women Newly Diagnosed with Early Stage Breast Cancer**

Collins ED (1), O'Connor AM (2), Clay K (3), Kearing S (4), Llewellyn-Thomas HA (4), Moore C (1), Sepucha KR (5), Maheu L (3), Gallagher S (6), Chambers K (6), Aman D (6)

(1) Dartmouth Hitchcock Medical Center, Comprehensive Breast Program, Lebanon, NH; (2) University of Ottawa, Faculty of Health Sciences & Faculty of Medicine, Ottawa Health Research Institute, Ottawa, Canada; (3) Dartmouth Hitchcock Medical Center, Center for Shared Decision Making, Lebanon, NH; (4) Dartmouth Medical School, Center for Evaluative Clinical Sciences, Hanover, NH; (5) Harvard Medical School, Massachusetts General Hospital, Boston MA; (6) Dartmouth Medical School, BioInformatics, Lebanon, NH

Background: An integral function of decision aids is to help patients clarify their preferences for competing treatments, thus improving the concordance between personal values and individual choice. The Comprehensive Breast Program and the Center for Shared Decision Making at Dartmouth Hitchcock Medical Center have implemented several strategies to aid women facing a surgical treatment choice for early stage breast cancer. This report addresses the feasibility of integrating decision support into routine clinical care and describes the impact on decisional conflict. In addition, we report on the concordance of treatment choices with personal values.

Methods: All eligible patients complete: 1) a computerized health history and assessment of baseline decisional conflict and 2) a video-based decision aid on the surgical treatment choices for early stage breast cancer (FIMDM, 2004) prior to surgical consultation. For the subset of eligible women who agree to participate in an observational study, a secondary computerized assessment is performed. In addition to a post-video evaluation of decisional conflict, this includes an automated version of the Ottawa Personal Decision Guide and Balance Scale to elicit and communicate values in preparation for the surgical consultation. A printed report incorporating the patient's post-video treatment choice and personal values is provided to the surgeon's review at the time of initial surgical consultation.

Results: All eligible patients (n=116) have completed the computerized intake since implementation in March '04. Fifty-three women with early stage breast cancer have enrolled in the post video study. Decisional conflict is significantly reduced after viewing the video, particularly with regard to knowledge and values clarity. Post video treatment choices are almost evenly split between mastectomy (30%), lumpectomy followed by radiation (32%) and unsure (34%). Values clarification using the Balance Scale demonstrates a high concordance between personal preferences for key aspects of each treatment and post-video choices.

Conclusions: In our experience, the integration of decision support into routine care is both feasible and beneficial. Using a computerized assessment and printed report, we are able to efficiently summarize and communicate women's values and understanding of treatment choices so that this information can be addressed as part of the clinical encounter. This allows for feed forward of real time clinical and decision process data. We believe this exposure improves the quality of the subsequent clinical interaction with the surgeon and increases satisfaction with the decision-making process, while lessening distress and decisional conflict among women facing these difficult choices.

4A3

Introducing patient decision aids into treatment pathways – lessons learnt from a pilot implementation of decision aids in England.

Wirmann E, Askham J

Picker Institute Europe

Background: We know of several perceived barriers to the implementation of decision aids, including concerns around time, cost, and acceptability to clinicians and patients. However, despite the growing evidence base supporting their efficacy, decision aids are seldom used in the UK, and have never been implemented in routine practice in the National Health Service (NHS). We have very little information, therefore, about how real some of the perceived barriers are, or how we might overcome them to facilitate programme implementation.

In 2004, 5 NHS urology departments across England began implementing a patient decision aid programme designed to promote shared decision making around treatment options for patients diagnosed with specific prostate conditions.

The programme consists of a decision aid video; a centrally organised training day on decision support for urology nurses; and a Decision Quality Assessment (DQA) form, designed to help the clinician ensure the patient has sufficient knowledge of the treatments and outcomes, and to elicit the patient's values and preferences associated with those.

Methods: The research monitored the implementation in order to explore the practical implications, as well as the professionals' and patients' experiences of participating in the scheme. It drew on interviews with patients, clinicians and project managers, and the collection and analysis of the DQA forms both before and after the full scheme was implemented.

Results: This paper highlights some of the key implementation issues from three perspectives: administrative; professionals'; and patients'. It will reflect on the way in which the different sites implemented the scheme, and explore some of the issues they faced.

Conclusions: In particular, it focuses on practical, political, professional and cultural challenges of designing and introducing an innovative programme into routine practice.

4B1**Evaluation of two mammography decision aids for women outside the target age for screening: deciding to start (40-49) or stop (70+) mammography screening.**

Mathieu E, Barratt A, Davey H, Page A, Houssami N, Butow P, Higginson R

Screening and Test Evaluation Programme, University of Sydney

Background: Although decision aid research has focused on treatment, decision aids are suitable for some screening decisions. Two such decisions are whether to start mammography screening for women aged 40-49, and whether to continue or stop screening for women aged 70 and older. Although these women are eligible for government-funded biennial screens under the national program, BreastScreen Australia, they are outside the target age group of 50-69 years. As it is unclear whether the benefits of screening in these age groups outweigh the harms, decision making responsibility rests with the women themselves. Despite this responsibility, there is no literature to assist them that includes numerical information on the benefits and harms of screening. The aim of this study is to develop and test decision aids for these groups.

Methods: The decision aids were developed using quantitative estimates, the Ottawa decision support framework, and a new way of presenting benefits and harms. The 70 plus decision aid is a paper based aid to help women who have previously attended screening decide whether or not to continue. It was evaluated by thematic analysis of qualitative telephone interviews with 30 women aged 70-71 who were due for their next mammogram. The 40-49 year decision aid is an internet based aid to help women decide whether to commence screening. It was evaluated with a convenience sample of 60 women aged 38-43 years. Both decision aids were assessed for clarity, balance, presentation, content and usefulness.

Results: Analysis of pilot data for the 70 plus decision aid highlighted issues regarding presentation of information, completion of the weigh scale and understanding of information. These results led to changes to the decision aid. The presentation will discuss the results of the pilot testing and the implications of these results.

Conclusions: Decision aids for screening decisions show promise but need further evaluation.

4B2**Can you have agency and not choose? Older people's involvement in decision making about prevention and treatment of falls and fractures**

Murtagh M (1), Stobbart L (1), Newton J (2), Fay M (1), Thomson RG (1)

(1) School of Population and Health Sciences, University of Newcastle upon Tyne; (2) Falls & Syncope Service, Royal Victoria Infirmary, NUTH NHS Trust,

Background: Falls are a major health and socio-economic problem affecting 30% of people over the age of 65 each year, with potentially profound effects on a person's mortality and ability to live independently. Treatment and prevention after a fall may itself be hazardous therefore decisions are complex and ideally require that patients are fully engaged in the decision making process. Patient engagement in decisions about their health has become a key strategy in contemporary health care policy and practice. However older people are consistently described as preferring less engagement in decision making in studies of patient preference for shared decision making. We therefore sought to understand this phenomenon and the potential tensions between contemporary policy and patient preferences for shared decision making.

Methods: Discursive analysis of an interview study involving 25 patients and 19 healthcare professionals from Newcastle Royal Victoria Infirmary's Falls and Syncope Service about their decision making.

Results: We discuss three themes arising from interviews with patients:

- faith and respect in the doctor patient relationship
- ageing, vulnerability and the illness experience
- the imperative to choose

We discuss three themes arising from interviews with healthcare professionals:

- the improbability of shared decision making
- doctor/patient subjectivity in decision making
- rationalities of care: respect for patients and practitioner responsibility

Conclusions: We demonstrate that where older patients feel considerable vulnerability about their condition (for example in vasovagal syncope where they fall without warning) they express the desire to derive confidence from the authority of their health care practitioner and may appear to devolve decision making to the practitioner. These patients felt tension between a desire to derive comfort and reassurance from the clinical interaction and expectations of a particular form of involvement in decision making. Nonetheless they maintained a demand for respect and agency in the encounter.

4B3

Shared Information Improves Elders' Recovery After Major Abdominal Surgery

Lawrence VA, Cornell JE, Hazuda HP

South Texas Veterans Health Care System and University of Texas Health Science Center at San Antonio

Background: Informed, shared decision making about elective major surgery should include information exchange about activities and helpful coping strategies. Yet little is known of elders' coping strategies during postoperative recovery.

Methods: Prospective cohort study, 187 patients 60 or more years old undergoing major elective abdominal operations interviewed at 1, 3, 6, 12, and 24 weeks postoperatively with a semi-structured, open-ended questionnaire to elicit patient-perceived recovery aids. A clinician and social scientist jointly coded themes in subjects' responses.

Results: Mean age was 68.6 plus or minus 6.38 with 53% men, 34% nonHispanic Caucasian, and 57% Mexican American. Educational strata were less than high school – 59%, high school – 16%, and greater than high school – 25%. The most reported themes were family, tangible social support, and medical advice. The most cited medical advice was walking or exercise (43% of patients, 54% of responses). Other major themes included cognitive strategies (e.g., determination, humor), spirituality, and medical devices (e.g., abdominal binder).

Walkers did not differ from nonwalkers in age, ethnicity, or marital status but had marginally significantly higher educational level ($p=0.052$). Walkers recovered significantly faster in Instrumental Activities of Daily Living (OR 2.5, 95% CI 1.1-5.9, $p=0.03$), even after adjusting for educational level (OR 2.4, 95% CI 1.1-5.7). After adjusting for other predictors of recovery, ORs for walkers remained approximately 2 but no longer statistically significant because of limited statistical power.

Conclusions: Patients thought a variety of supports helped postoperative recovery; family, tangible social support, and medical advice were most prominent. The results confirm the overall value of medical information, suggest that simply advising patients to walk may improve recovery, and support prior hints that more educated patients have better disability coping skills. Future research should test the effectiveness of advice to walk plus interventions to enhance providers' information transfer and teach coping skills of more educated patients to those with less education.

4B4

Patient preferences for participation in decision making

Flynn KE, Smith MA, Vanness D

University of Wisconsin Medical School

Background: To promote patient-centered care we must understand patient preferences for participation in decision making. We categorized older adults into types based on preferences for information exchange, deliberation, and decisional control per Charles' model of decision making.

Methods: Telephone and mail surveys from the first seven random replicates of the 2003 Wisconsin Longitudinal Study, a random sample of graduates from Wisconsin high schools in 1957 (N=10,317), were completed with sample retention >80%. We used cluster analysis to characterize preference types based on four items from the 2003-04 mail survey on preferences for information to and from providers, deliberation, and control over important medical decisions, coded on a five-point scale from strongly agree to strongly disagree.

Results: Of 3910 respondents aged 63-65, 96% are represented by four preference types. These types preferred high information exchange with providers (labelled “informed.”) These types are differentiated by preferences for deliberation (low labelled “classical” and high labelled “modern”) and decisional control (low labelled “paternalist” and high labelled “autonomist.”) 48% of respondents were informed modern autonomists; they tended to be female, have higher education and excellent self-rated health. 18% were informed classical autonomists; they tended to have lower education. 15% were informed modern paternalists; they tended to have good self-rated health. 15% were informed classical paternalists; they tended to be male, have lower education and fair or poor self-rated health. The remaining 4% of respondents were represented by types that preferred low information exchange.

Conclusions: Older adults prefer high levels of information exchange with providers almost universally. Contrary to conventional wisdom, most also prefer to retain control over important medical decisions. Preferring doctor control over decisions does not mean that older patients do not want to deliberate with providers. To optimize patient outcomes, health care providers ought to accommodate individual patient preferences while encouraging participation.

4C1

A Theory-based process evaluation of a multifaceted intervention to implement the Ottawa Decision Support Framework (ODSF) in clinical practice

Légaré F, Graham ID, O’Connor AM, Wells G, Turcot-Lemay L, Aubin M, Baillargeon L, Leduc J, Maziade J
Université Laval, Département de médecine familiale

Background: The Decisional Conflict Scale (DCS) that is provided by the Ottawa Decision Support Framework (ODSF) helps to quickly identify the areas that need to be addressed in order to provide decision support. Therefore, the aim of this study was to assess the effects of a multifaceted implementation intervention (workshop, feedback and a reminder) on physicians’ intention to adopt the DCS in clinical practice.

Methods: A before-and-after study was conducted in 5 family practice teaching units. Based on the Theory of Planned Behavior, intention to use the DCS in clinical practice was assessed with self-administered questionnaire at baseline and at exit to the study. For all participants, a paired t-test was used to assess the difference in score between intention at the exit from and at the entry into the study. Mixed models for unbalanced repeated measures analysis of variance were used to explore the effect of the level of exposure to the multifaceted implementation intervention on the intention.

Results: A total of 122 primary care providers entered this study. Overall, no change between the entry and the exit intention was observed ($p=0.375$). However, given the pragmatic nature of the study design, participants fell into one of three following groups: no exposure ($n=15$), incomplete exposure ($n=19$) and complete exposure ($n=88$) to the intervention. There was a statistically significant difference between the entry and the exit in the effect of the level of exposure to the intervention on the intention ($p=0.003$) as well as on the perception of control ($p=0.002$).

Conclusions: Given the pragmatic design that was used in this trial, we can not infer that the intervention had an impact on the intention. Nonetheless, a multifaceted intervention appears to have protected against a decrease in the intention to use the DCS in clinical practice.

4C2

The teaching and learning of informed and shared decision making

Godolphin W, Towle A, Kline Catherine, Grams Garry

Division of Health Care Communication, College of Health Disciplines and Faculty of Medicine, The University of British Columbia

Background: In the face of much evidence that physicians rarely engage their patients in the practice of informed and shared decision making (ISDM) and that conventional CME interventions do not make much difference, we tested a sequence and variety of interventions.

Methods: These included videotape of ‘mastery’ encounters, situating the competencies for ISDM within the framework of the typical short office interview, workshops with standardized patients (SPs), audio tape encounters in daily practice with self-scoring of transcripts, moderated peer discussion of the successes and failures. The subjects were family physicians, self-identified as predisposed to learning the competencies of ISDM because the ethic fitted with their personal values. They had mixed practices, some with a ‘specialization’ (e.g., obstetrics, gender-identity clients). The interventions were structured to enable and reinforce.

Results: The most important things they identified that helped them to learn were (1) a schema that presented a workable sequence in the context of their typical interviewing practice, (2) fixing on a subset of one or two skills for attention and repeated encounters with SPs in a workshop, (3) an aide-mémoire at their desk, (4) review and discussion with peers of their transcripts, (5) the use of our analytical instrument as a self-assessment tool. The reinforcement of the skills came from episodic audio tape encounters and their discovery of the problem-solving utility of the skills. Scoring of transcripts indicated that the skills that were the strongest were in offering of choices and the weakest were explicit inquiry about preferences for information and decision making role.

Conclusions: Though they embraced the concept of ISDM and sought to model it as preceptors they were not able to demonstrate all the competencies consistently.

4C3

Impartial Evidence: An oxymoron or just difficult to find? An examination of the discursive construction of risk, agency and evidence

Robertson M, Dowell J, Cowan S, Sullivan F, Moir J

University's of Stirling, Dundee & Abertay

Background: The principles of shared decision-making advocate that patients should be given the opportunity to participate in their own healthcare decisions (Coulter et al 1999) and make choices about treatments which are informed by sound and impartial evidence (Elwyn and Charles 2001). In a recent study of SDM in general practice it was found that within 59 decisions patient participation could only be identified explicitly in four of these (work in progress). We sought to explore these sequences of ‘decision-talk’ and identify discursive activities that could be seen to affect/influence/control the lack of patient choice and participation.

Methods: Six GPs (2 female, 4 male), five of whom had additional training in decision sharing were recruited to audio-tape two routine surgeries (Dowell et al, 2004). A sample of 30 consultations scoring above the mean on COMRADE (Combined Outcome Measure for Risk Communication And Treatment Decision-making Effectiveness, Edwards et al, 2001) was identified as examples of ‘best practice’ for discourse analysis.

Results: Evidence and risk were seldom presented impartially. The language used during the treatment plan provided the doctors with strong justificatory claims for not prescribing particular courses of actions (e.g. not prescribing anti-hypertensive medication when guidelines suggest otherwise. GPs deployed a number of rhetorical devices that worked to side-step the issues of agency or responsibility away from the doctor and onto the patient. In addition, the raising of potentially negative risks was avoided in order to by-pass the responsibility for the decision away from the doctor. Consequentially, patients were not provided with the information required to make informed decisions.

Conclusions: The findings from this study do not reflect practice as advocated in existing models. GPs appear to have evolved discursive strategies that prevent true decision-sharing. It is suggested that practitioners need to be more reflective about their own practice and become more aware of how risk, evidence and responsibility can be constructed and used to compromise sharing.

4C4

Guidelines for GP referrals to elective surgical specialties and the role of patient involvement in the referral decision: A systematic review

Clarke A, Le Maistre N, Van der Meulen J, Rashidian A

Public Health and Policy Research Unit, Queen Mary, University of London

Background: In countries with publicly funded healthcare systems, referral guidelines can promote efficient use of limited resources by helping general practitioners (GPs) carry out their role as gate-keeper to secondary care services. A systematic review was carried out on guidelines to assist GPs in the decision to refer patients for elective surgical assessment. The review aim was to identify evaluations of existing referral guidelines, and to examine the role of shared decision-making in these guidelines.

Methods: A Medline search strategy was developed through discussion with information skills, health and policy experts. Key search terms related to and included “primary care”, “guidelines”, “referral” and “surgery”. Guidelines for urgent or non-surgical referral were excluded. Abstracts were assessed by two reviewers (AC and NL).

Results: The search yielded 569 papers, of which 5 met our inclusion criteria.

Conclusions: While changes in the appropriateness of referrals were often selected as the main outcome measure in studies evaluating referral guidelines, changes in health outcomes were rarely measured. Despite increasing recognition of the value of involving patients in decisions made within the primary care consultation, shared decision-making remains an alien concept in referral guidelines. This may be because the focus of guidelines has been upon reducing numbers of referrals to a specialty, or on reducing variations in numbers of referrals. By ensuring that shared decision making is an integral feature of future referral guidelines, we can improve patients’ experience of the referral process, increase adherence to treatment pathways and contribute to better health outcomes.

4D1

Patients’ Time Trade-off preferences predict smoking cessation.

Wiggers LCW, Stalmeier PFM, Oort FJ, Smets EMA, Legemate DA, de Haes JCJM

Radboud University Nijmegen Medical Center, Nijmegen and Academic Medical Center, University of Amsterdam

Background: Various models of decision support exist. In formal decision support, patient preferences for treatment related outcomes are obtained, implemented in a medical prognostic model, and the results are communicated to the patient. Of course, the preference measure should be valid. One criterion for validity is the ability to predict behaviour. In the case of health behaviour such as smoking cessation, social cognitive theories propose that smoking cessation can be accomplished by changing underlying cognitive determinants (attitudes, social influence, and self-efficacy). The aim of this study is to compare the relative impact of cognitive determinants and patients’ preferences on the prediction of smoking cessation.

Methods: In this study preferences constitute the degree to which one is willing to give up a valuable good, that is survival, to obtain a desirable behaviour (e.g. to quit smoking). Data were collected as part of a randomised clinical trial. Smoking outpatients (N=217) with documented atherosclerotic disease were included. At baseline (T0), socio-demographic and clinical characteristics were measured. Social cognitions (pros of quitting, pros of smoking, social influence and self-efficacy) and preferences (using a paper Time Trade-Off measure (TTO)) were assessed at T1 (1 week). Smoking cessation was assessed at T2 (8 weeks).

Results: Logistic regression analysis showed that socio-demographic ($p = .92$) and clinical ($p = .26$) factors did not predict smoking cessation, whereas social cognitions ($p = .02$) and preferences did ($p = .00$). On average, quitters were willing to give up 50% of their survival years in order to quit smoking.

Conclusions: Preference for quitting was the strongest single predictor of smoking cessation. This result supports the use of TTO preferences in formal decision support tools.

4D2

Patients and Consumers of Health Care Engaged in Shared Decision-Making Processes: A Canadian Story

Kovacs Burns K

University of Alberta

Background: The issue which patients face, not only in Canada but also globally, is not being involved in discussions and decisions which are made about health care generally, program or service delivery, and policies. Patients' health outcomes are the real test of what works best in the health care system, and what needs to change to better meet their needs. However, decision makers at all levels of government and within the health care system have traditionally stereo-typed the patient's viewpoint as self-serving, and have directed rather than involved the patient in his/her own health care treatment program. Policies are generally thought to be made by only those in higher levels of authority or administration or government, and really do not impact the patient. The impact of this has been that the health care system is not working efficiently or effectively to meet the health needs of many patients, especially those with chronic illness or conditions. Consequently, the system could end up paying more.

Methods: There are two purposes served by this proposal. One is exploring an issue which is how patients are often viewed by policy decision-makers, which results in patients not being included in policy processes. The follow-up purpose is to describe a process in which patients and stakeholders can and should be involved or engaged in policy decision-making processes.

Results: Patients have said that they want to become actively involved in discussions and decisions concerning health care services, delivery and policies. The process which is needed is one which removes the 'framing' or stereotyping of patients and replaces it with 'active involvement or engagement of patients' such as in a decision-making process framework.

Conclusions: The development of a Framework for Patient, Consumer and Stakeholder Involvement in Decision-Making Processes, including participant training on regulatory or policy processes, is a good start.

4D3

'Rhetorical' styles of communication in everyday decision-making: an ethnographic observation study in heart failure

Sanders T, Harrison S

University of Manchester

Background: This paper presents findings from observations of doctor-patient consultations at two heart failure clinics in the UK, to demonstrate how the power disparity that exists within the therapeutic relationship is actively maintained and reinforced, often through the use of 'persuasive' styles of communication. This idea supports previous literature that the asymmetry within the doctor-patient relationship is actively managed or reproduced, and does not simply exist independently of the therapeutic relationship. The paper argues that one of the ways cardiologists maintained a dominant relationship with patients and retained control over treatment decision-making was to employ a number of 'rhetorical' communication strategies.

Methods: An ethnographic observation study was carried out at two organisationally different heart failure clinics in the UK. In total, 65 taped observations of consultations between patients with heart failure and specialist registrars were conducted at both sites. The data were analysed using a variation of the 'constant comparison' method where coded transcripts were subjected to direct comparison and thematic analysis.

Results: Five distinct types of ‘rhetorical’ strategy employed by specialist registrars in the treatment decision-making process emerged from the analysis: juxtaposition of positive and negative information; positive talk; framing of choice; instrumental use of scientific evidence in the consultation; and, the presentation of heart failure as an urgent problem. These strategies were employed to maximise patient compliance with the treatment recommendation.

Conclusions: Evidence-based medicine has been a principal motive for the utilisation of ‘rhetorical’ styles of communication by cardiology registrars, introducing pressure on doctors to follow clinical guidelines and protocols. This trend is likely to impede a patient’s ability to participate autonomously in the decision-making task.

5A1

Chronic Illness Care Management (CICM): A Patient Centered Team Approach to Managing Chronic Illness to Improve Quality of Care. A Progress Report.

Hogg W, Lemelin J

Department of Family Medicine, Institute of Population Health, University of Ottawa

Background: The objective of the chronic illness management (CICM) care plan approach is to improve the quality of care given to chronically ill patients by introducing a tailored systems method of planning care over 12 months. This structured care approach is important since an increasing proportion of the population will experience chronic illness in the future. The organized patient care delivery system ensures that the initial CICM planning visit provides the patient and the physician with time to discuss, assess choices, and negotiate goals that meet both the patient and medical objectives. Care planning is an active partnership. The interaction encourages patient involvement in their own care decisions by contributing to their planned care.

Methods: The CICM is a nested, randomized, controlled trial within the “I Care FOR Primary Care” program. Thirty Ontario Family Health Network practices can adopt the chronic illness care management care plan. The program aims to introduce the CICM care plan approach while sustaining prevention. Each practice will be offered support throughout the implementation of the program by an Outreach Nurse Facilitator who will visit each practice every 3 weeks. Through a process evaluation of the trial, the project will assess patient satisfaction with the CICM.

Results: The CICM project has been piloted and is being implemented with expected completion, March 2006. For the CICM component, the process of implementing a care plan approach to chronic illness management with the challenges and victories experienced will be outlined and discussed.

Conclusions: The program experience of facilitating practice change up to now, including previous experience by the research team, suggests that the introduction of preventive practices through facilitation is feasible and successful.

5A2

Measuring client’s involvement in decision making: An evaluation of WHO’s Decision-Making Tool for Family Planning Clients and Providers in Mexico

Kim YM, Kols A, Rinehart W

Johns Hopkins University, Center for Communication Programs (JHU/CCP)

Background: Family planning (FP) counseling is based on the principle of informed choice, for which client participation is essential. However, decision-making (DM) studies seldom measure patient involvement. In addition, the need for a decision and the DM process is not obvious for continuing clients. This study poses two questions on FP counseling in Mexico: (1) Did the introduction of a DM tool developed by the World Health Organization enhance client involvement? (2) What issues arise in measuring the participation of continuing clients in DM?

Methods: Data were collected by videotaping 84 FP counseling sessions in, before and after the intervention. The clients were attended by 9 physicians and 4 nurses in 9 government facilities. All of the providers were trained in the use of DM tool and practiced with it for one month. An adaptation of the OPTION tool was used to answer the first research question, while qualitative analysis was used to answer the second question.

Results: Client’s involvement improved significantly for all OPTION items ($p < .001$). For each item, the percentage of sessions in which clients performed adequately rose from 0% - 3 % at the baseline to 24% - 71% during the post-intervention round. The least improved areas related to the client defining a problem requiring a decision and discussing the possibility of changing the decision in the future. The most improved areas were clients asking questions and expressing concerns. Qualitative analysis reveals that there are many missed opportunities for decision-making during counseling sessions with continuing clients due to provider bias and clients not asserting their needs. Providers rarely articulate the concept of watchful waiting when clients complain about side effects.

Conclusions: The FP DM tool helped enhance client involvement greatly during decision making. The conceptualization and measurement of client involvement, especially for continuing clients, needs to be reviewed.

5A3**Decision support for patients to enhance GPs' implementation of a national cholesterol guideline in primary care: a randomized cluster controlled trial**

van Steenkiste B, van der Weijden T, Schouten B, Stoffers H, Grol R

Centre for Quality of Care Research (WOK), Maastricht University, Maastricht, The Netherlands; Department of General Practice, Maastricht University, Maastricht, The Netherlands; Care and Public Health Research Institute (CAPHRI), Maastricht University, Maastricht, The Netherlands

Background: Many barriers hamper the performance of GPs with respect to the high-risk approach in primary prevention of cardiovascular diseases (CVD). Physicians find it difficult to assimilate multiple risk factors into an accurate assessment of cardiovascular risk. In addition, communicating cardiovascular risk to patients to reach a common understanding has proven to be difficult for physicians.

Objective: to evaluate whether a decision support tool for both doctors and patients improves the performance of GPs in primary prevention of cardiovascular diseases (CVD).

Methods: Design: cluster randomized trial

Setting: GPs with special interest in primary prevention invited patients (40-75 yrs) without CVD to read the booklet at home and return to discuss their risk of CVD.

Participants: 34GPs, each GP was asked to record data on 30 consecutive consultations in which patients' cardiovascular risk was discussed.

Intervention: use of an evidence-based decision support tool, in the form of a booklet explaining showing the patients' risk with comparative data on other patient groups to guide patients in their management of (high) cardiovascular risk.

Measurements: clinical performance of the GPs in terms of key recommendations of the cholesterol guideline, and physician's opinion and self-efficacy regarding those recommendations.

Results: 34 GPs recorded 490 consultations, 276 in the intervention and 214 in the control arm. Performance ranged from 25 % adherence for management to 85% for screening and risk classification. There was no significant effect of the intervention on the GPs' performance.

Conclusions: The two new techniques used, viz., the guideline in the form of a risk table and a new method to enhance patient involvement, demand a two-level implementation strategy. The classical transfer of knowledge and a 4-hour training are not enough.

5A4**The use of the OPTION scale as a measure for patient involvement in a sample of General Practitioners in Italy**

Goss C, Fontanesi S, Mazzi MA, Del Piccolo L, Rimondini M, Zimmermann C.

Department of Medicine and Public Health, Section of Psychiatry and Clinical Psychology, University of Verona

Background: The OPTION scale (Elwyn et al. 2003) assesses the extent to which clinicians involve patients in decisions across a range of situations in clinical practice. The English version has a Cohen's kappa score ranging from 0.45 to 0.98 and an ICC for the total score 0.77.

Aim of this study is to provide inter-rater reliability data of the Italian version of the OPTION scale and descriptive statistics on how Italian General Practitioners (GPs) involve their patients in the decision making process.

Methods: 252 transcripts of audio taped consultations by 6 male GPs were rated with the OPTION scale. The 252 patients were all consecutive patients who saw a GP for a new illness episode over a two-month period. GPs had received no formal training in shared decision making techniques. 30 interviews (5 for each GP) were rated by two trained and calibrated observers. Inter-rater agreements were assessed with weighted Cohen's kappa. Inter-rater intraclass correlation coefficient (ICC) was also calculated.

Results: Agreement between two raters for each item was between 63.3% and 96.7% (mean 71.7%); weighted Cohen's kappa was between 0.43 and 0.73 (mean 0.53) excluding item 3 (perfect agreement). The ICC on the global score was 0.85.

The ratings for each desirable behaviour item showed a skewed distribution: the vast majority of scores given (> 70%) were between 0 (behaviour absent) and 2 (minimum skill level). A score of 4 (high standard) was nearly absent and 3 was rare.

Conclusions: The inter-rater reliability was satisfactory although the kappa scores for the single items were lower than those reported by Elwyn et al. (2003). The clustering of low scores parallels the findings of Elwyn et al. (2003) and confirms that GPs without a specific training obtain very low levels of patient involvement in the decision making process.

5B1

Using patients to evaluate decision aids about the risk of breast cancer: a focus group study

Elwyn G, Rapport F, Edwards A, Jones W, Iredale R, Gray J

Cardiff University

Background: Screening and predictive genetic testing for breast cancer requires women to consider personal risk and to decide actions for their circumstances. This study involved purposively selected patients in a qualitative evaluation of three existing decision aids for breast cancer. Focus group methodology was used to assess their reactions and views.

Methods: A pilot interview was followed by six focus groups of women at inherited risk of breast cancer, stratified into high, moderate and population risk groups (40 in total). These extended interview sessions involved presenting three 'decision aids', all developed in the USA, selected for their prominence in the literature. Two were CDs (MJ Green's (Penn State University), PREDICT <http://www.genetic-testing.com/predict>), and one a web-based decision aid that is also available in a paper format, "Deciding about Mammography for Women Age 40-49" <http://www.aafp.org/x19498.xml>. The aids were assessed using five criteria: usefulness, information clarity, emotive response, knowledge and informed choice.

Results: The women found the aids useful and often expressed strong criticisms that this type of information had not been readily available earlier in their patient careers. They were supportive of both formats, but had a preference for CDs. Both CDs were considered user-friendly and to contain clear information, with divided opinion between groups as to which of the two CDs was best at communicating risk. Positive features of the CDs were the ability to navigate information and the availability of interesting narrative elements. When comparing formats, women expressed that patients should have both interactive and paper based formats available, as they serve different purposes. Patients noted the different healthcare context of the developers and stated the need for substantive adaptation before implementation in their other settings.

Conclusions: There seems to be significant unmet demand for information and decision support in this context. Patient evaluations provide unique insight into issues of information design and risk communication methods.

5B2**Screening mammography: presenting evidence to support informed choices by women**

Barratt A, Howard K, Irwig L, Salkeld G, Houssami N

Screening and Test Evaluation Program, University of Sydney

Background: Information about screening should be balanced, present cumulative benefits and harms over comparable timeframes (e.g. 10 years) using consistent denominators (e.g. per 1000 people), and include information about detection of inconsequential disease. Our aim was to provide easy-to-use estimates of the outcomes of biennial screening mammography for women aged 40, 50, 60 and 70 years that meet these information goals to help women decide whether and when to begin (and finish) screening.

Methods: A Markov process model was developed; data from BreastScreen Australia, the Australian Institute of Health and Welfare and the Australian Bureau of Statistics were used. Age-specific outcomes are expressed per 1000 women over 10 years.

Results: Over 10 years, 167-251 per 1000 women (depending on age) receive an abnormal result and are recalled for more tests; 55-65 of these women have a biopsy. 9-26 women (depending on age) have an invasive cancer detected by screening and 3-6 have DCIS detected by screening. More breast cancers are diagnosed among screened than unscreened women. For example, among 1000 women aged 50 who have 5 biennial screens, 33 breast cancers are diagnosed: 28 invasive cancers (18 screen detected and 10 interval cancers) and 5 screen detected DCIS. In comparison among 1000 50-year-old women who decline screening, 20 cancers are diagnosed (19 invasive and 1 DCIS) over 10 years. There are approximately 0.5, 2, 3 and 2 fewer deaths from breast cancer over 10 years per 1000 women aged 40, 50, 60 and 70 years respectively who choose to be screened compared to women who decline screening at policy relevant decision times.

Conclusions: These estimates allow presentation of evidence about the benefits and harms of screening mammography. We are now using them in decision aids to help women make informed choices about whether and when to be screened.

5B3**Examining the acceptability of a Decision Aid developed for HRT among consumers from multiethnic backgrounds and health practitioners**

McCaffery K, Trevena L, Barratt A, Clarke J, O'Connor AM, Armstrong B

Sydney Health Decision Group, School of Public Health, University of Sydney.

Background: Recent evidence on the harms of long-term HRT use has prompted the need for updated consumer information on hormone therapy. This paper will describe the qualitative evaluation of a decision aid (DA) for HRT developed as part of a government tender for evidence based consumer information on HRT for Australian women.

Methods: The DA was evaluated among health practitioners (n=8) and consumers (n=51) to examine the acceptability of the DA and to inform its final content and design. Interviews were held with 8 clinicians across a range of clinical areas relating menopause. Ten focus groups were run with women aged 40-65 years from Anglo Australian, Indigenous Australian, Greek, Arabic and Italian backgrounds (n=51). Comprehension, attitudes to the DA content and design, and preferences for the presentation of risk information were examined. Interviews and focus groups were audio-taped and thematic analysis was carried out of verbatim transcripts.

Results: Consumer's response to the DA and preferences for risk information will be presented alongside findings from the practitioner interviews. There were striking differences between practitioner's beliefs about what information they thought women wanted and women's actual stated preferences for information. There were strong similarities in preferences for content and design of the DA across the ethnic groups we sampled and areas for improving understanding and accessibility to women from different ethnic backgrounds were identified.

Conclusions: How the data was then used to inform the final version of the DA and its implications for DA development more broadly will be discussed.

5B4

What does order have to do with it?: The role of risk/benefit order in shaping risk perception

Fagerlin A, Zikmund-Fisher BJ, Derry HA, Sarr BJ, Smith D, Ubel PA

Ann Arbor HSR&D Center for Practice Management & Outcome Research and University of Michigan

Background: When presenting risk information in decision aids, several questions arise: Should risks or benefits come first? Should risks/benefits be framed in terms of gains or losses? Little research has compared the use of different presentation methods in the context of the efficacy of decision aids.

Methods: We tested a decision aid describing prophylactic tamoxifen for women with a high risk of developing breast cancer. We manipulated: 1) whether risks and benefits were described using gain- or loss framing and 2) the order in which the risks and benefits of tamoxifen were presented. 400 decision aids and surveys were sent to participants of a woman's health registry who were aged 40 and older.

Results: 313 women returned surveys. Participants were on average 54 years old, Caucasian (89%) and well-educated (70% had at least an associate's degree). While risks/benefits order had an impact on women's risk perception of tamoxifen and in their interest of pursuing tamoxifen information, gain/loss framing did not. Compared to those who read about the risks of tamoxifen first, women who read about benefits first were more worried about the side effects of taking tamoxifen (3.55 vs. 3.24, $F=4.27$, $p<.04$) and were marginally more likely to think that the side effects of tamoxifen were common (2.78 vs. 2.55, $F=3.29$, $p=.071$). Those who received the risk information first were more likely to talk to a doctor (2.62 vs. 2.20, $F=4.32$, $p<.04$) and to look for more information (2.76 vs. 2.35, $F=3.7$, $p=.055$).

Conclusions: The impact of the order of presenting risks and benefits may be due to recency effects such that when risks are described last, the risks seemed greater and pursuing tamoxifen seems less appealing. This suggests that decision aids developers must be aware that treatment decisions could be influenced by the order that risks and benefits are discussed.

5C1

Patients' preferences vs. oncologists' perceptions of treatment decisions: are there predictors of better agreement?

Gabrijel S, Herrmann R, Wernli M, Rochlitz C, Bargetzi M, Pless M, Betschart P, Kiss A

Psychosomatik, Universitätsspital Basel; Onkologie, Universitätsspital Basel; Onkologie/Hämatologie, Kantonsspital Aarau

Background: Patient participation in treatment decision making has been encouraged recently. But to the authors' knowledge little is known about who wants to be involved in treatment decision making. The purpose of this cohort study was to explore predictors of better agreement between patients' preferences and oncologists' perceptions of these preferences.

Methods: Cancer patients and their oncologists of two outpatient oncology clinics in a university hospital and in a teaching hospital were assessed with a questionnaire which is based on a previously developed tool (Bruera et al., 2001). Both, patients and attending oncologists completed the questionnaire separately, patients for their preferences and oncologists for their perceptions of these preferences.

Results: 189 patients aged 20-82 years, confronting one of four decision situations regarding further treatment (1: therapy yes or no; 2: change of therapy; 3: therapy A or B or C; 4: clinical trial yes or no) and 21 physicians aged 29-56 years.

The weighted kappa coefficient for agreement between physician and patient was poor: before consultation (excluding first consultations, $n=48$) 0.15 (95% confidence limit, 0.02 to 0.29), after consultation 0.2 (95% confidence limit, 0.07 to 0.34).

Of physicians' characteristics (age, sex, years of practical experience, number of psycho-oncology courses, number of communication skills trainings) only oncologists with a specific communication skills training seemed to perceive their patients' preferences more accurately ($OR=2.83$, $p=.02$).

Conclusions: Our results confirm previous results of low agreement between patients' preferences and oncologists' perceptions of these preferences. A specific communication skills trainings seems to enhance correct oncologists' perceptions of patients' cues during the consultation concerning their decision-making preference.

5C2

Evaluating Uptake of Cancer Genetic Testing As An Outcome for Shared Decision Making: All That Glitters Isn't Real!

Ropka M, Phillips E, Wenzel J, Philbrick J

Fox Chase Cancer Center, University of Virginia School of Medicine, University of Virginia School of Nursing

Background: Measurement of cancer genetic testing (CGT) uptake is a key part of the basic science of shared decision making. CGT uptake is used as an outcome measure in studies of decision support interventions and implementation strategies. The purpose of this qualitative systematic review was to identify, critically appraise, and synthesize evidence from studies related to decisions about breast cancer genetic testing (BCGT).

Methods: Using MEDLINE, CINAHL, and PSYCHINFO, we identified 40 studies in May 2002 that: examined breast cancer-related decisions; addressed the outcome of CGT; enrolled adult participants; were published in 1990 or after; constituted peer-reviewed primary clinical studies; and reported CGT uptake rates. We examined definitions and measurement of CGT uptake, interest/intent for CGT (hypothetical decision), and/or actually obtaining CGT (real decision). Information regarding study methods and CGT uptake decisions was abstracted. Each article was reviewed for methodologic quality using a flexible quality review system applicable to all study types.

Results: Of the 40 studies, 25 reported HYPOTHETICAL BCGT decisions, 14 reported REAL decisions, and one gave BOTH. Mean HYPOTHETICAL uptake was 66% (range 20% to 96%); mean REAL uptake was 59% (range 25% to 96%). Personal history, family history, and other clinical variables usually presumed to account for uptake variability did not do so. Our methodologic review identified alternative explanations for variability in the outcome of BCGT uptake, including: differences in uptake definition, completed versus ongoing studies, investigator influences, small sample sizes, diverse study settings and target populations, poorly described sampling strategies, biased sampling methods, and variability in associated risk factors.

Conclusions: Rather than clinical characteristics, research methodologic issues are major determinants of variability in the outcome of BCGT uptake rates. Understanding these issues will reveal why clinical experience may not be congruent with published rates, inform future shared decision making research, and facilitate legitimate comparisons across studies.

5C3

Measuring the Physician-Parent Relationship in Pediatric Care

Cox E (1), Smith MA (1), Brown R (1), Fitzpatrick M (2)

(1)University of Wisconsin Medical School; (2)University of South Carolina

Background: Provider-patient relationships are key to shared decision-making (SDM), yet no standard relationship measure exists. Using the Roter Interaction Analysis System (RIAS), we develop and test a model of the physician-parent relationship in pediatric visits while incorporating two established relationship domains ("liking" and "understanding").

Methods: Videotapes of 100 parent-child dyads visiting one of 15 physicians were coded with RIAS, categorizing utterances into 34 categories. ICCs of >0.70 for RIAS codes ensured interrater reliability. Indicator variables included personal remarks, laughter, agreements, approvals, compliments, disapprovals, concerns, reassurances, understanding and empathy. Models were evaluated using confirmatory factor analysis (CFA) in LISREL 8.54 with polychoric correlation matrices, asymptotic variance/covariance matrices and weighted least squares estimation as appropriate for variables whose correlations are not bivariate normal.

Results: Unidimensional models of “relationship building” based upon indicators commonly summed in prior work with RIAS demonstrated poor fit (X^2 of 111.4 with 28 degrees of freedom; RMSEA of 0.17). An alternative single factor model of the physician-parent relationship including nine indicators (compliments and statements of understanding, approval, agreement, and empathy) had good fit (X^2 of 38.6 with 27 degrees of freedom; RMSEA of 0.07). A 4-factor model with latent variables for liking and understanding by both physician and parent had good fit (X^2 of 27 with 21 degrees of freedom; RMSEA of 0.05). The X^2 difference between the latter models was 11.5 with 6 degrees of freedom, representing no significant change in fit ($p < 0.10$). Equating factor loadings within either of these models resulted in significant misfit.

Conclusions: CFA supported a multidimensional measure of the physician-parent relationship, suggesting the existence of domains such as “liking” and “understanding” for both parent and physician. Additionally, item weighting is indicated when creating physician-parent relationship measures. Future work will explore a second order factor structure and expand the measure to include non-verbal indicators.

5C4

Development and validation of a new questionnaire to measure process and outcome of shared decision making

Simon D, Loh A, Härter M

Department of Psychiatry, University Hospital of Freiburg, Germany

Background: Validation results of instruments measuring the process and effects of shared decision making (SDM) have shown that an improvement of instruments is necessary. Based on these results the working group methods within the German research consortium on SDM has developed a new questionnaire (SDM-Q).

Methods: In a theory driven method eight steps of the SDM-process were defined. For each of these steps items were generated and formulations were discussed in expert groups based on the Delphi-method. This process resulted in a new questionnaire (SDM-Q) consisting of 24 items which has already been used in German projects on SDM in psychiatry, neurology and internal medicine.

Results: First results can be reported from a sample of $N=220$ depressed patients in GP treatment. The treating GPs were either randomised to a group with SDM training ($N=20$) or to another group ($N=10$) without any kind of training or information on SDM.

With scores between 0.66 and 0.92 item difficulties range from moderate to easy. Cronbach’s alpha was identified as good with a score of 0,85. A separate analysis for intervention group ($N=141$) and control group ($N=71$) brought significant differences ($p < .05$, Mann-Whitney-Test) in the statistical distribution for 21 of the 24 items. Patients of SDM-trained physicians reported a high extent of SDM while patients’ results of non-trained physicians can be found across all answering possibilities of the scale. Content validity was assessed by comparing the SDM-Q with the Perceived Involvement in Care Scale and the Man-Son-Hing Participation Scale. Significant correlations ($p < .05$) were found with both questionnaires.

Conclusions: The results indicate first hints for the suitability of the SDM-Q to measure changes in the extent of SDM. Psychometric tests on larger samples and in different indications are currently being conducted.

5D1

A randomised controlled trial of shared decision making in primary breast cancer patients – effects on patients’ perceptions and psychological outcome

Vodermaier A, Caspari C, Koehm J, Untch M

University of Munich, Department of Obstetrics and Gynecology - Grosshadern

Background: Therapy for breast cancer is complex and in spite of existing guidelines patients receive contradictory recommendations concerning their therapy contributing to additional uncertainty and anxiousness on the patients side. Therefore we have identified three treatment options for primary breast cancer which are considered as

equivalent options concerning prognosis. These are type of surgery (breast conserving vs. mastectomy), time of surgery (pre vs. postoperative chemotherapy) and additional chemotherapy in patients with hormone receptor positive tumors. A shared decision making intervention for the treatment of newly diagnosed breast cancer patients tries to enhance existing shortcomings.

Methods: In a randomised controlled trial we used the decision board and information brochures as a decision aid in a half hour intervention before therapeutic decision making with the surgeon. Dependent measures were preferences for participation in treatment decision making, decisional conflict, perceived involvement in care, health related locus of control, anxiety and depression symptoms, coping, body image and health related quality of life. Patients were asked by questionnaire before and one week after treatment decision making up to a one year follow up. Preliminary data involving short term effects of the intervention are presented.

Results: We analysed data of 57 breast cancer patients with a mean age of 58. There were no differences between experimental and control group in regard to sociodemographic and clinical variables and interest in participation in treatment decision making. Patients in the shared decision making condition defined their situation more actively and had higher internal health locus of control perceptions. In addition they were more obvious about the advantages and disadvantages of the therapy chosen and showed more satisfaction with the decision made. Breast cancer patients in the experimental condition had a more positive body image, too. There were no group differences concerning anxiety and depression symptoms, coping and quality of life.

Conclusions: Where as there have been found several favourable results of a decision aid intervention in respect to shared decision making variables, there were no short term effects on distress measures, coping and health related quality of life. However body image was assessed better in the experimental group than in the control group. Whether shared decision making does not effect psychological distress and coping or effects are long-term will be found out by considering a larger sample and follow ups.

5D2

Effects of an American decision aid for surgical options in primary breast cancer in Germany: a feasibility study with German medical students

Scheibler F, Schloer B, Jessie M, Kuch C, Pfaff H

Dept. for Medical Sociology, Institute for Occupational and Social Medicine, Univ. of Cologne, Germany

Background: Videotapes are commonly used as decision aids in the English-speaking world. Their beneficial effects have been evaluated in several RCTs. The aim of this study was to analyse the feasibility of an American videotape in the German health care setting. In a preliminary study we evaluated the effects of the tape on German medical students.

Methods: RCT with three groups of medical students in the second year of university. A videotape of the Foundation for Informed Medical Decision Making (FIMDM) was shown to 50 students, two different other tapes which are designed to inform BC-patients but not to facilitate SDM were shown to 60 other students. Students were randomly assigned to seven different groups. Baseline Data was collected with a questionnaire consisting of instruments to measure preferences towards lumpectomy or mastectomy, control preference, decision conflict and socio-demographic variables. After watching the movie the students were asked to complete another questionnaire including the same scales and some additional questions on information, length, comprehensibility, and an open question.

Results: At baseline there were no significant differences in the socio-demographic, or control-preference-data between the groups. Although the FIMDM videotape was shown in English most of the students could easily understand its contents. The FIMDM tape reduced decision conflict slightly more than the two other tapes. Also students who had watched the decision aid felt less insecure. All the groups desired more Information about self-help groups, psycho-social and everyday aspects of the different treatment options. After watching the decision-aid the students slightly more tended towards mastectomy.

Conclusions: This preliminary study has two major limitations: first the videotape was not translated into German language. This might have influenced its comprehensibility for German students. Second the study was conducted with medical students. Transferability of the results to women with breast cancer has to be examined in future studies. The results of this preliminary study indicate that the videotape might be feasible also for German women with breast cancer. We are grateful for the support of Nancy Britton and Floyd J. Fowler (FIMDM).

5D3

Development of and pilot evaluation of a decision aid for advanced breast cancer patients considering chemotherapy

Shepherd H (3), Tattersall MHN (1), Leighl N (2), Butow P (3), Sullivan A (4), Hamilton A (4), Beith J (4), Vardy J (2), Chiew K (2)

(1) Department of Cancer Medicine, University of Sydney, (2) Division of Medical Oncology, Princess Margaret Hospital/University Health Network, Toronto, (3) Medical Psychology Research Unit, School of Psychology and Department of Medicine, University of Sydney, (4) Royal Prince Alfred Hospital, Sydney

Background: Treatment decisions in metastatic breast cancer are complex and many women want to be involved in these decisions. Decision aids have rarely been applied to the advanced cancer setting.

Methods: 1. Development of Decision Aid (DA). A decision aid modelled on the O'Connor format was developed for women with advanced breast cancer considering chemotherapy with their oncologist. The DA presented the options of supportive care with or without several reasonable chemotherapy options and included a worksheet to allow women to clarify their values. Chemotherapy options were shown with their likely benefits and side effects including survival statistics. The DA is presented as a booklet and as an audiotape/CD. 2. Pilot evaluation. Women with advanced breast cancer in Sydney (Australia) and Toronto (Canada) who had considered chemotherapy were invited to review the draft DA and complete a questionnaire assessing their involvement and information preferences and attitudes to the decision aid (regarding amount of information, distress caused, length, clarity, helpfulness, whether aid would be shown to significant others and whether they would recommend it to others).

Results: 17 out of the 20 patients approached returned completed questionnaires. 15 participants stated they wanted as much information as possible good and bad. All of the participants stated they wanted some involvement in the decision making process, with 7 stating that they wanted to make the decision themselves. 11 participants stated the DA contained about the right amount of information (4 reported it was a little too long), with just one respondent stating they found some things unclear. Comments included finding the DA, "concise and informative", that "it covered everything", that it was "balanced" and that it "gave a lot of information". 7 respondents found the DA a little or somewhat upsetting, with this illustrated by comments such as, "it made me feel my option for chemo was just biding time... feel there needs to be something positive included", that it "dwells on the negative" and "references to extension of life,didn't help my confidence". One respondent reported that the DA gave her a lot more information than she needed. All of the respondents stated that they found the DA helpful, commenting that they liked "its logical progression", that "it shows there is no right or wrong way" and that it can be "read at leisure after shock of consultation". One of the respondents stated that she would probably not recommend the DA, commenting that she " [does] not want to think of what tomorrow holds and will take each day and every pain as it comes".

Conclusions: The DA was acceptable to all patients although some found it confronting. Based on the pilot study minor wording changes were made and a randomised trial of the usefulness of the DA has been commenced.

6A1**Definitions of “shared decision making” evident in the medical literature: Back to basics**

Makoul G, Clayman M

Northwestern University Feinberg School of Medicine, Program in Communication & Medicine

Background: Shared decision making (SDM) is a term frequently advocated in teaching and research about physician-patient communication. However, the concept is poorly understood because the multiple definitions of SDM are rarely acknowledged or reconciled. We conducted a systematic review of articles that specifically address SDM to determine the use and range of conceptual definitions.

Methods: In October 2004, we conducted a Pubmed (Medline) search to identify articles published through the end of 2003 that included the words shared decision making in the title or abstract. The search yielded 593 citations. Of these, 273 were rejected because they were either not in English (n=39), or they contained the keywords but not in the context of physician-patient decisions (n=234). Of the remainder, 135 articles contained conceptual definitions of SDM. In addition, we reviewed articles obtained from other investigators, and examined references in all articles with a conceptual definition in order to identify any non-redundant SDM citations. These steps yielded an additional 25 articles, for a total of 160 with conceptual definitions of SDM.

Results: While the first English-language article with a conceptual definition of SDM appeared in 1982, the number of articles with conceptual definitions increased considerably in 1999. Overall, the majority of the 160 articles offered broad definitions (e.g., patient involvement in medical decisions), and focused on concepts such as patient preferences and partnership. Most of the articles that cited models of SDM invoked the Charles, Gafni & Whelan (1997) description of key characteristics and/or the Charles et al (1999), Towle & Godolphin (1999), and Elwyn et al (2000) outlines of stages and competencies.

Conclusions: Given the significant attention devoted to SDM, there is scope for integrating and building upon existing conceptual definitions. Based on this review, we propose a comprehensive model that incorporates the most commonly cited elements of SDM while maintaining the flexibility necessary to reflect everyday clinical practice.

6A2**Pediatric cancer choices: decisions both shared and not**

Whitney S, Volk RJ, Ethier A, Barrera P, Hockenberry M

Baylor College of Medicine, Houston, TX

Background: Some ethical theorists believe that all medical decisions should be shared between physician and patient (or parent, in the case of a child). Our clinical experience with children with cancer suggests just the opposite: that the physician makes many decisions, and the more important the decision, the more likely the physician is to make it. The parents' role is reduced to passive acceptance. We sought to understand why clinical practice in pediatric oncology is so at odds with ethical theory.

Methods: Our research was wholly theoretical. We first considered previous research in shared decision making, then applied it to the specific circumstances of the child with a relapse of pediatric cancer.

Results: There are different types of decisions for children with relapsed cancer. Two decision characteristics are most important. (1) Is a cure possible? and (2) Is there one clear best treatment option, or are two or more options reasonable? . . . This analysis enables us to create a decision plane and array all decisions based on these two characteristics. We then determined the appropriate sharing of decisions in each part of the decision plane. Finally, we distinguish decisional priority and decisional authority. The participant with decisional priority is the first to suggest a plan of action, and the participant with decisional authority makes the final decision. Decisional priority may be assumed by either physician or parent, but decisional authority always resides with the parent. This satisfies the ethical imperative that parents are given guidance without being stripped of the ultimate responsibility for their child's well being.

Conclusions: This model presents the different types of decisions confronted in childhood cancer and resolves the seeming contradiction between the clinical reality in which the physician sometimes takes the lead in decision making and the ethical norm of shared decision making.

6A3

Shared decision-making in the medical encounter: are we all talking about the same thing?

Moumjid N (1), Gafni A (2), Brémond A (1), Carrère MO (1,3)

(1) GRESAC, LASS, CNRS (FRE 2747), Centre Léon Bérard, Lyon, France., (2) CHEPA, Department for Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ontario, Canada., (3) Claude Bernard University, Lyon 1, France.

Background: Since the mid-1990s, an increasing number of papers, studying different aspects of ‘shared decision-making’ in the medical encounter, have been published by researchers from different areas (e.g., sociology, psychology, economics, medicine, ethics etc.).

Objective: Through a literature review to find out whether after all the research done on ‘shared decision-making’ (SDM) in the medical encounter, some authors propose a clear definition of the term or not.

Methods: We scanned different databases (Medline, HealthStar, Cinahl, Cancerlit, Sociological Abstracts and Econlit) from 1997 until June 2004. The keywords we used were ‘informed decision-making’ and ‘shared decision-making.’ The languages we selected were English and French.

Results: The 76 reported papers show that: 1) Charles, Gafni & Whelan (1997, 1999(a)), Coulter (1999(a)), Towle (1997) and Towle & Godolphin (1999) clearly define what they mean by ‘SDM’ or another term stemming from it. Their definitions are very similar. 2) A large majority of authors cite Charles et al., and/or Coulter, and/or Towle & Godolphin. 3) Certain authors use the term ‘SDM’ inconsistently with the definition they propose and some use the terms ‘informed decision-making’ and ‘SDM’ as if they were synonymous. 4) Certain authors remain vague as to what is ‘informed decision-making’ and what is ‘SDM’, and others even provide no definition and do not quote authors who have provided definitions.

Conclusions: ‘Shared decision-making’ in the medical encounter is still a topic of research. Closely related and clear definitions have been proposed, but new and different ones are currently emerging, showing that the concept of ‘SDM’ might still need further conceptual research.

6A4

It's more than talk about treatment options: a broader conceptualisation of patient involvement in decision making

Entwistle VA, Watt IS

Health Services Research Unit, University of Aberdeen; Department of Health Sciences, University of York

Background: Discussion about shared-decision-making often focuses on (1) the provision of information to patients about health care options and (2) communication within consultations about the selection of one of these options. This focus encourages a view of patient involvement in decision-making that is unduly restricted in terms of both the senses of involvement and the aspects of decision-making that it considers.

In day-to-day talk, people can be said to be ‘involved’ both in activities and with other people by virtue of what they think, feel, say and do. Decision making about the management of many health conditions involves a number of complex stages, including the recognition and clarification of a problem, the identification and appraisal of possible solutions, the selection and implementation of a particular option, and the evaluation of the implemented solution, which may lead to a new stage of problem recognition and clarification.

Methods: Reflecting this, we propose a broad conceptual framework for considering patient involvement in decision-making.

Results: Our conceptual framework accommodates the various cognitive, emotive and behavioural aspects of involvement, encourages attention to the full range of activities associated with decision making, and differentiates between patients' involvement in decision-making tasks and their involvement with health care professionals while still allowing for a relationship between these.

Conclusions: The proposed framework should encourage more precise description and measurement of patient involvement in decision-making. It could thus facilitate more sophisticated investigations of the relationships between patient involvement in decision-making and other variables (including health care outcomes), and more nuanced considerations of the appropriateness of particular forms of patient involvement across different health care contexts. The framework also paves the way for a clearer elucidation of the relationship between the concepts of shared decision- making and patient centred care.

6B1

How do elements of the decision-making process for localized prostate cancer impact long-term decision regret?

Gurmankin AD Ubel PA, Badler A, Dean LT, Coyne J, Armstrong A

Harvard School of Public Health, Dana-Farber Cancer Institute, University of Michigan, Veteran's Affairs Medical Center, Ann Arbor Michigan, University of Pennsylvania School of Medicine, Abramson Cancer Institute, University of Pennsylvania

Background: Despite attention to the difficult localized prostate cancer treatment decision, little is known about how long-term decision regret is influenced by the treatment choice as well as reasons for the choice and difficulties in the decision-making process.

Methods: Surveys of newly-diagnosed localized prostate cancer patients just after making a treatment decision and again one year later (N=169).

Results: Compared to patients who chose surgery, those who chose nonsurgical treatment more strongly agreed one year later that they would have gotten more information about their treatment options ($p=.022$), would have gotten a second opinion (among those who did not) ($p=.041$), and would have followed the urologist's recommendation ($p=.009$), but were no different in agreement that would have gotten a different treatment ($p=.164$) and would have gotten more advice from other patients ($p=.831$). A significant interaction was found between treatment choice and concern about chance of cure at baseline when predicting regret one year later. Among patients who did not choose surgery, there was no association between concern about cure and agreement with the aforementioned measures of regret one year later, but among those who chose surgery, those who were less concerned about cure more strongly agreed with each regret statement (interaction: $p<.05$ for all except "would have followed urologist's recommendation"). In addition, wanting more information from the urologist and more time with the urologist and having greater conflict with their spouse about the treatment decision at baseline was associated with stronger agreement with each regret statement one year later ($p<.05$ for all). These associations remained significant ($P<.05$) when adjusting for the treatment obtained.

Conclusions: These results reveal that treatment choice, the reasons for treatment choice and their interaction with the treatment chosen, and communication difficulties during the decision-making process can have long term consequences for patients' satisfaction with their prostate cancer treatment decision.

6B2

Shared Decision Making and Posttraumatic Growth in Early-Stage Breast Cancer Survivors

Farrelly KA, Hughes KS, Mulley AG, Partridge AH, Sepucha KR

Massachusetts General Hospital, Dana Farber Cancer Institute

Background: Researchers have found posttraumatic growth (PTG) in breast cancer survivors. Personal support and perceived control over the stressor are positively correlated with PTG. This pilot explored whether increased

involvement in treatment decisions is associated with increased feelings of support and control and thus with increased PTG.

Methods: The investigators mailed surveys to 62 early-stage breast cancer survivors. A modified version of the Posttraumatic Growth Inventory (PTGI) was included to assess PTG. The PTGI has five subscales: relating to others; new possibilities; personal strength; spiritual change; and appreciation of life. Support was assessed with the support subscale of the Decisional Conflict Scale. Two questions assessed control over cancer. Involvement in decision-making was assessed with the written version of the Control Preferences Scale. The Massachusetts General Hospital's IRB approved all study activities.

Results: Forty patients completed surveys. The median time since diagnosis was 19 months. Some participants reported no change (10.3%) but most reported positive changes (89.7%) in total PTG. Most reported increases in their appreciation of life (85.3%), personal strength (70.6%), ability to relate to others (76.5%), spiritual growth (52.9%) and new possibilities in life (64.7%). Some participants reported negative changes on individual items (4.9% of responses) or subscales. Neither support nor control was related to overall PTG scores ($r = -.058, p > .05$; $r = -.032, p > .05$). Lower involvement in decision-making was correlated with greater support ($r = .450, p < .01$).

Conclusions: This pilot data supports previous research showing that many early-stage breast cancer patients experience psychosocial benefits. The results show the importance of assessing both positive and negative changes. The pilot did not demonstrate a correlation between support, control, or involvement and PTG. Future research will explore the use of different measures of support, control and involvement to assess the relationships between these factors and PTG.

6B3

Impact of Cancer-related Decision Aids: A Systematic Review

O'Brien, MA, Whelan TJ, Villasis M, Gafni A, Charles C, Willan A

McMaster University, Instituto Mexicano del Seguro Sociales, Hospital for Sick Children

Background: Decision aids (DAs) have been developed to improve communication between health professionals and patients, and to involve patients in decisions about their health care. Cancer-related decisions can be particularly problematic due to difficulties in communicating complex and threatening information about prognosis and the modest benefits of available treatments. We recently updated our previous review of cancer-related DAs (Whelan et al. 2002).

Methods: Primary studies of randomized controlled trials (RCTs) of cancer-related DAs about prevention, screening and treatment decision making (DM) were included. We searched multiple electronic databases including MEDLINE, EMBASE, and the Cochrane Library, reference lists and personal files of experts. Both qualitative and quantitative analyses were conducted. For the quantitative analysis, we used a random effects model to pool data.

Results: We identified 24 RCTs (30 comparisons) of DAs in a cancer context. A prevention/screening decision was the focus in 17 trials while a treatment decision was studied in 7 trials. Outcomes included patient knowledge, the test or treatment that was chosen as well as processes related to DM such as decisional conflict and satisfaction. Across all trials, patient knowledge was significantly increased in 18 of 26 comparisons. The test or treatment that was chosen was significantly different in only 8 of 27 comparisons. In 11 comparisons, anxiety was not increased with the DA and in one trial, it was reduced. Decisional conflict was significantly reduced with the DA in 4 of 6 comparisons. Results from the meta-analysis will be presented.

Conclusions: Most of the trials in this review studied the effectiveness of DAs in a screening rather than treatment context. Across all studies DAs appear to be effective in increasing patient knowledge compared to usual care. In a small number of trials, the use of DA appeared to alter the test or treatment that was chosen.

6B4**Patients with incurable cancer: discussions and decision making about medical treatment in the last phase of life**

Visser AP (1), Voogt E (2), van der Heide A (2), van Leeuwen AF (2), van der Rijt CCD (3), van der Maas PJ (2)

(1) Helen Dowling Institute, Centre for Psycho-oncology, Utrecht, The Netherlands; (2) Dept of Public Health, Erasmus MC, University Medical Centre Rotterdam, Rotterdam, The Netherlands; (3) Dept of Medical Oncology, Erasmus MC, University Medical Centre Rotterdam, Rotterdam, The Netherlands

Background: When cancer has advanced to a stage in which cure is unlikely, patients may have to consider the aim of further treatment. We studied the attitude of patients about medical treatment and discussion with physicians and relatives about decision-making in the last phase of life.

Methods: Patients with incurable cancer were interviewed about their discussions of wishes toward medical treatment with health care professionals and relatives about decision-making in this phase of life. These questions were repeated after 6 months. In case patients passed away during the research period, their bereaved relatives were asked to participate in a personal interview at home.

Results: One hundred and twenty-two patients participated in the study. At the first interview, only a few patients (5%) refused a potentially life prolonging treatment and 8% had filled out an advanced directive. At that time point twenty percent of the patients had discussed their wishes toward medical treatment with health care professionals, however thirty-nine percent discussed those wishes with family members. Of the 67 patients who participated 6 months or more in our study, a growing number of patients (12%) had refused a potentially life-prolonging treatment, and 43% had discussed their wishes concerning end-of-life treatment with health care professionals. The bereaved relatives (n=63) confirm that 11% of the patients had refused a potentially life-prolonging treatment, but 62% had discussed their wishes toward end-of-life treatment with health care professionals, and 24% had filled out an advance directive.

Conclusions: At the end of life a growing number of Dutch patients is refusing a potentially life prolonging treatment. However, two third of the patients did not discuss their wishes concerning end-of-life treatment with their physicians. Also the interviews among the relatives confirm that there is room to improve the shared decision making about medical treatment during the last phase of life.

6C1**An Entertainment-Education Approach to the Development of Decision Aids for Lower Literate and Naïve Computer Users**

Jibaja-Weiss ML, Volk RJ, Granchi TS, Neff NE, Spann SJ, Beck JR, Aoki N

Baylor College of Medicine, Department of Family and Community Medicine, Houston, Texas, USA

Background: Decision aids provide information and support patient involvement in decision making about treatment. Although decision aids have been developed utilizing various delivery methods, including interactive computer programs, such programs still rely heavily on written information, health and digital literacy, and comfort with reading. These are potential barriers for the lower-literate, underserved populations.

Methods: This paper describes the design and development of a computerized decision aid to overcome the limitations of traditionally designed computer-based systems by making considerations for poor readers and naïve computer users, and by using concepts from entertainment education in order to engage and contextualize the content for the user. The design and development of a bilingual (English and Spanish), computerized support system to aid women in making an initial treatment breast cancer surgery decision serves as exemplar for the presentation of this approach.

Results: The system design goals were to make the program both didactic and entertaining, and the navigation and graphical user interface (GUI) as simple as possible. We structured the program into two major components: soap opera episodes with a didactic purpose seamlessly linked to Interactive Learning Modules (ILMs) for enhancing the content of the soap opera episodes. Both the dramatizations and the ILMs were adapted to viewer's characteristics. The soap opera storyline included background processes identified to be necessary for making an informed breast

cancer treatment decision. Overall, the learning environment was fully narrated and designed to “walk” women through the process of making an informed breast cancer treatment decision.

Conclusions: Designing decision-aid tools that provide personalized messages, that are educational, yet entertaining, and that are especially designed to aid poor readers and those with limited computer skills is a complex proposition, yet it is a promising strategy for aiding this population when making medical decisions.

6C2

Development and pilot testing of two decision aids for genetic testing for hereditary cancer

Wakefield C, Meiser B, Homewood J, Kirk J, Peate M, Tucker K et al.

(1) Department of Psychology, Macquarie University, NSW, Australia; (2) Department of Medical Oncology, Prince of Wales Hospital, Randwick, NSW, Australia; (3) Familial Cancer Service, Westmead Hospital, Westmead, NSW, Australia.

Background: The demand for genetic counseling and genetic testing for individuals with a family history of cancer is considerable and increasing. Current best practice in genetic counseling may not allow a full deliberation of the consequences of decisions about genetic testing for cancer susceptibility. Literature on risk perception in high-risk breast cancer families reveals persistent over-estimation of risk, even after counseling. In this study, two decision aids were designed to assist people to participate actively with practitioners in deciding about genetic testing for cancer susceptibility.

Methods: Stage 1. Two decision aids for individuals considering genetic testing for breast/ovarian cancer and hereditary non-polyposis colorectal cancer (HNPCC) susceptibility were developed and pilot tested. The aids were developed by a team of experts guided by expectancy-value decision theories and the literature on risk communication and the psychological impact of genetic testing. Stage 2: Involves two concurrent randomised controlled trials of the decision aids, each with 120 patients, assessed by questionnaire at two time points after genetic counseling.

Results: Stage 1. Two 20 page full-colour decision aids were developed using varying formats of words, numbers, graphs, pie-charts and illustrations. Most of the 40 participants who participated in the pilot phase reported that the amount of information and length was ‘about right’ in each decision aid. Participants also reported that the booklets were clearly presented, informative, easy to read, and useful. In general, participants reported that it had improved their understanding of genetic testing. Stage 2 of the study is on-going.

Conclusions: Preliminary results of the breast and ovarian cancer arm of the trial show that most women found the decision aid increased their understanding of the genetic testing process and of the impact of genetic testing. The booklet was helpful to them in reaching a decision.

6C3

Pilot Study of a Decision Aid for Patients with Metastatic Colorectal Cancer

Leighl N, Butow P, Tattersall MHN, McJannett M, Clarke S, Boyer MJ, Barratt A, Glare P, Princess Margaret Hospital GI Medical Oncology Site Group

Princess Margaret Hospital, University of Toronto, Canada; Medical Psychology Research Unit, University of Sydney; Sydney Cancer Centre/Royal Prince Alfred Hospital, Australia.

Background: We have developed a decision aid to assist patients with metastatic colorectal cancer in making a treatment decision about adding chemotherapy to supportive care. We previously demonstrated the aid improves patient understanding and in a small number of newly diagnosed patients, did not appear to increase anxiety. We piloted the aid in a larger group of Canadian patients, newly diagnosed with metastatic colorectal cancer.

Methods: Patients with newly diagnosed metastatic colorectal cancer referred to a medical oncologist at a major Canadian cancer centre were approached to participate. Patients reviewed a shortened version of the aid (flip-chart) with their doctor, and later the decision aid booklet and accompanying soundtrack (DA). Patients completed questionnaires prior to the consultation, and after the consultation and DA review.

Results: Eighteen patients participated; the median age was 60 years, 8 were male, most good performance status (PS 0 or 1), and 10 received prior adjuvant chemotherapy. Half were of non-English speaking background. Most (78%) decided to pursue chemotherapy. All patients wanted as much information as possible, one third desired to share decision-making with their doctor, while half felt the doctor should lead the decision-making process. Patients demonstrated evidence of clear understanding of prognosis and chemotherapy effects after reviewing the decision aid, although several overestimated the chance of severe chemotherapy toxicity. Patients were anxious before (mean 41.5) and after the consultation (mean 39.4), but anxiety levels did not increase as a result of the DA (mean change score -2.1, t17 2.56 p=0.02).

Conclusions: Patients with advanced colorectal cancer want full information, with at least some involvement in decision-making. The DA appeared to improve understanding of prognosis and chemotherapy effects without increasing anxiety in newly diagnosed colorectal cancer patients. A randomized trial to assess the DA's impact on understanding, treatment decisions, decisional conflict, anxiety and satisfaction is underway.

6C4

A decision aid for patients with metastatic colorectal cancer deciding between supportive care and supportive care plus chemotherapy

Butow P, Leigh N, Tattersall MHN, Shepherd H, Clarke S, Beale P, Wilkin N, Horvath L

University of Sydney; Princess Margaret Hospital, Toronto; Concord, Westmead and Royal Prince Alfred Hospitals, Sydney

Background: We developed a decision aid (DA) to assist patients with metastatic colorectal cancer to decide between supportive care, and supportive care plus chemotherapy. We are evaluating its impact on patient: a) understanding of prognosis and treatment options; b) anxiety; c) satisfaction with the consultation; d) decisional conflict; e) management decisions.

Methods: A randomised controlled trial of standard care versus provision of the DA is underway in Sydney, Australia and Toronto, Canada. In the DA arm a shortened version of the DA (a flip-chart) is used during the first consultation with the medical oncologist and patients are given the DA booklet to take home. Participants complete questionnaires prior to and immediately after the initial consultation, and 2 and 4 weeks after the decision has been made. Data are currently available for the baseline and 2nd questionnaire only.

Results: 119 patients have been recruited to date, 63% male, on average 62 years (19-85). 66% preferred maximum information. 44% preferred shared decision making, but many (35%) preferred the doctor to take the leading role. Younger patients wanted more detail (chi sq=13.7, p<0.01) but not more involvement in decisions. Anxiety levels were high prior to (mean=40) and after the consultation (mean of 37.5). Patients responded incorrectly to many of the knowledge items (scoring on average 8 out of 16). Patients commonly over-estimated the likelihood of severe side effects from chemotherapy (77%), and did not know the 12 month survival statistics with chemotherapy (68%). After the consultation 7.5% of patients were leaning towards supportive care, 20% were unsure and 72.5% wanted chemotherapy.

Conclusions: The majority of patients with metastatic disease want full information and to be involved in decision-making. Misunderstanding of treatment options is common following an initial consultation with an oncologist. A decision aid will assist this group of patients.

6D1

Creation of Lung Cancer Caregiver Planning Aids Within an Online Support System

Kopetsky DJ, Bernard LL, Gustafson DH, Cleary JF, McTavish FM

University of Wisconsin - Madison

Background: The Comprehensive Health Enhancement Support System (CHESS) is a computer-based health resource designed to educate and equip people facing a health crisis, particularly cancer. With funding from the National Cancer Institute and the National Institute of Nursing Research, CHESS has recently expanded its focus to

serve both patients and their informal caregivers. CHES aims to improve patient quality of life and symptom distress, and reduce caregivers' negative affect and difficulty of bereavement adjustment. The nature of cancer caregiving involves decisions that can be distressing. The decision and planning aids are designed to ease this process in hopes to reduce decision-related distress.

Methods: The CHES decision and planning aids are one among many tools available to patients and caregivers. The development of these aids came from a comprehensive literature review, focus group consisting of a multidisciplinary palliative care team, and prototyping with cancer caregivers. These sources helped us realize the need for a structure including both an informed decision and follow-up to help activate a decision. Our resulting theoretical model consisted of a preliminary assessment/feedback stage, user education, and planning.

Results: We plan to describe the methodology leading to our model for psychosocial decision/planning aids. We will present challenges of applying our general model to multiple illness-related decision topics. Specific examples from our developed aids will be highlighted.

Conclusions: Initial caregiver review has revealed a positive response to both the general framework and specific content of our decision and planning aids.

6D2

Demonstration of the Adjuvant Survival Presentation for breast cancer patients

Byers A, Belkora J

University of California, San Francisco, Stanford University

Background: For many cases of early stage node-negative breast cancer, there is no consensus about whether patients should take adjuvant therapy. This decision is often difficult because it involves trading off small benefits and harms. Various decision aids focus on adjuvant therapy for breast cancer, but we identified a gap because none presents individualized survival estimates in a patient-friendly interface. Specifically, Whelan's Decision Boards focus attention on recurrence, while Ravdin's Adjuvant! is intended for use by oncologists. We therefore proposed to build a decision aid that helps our oncologists explain how adjuvant treatment options will affect patient survival prospects and quality of life.

Methods: We have completed three phases of our CReDITED development process in creating the decision aid. We first Chartered the project (articulating reasons to proceed, identifying stakeholders); then documented stakeholder Requirements, and Designed a prototype.

Results: Stakeholders (especially patients and providers) requested a teaching tool that could be used during the oncology visit. Our resulting Adjuvant Survival Presentation (ASP) can be used interactively during the consultation to facilitate the discussion of choosing adjuvant therapy. The oncologist uses it to characterize the patient's situation and available treatment choices. The ASP then incorporates ten-year survival estimates from Adjuvant! (www.adjuvantonline.com) for each treatment option including no further treatment. The presentation concludes with a table contrasting the survival benefits and potential harms from treatments. Several stopping points have been incorporated to cater to patients with different information seeking attitudes. We are conducting in-depth case studies with patients actively making adjuvant therapy decisions, and preliminary results show potential to improve risk perception and decisional conflict.

Conclusions: In completing our CReDITED process, we will be conducting a pilot study of the decision aid, to be followed if appropriate by a multi-site randomized controlled trial.

6D3**Using an innovation process to develop a decision aid**

Weymiller A, Whitt I, Montori VM

Knowledge and Encounter Research Unit, Mayo Clinic College of Medicine, Rochester, MN

Background: Development of decision aids (DA) is informed by decision making frameworks and other theoretical concerns (e.g., risk presentation, numeracy). Finalized products are then tested and published. However, few if any DA are used routinely in practice. An innovation process, adapted from industrial design, can help connect with the users at all stages of development and may facilitate DA designs that get used in real clinical practice. We sought to develop a DA that informs the use of statins (cholesterol and cardiovascular risk lowering medications) in patients with diabetes. This is a simple decision that is often not discussed but rather comes as "doctors orders" to the patient with minimal investment of time. Further, up to 50% of patients discontinue this medication in the next 2 years.

Methods: The steps followed included: (1) systematic review of RCTs of statins in patients with diabetes; (2) field observation of patients making choices in healthcare and non-healthcare settings; (3) field observations of diabetes encounters; (4) brainstorming for opportunities ("how might we...") from stories following the observations; (5) synthesis of opportunities and prioritization; (6) brainstorm of solutions to top opportunities; (7) synthesis of solutions and priorities; (8) fast and frugal prototypes with extensive user feedback; (9) formal testing (RCT).

Results: The "design challenge" that inspired the process was How do clinicians and patients share treatment information to make decisions consistent with patients values and preferences? We collected over 46 opportunities and 112 solutions. As of January 2005, we have developed 3 prototypes (booklet, web, single page) and we have received extensive feedback from patients and clinicians.

Conclusions: An innovation process adapted from industrial design can be used to develop DAs. Whether this process can lead to DAs that are more likely to improve decisional outcomes and be used in clinical practice remains to be determined.

6D4**Criteria for assessing the quality of decision aids**

Kasper J, Lenz M

Unit of Health Science and Education

Background: There is an ongoing discussion concerning quality assessment of decision aids. Trials using single outcome measures are not sufficiently meaningful to evaluate decision aids as they are complex interventions. Complexity is to be considered both regarding the development process and the various effects of those interventions. The wide range of possible solutions of a decision aid development for the same health decision requires particular regard to the viability of each single step. Quality criteria are to be handled as dynamic criteria whose relevance and importance fluctuates between different solutions of a decision aid.

Methods: Based on a systematic search, we developed an orientation frame for the appraisal of decision aid. We call it PROUD, a Reviewer's Orientation Under Discussion. It guides the reviewer along the steps of development. 1. what to be aided? (indication), 2. what is a suitable method to intervene? (didactic strategy) and 3. how to realise the strategy? (design). PROUD emphasizes the need for a clarification of the didactic strategy within the decision aid, as it is the lynchpin of the development process and the explication of the intended mediating principle. It offers a criteria matrix as a flexible orientation. Each particular decision aid unfolds its pattern as the basis for assessment. PROUD acts as a decision aid on the level of the reviewing process.

Results: The English manual undergoes a stepwise validation process: theory building, modelling, exploratory studies, proving effectiveness, implementation. The process is in the stage of exploratory studies. Compared with CREDIBLE the tool is expected to enhance transparency of the reviews as well as interrater-reliability regarding the quality assessment of decision aids.

Conclusions: PROUD seems sufficiently structured to prevent arbitrary appraisal and flexible enough to meet the variety of the decision aid development processes. Such an orientation would ensure transparency and traceability of the reviewing procedure.

**ABSTRACTS
POSTER PRESENTATIONS**



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Stability and Change in Men's Benign Prostatic Hyperplasia (BPH) Treatment Preferences in Response to a Videotape Decision Aid

Wills CE, Holmes-Rovner M, Rovner DR, Lillie JA, Kelly-Blake K, Bonham V

Michigan State University

Background: Patterns of stability and change in treatment preferences in response to decision aids need to be better understood because of the influence they may have on treatment choices. As part of a study of men's responses to a BPH videotape decision aid, the sources, types, and frequency of preferences for BPH treatments were examined.

Methods: A sample of 160 men stratified by race (Black, White) and education (College Educated, Non-College Educated) completed a semi-structured interview while watching the videotape. The interview included assessments of treatment preferences before, during, and following the videotape.

Results: Most men initially and ultimately favored watchful waiting over other treatments, and 56.6% never changed their preference rank orders. Men's most frequently cited rationales for their preferences were BPH severity in context of treatment risk avoidance, treatment efficacy, and expert opinions on the treatments. A substantial subset of men (~43%) did change their preference rank orders at least once. The types, frequency, and specific patterns of preference shifting were not well-modeled by any study variable. Lesser education was modestly associated with higher likelihood of changing preferences ($r = -.30$, $p < .001$). The percent increase in BPH knowledge pre- to post-videotape was weakly associated with fewer non-dominant preference shifts ($r = -.19$, $p < .05$). As expected, conservatism regarding BPH treatment appeared to be influenced by context-specific factors, including new information introduced by the decision aid.

Conclusions: Counseling in a provider-patient partnership model should address both sources of variation in men's treatment preferences. Preference vacillation reflecting decisional conflict about treatment options may mark a useful process of engagement with decision aids that provide fuller exposure to treatment benefit/risk issues. Additional research is needed to understand the specific sources and patterns of preference changes.

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Using Information Technology to Enhance Patient Decision Support

Jacobsen MJ (1,2), Saarimaki A (1), O'Connor AM (1,2), Tait V (2), Drake E (1,2), Khangura S (1)

(1) Ottawa Health Research Institute; (2) University of Ottawa

Background: Two factors have a major influence on the provision of patient decision support: a) availability of decision support tools, and; b) practitioners' skills in supporting patient decision making. Web based strategies can be used to increase access to both decision support tools (decision aids and guides) and practitioner training.

Methods: In April 2003 the Ottawa Health Decision Centre, located within the Ottawa Health Research Institute of the University of Ottawa, launched a patient decision making web site (<http://www.ohri.ca/decisionaid>). The web site has resources available for patients, practitioners, educators, researchers and anyone interested in accessing decision aids or other decision support tools, or in developing skills in providing decision support. The web site includes a searchable directory of available quality evaluated decision aids identified as part of the Cochrane Systematic Review of Decision Aids, and a self-administered, self-paced 'Autotutorial: Training Practitioners in Decision Support'.

Results: Web site usage: The 2004 web logs were analyzed using WebTrends v6.1. During 2004, the site had 206,000 page views generating over 2 million hits. Almost 44,000 unique visitors accessed the web site, and almost 6,000 made return visits. The most frequently downloaded file was the paper-based Ottawa Personal Decision Guide, (downloaded >10,300 times), and the most frequently accessed web page is the Decision Aid Summary page, (viewed >28,000 times), describing the results of the Cochrane evaluation of the decision aid, and providing a link to the on-line version of the decision aid where possible.

Autotutorial: Training Practitioners in Decision: The Autotutorial, released in May 2003, was created with 9 sections covered topics ranging from the concept of decisional conflict to provision of decision support. In 2004, a 10th

section dealing with communication techniques for decision support was added. Each section is followed by a mini-quiz, with tailored feedback for formative learning. A final quiz provides summative evaluation. Comments from participants' satisfaction surveys have been used to improve and revise the Autotutorial. As of January 2005, about 150 practitioners have completed the Autotutorial, and many others have visited it. Primarily developed to train Masters and PhD students at the University of Ottawa, the Autotutorial has also been used in studies evaluating the quality of decision support provided by nurses in call centres in the US and Canada. Examples of quizzes, average scores and participants' comments from the satisfaction survey will be presented.

Conclusions: Web based access to decision support tools and training is an effective and efficient strategy that can contribute to improving the quality of decision support provided. The ability to collect web statistics, monitor the use of the decision support tools and collect information on practitioner use of the on-line training offered in the Autotutorial has provided direction for improving content and ongoing development.

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CHAIN Canada – Contact, Help, Advice & Information, Network

McGowan J, Santesso N, Grimshaw G

The Cochrane Effective Practice and Organisation of Care (EPOC) Review group/ Institute of Population Health, University of Ottawa

Background: Policy makers, researchers and health care professionals continually face difficult decisions about providing effective health care. These decisions should be informed by evidence, but often evidence does not reach them. To support evidence based decision making, knowledge needs to be transferred and exchanged between producers and users. Linking decision makers and researchers can facilitate this process.

Methods: The Canadian network initiative is led by The Cochrane Effective Practice and Organisation of Care (EPOC) Review group in collaboration with the Centre for Best Practice, Institute of Population Health, University of Ottawa. Members have access to CHAIN resources including a directory of contact details and self reported interests of other members. Members can contact other members for advice and to collaborate and share experiences. In addition CHAIN can be used for targeted 'push' of information to members via e-mail based upon their interests.

Results: To date CHAIN has been a UK resource, with less than 2% of members being based outside of Great Britain. The launch of CHAIN Canada in 2004 is an exciting new development. CHAIN provides a mutual support network and an informal virtual space where critical interfaces are propagated. The network facilitates knowledge sharing, creation and dissemination and builds relationships between users and researchers.

Conclusions: CHAIN has been reported¹ as a successful model for linking professionals, organisations, researchers, practitioners and policy makers; and supporting knowledge transfer and exchange for evidence based decision making.

References:

1. Russell J, Greenhalgh T, Boynton P, Rigby M. Soft networks for bridging the gap between research and practice: illuminative evaluation of CHAIN. *BMJ*. 2004 May 15;328(7449):1174.

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MMR vaccination decisions - a case of message framing

Abhyankar P, O'Connor DB, Lawton RJ

University of Leeds

Background: Individuals' choices about health options are influenced by the way those options are presented. Prospect theory has been used to explore these 'framing effects'. Within the health communication context, prospect theory predicts that messages highlighting the potential "gains" of performing a behaviour facilitates those

behaviours aimed at prevention of the disease. Alternatively, messages emphasising potential “losses” of not performing the behaviour are beneficial in encouraging behaviours that will detect a disease.

Aim: to test the effectiveness of a gain framed message in promoting MMR immunisation behaviour.

Methods: a between subjects design, wherein message frame formed the between subjects factor, was employed. Participants responded to a handout containing information on the diseases, the Mumps, Measles and Rubella (MMR) vaccine and either a positively or a negatively framed message.

Sample: 142 women aged 18 years and above.

Measures: Questionnaire to assess risk perception and anxiety before the intervention and attitudes towards MMR, perceived control over behaviour, perceived social norm, perceived efficacy of vaccine and intention to have MMR after the intervention.

Results: Loss-framed message led to greater intentions to vaccinate than the gain-framed message (Pillai’s trace = 0.51 $F [2, 139] = 3.735, p = .026$). Framing did not have any effect on attitudes, perceived behavioural control, perceived social norm and perceived vaccine efficacy suggesting that the effect on intentions was not mediated by these variables.

Conclusions: The findings are contrary to those predicted by prospect theory. Levin et al’s (1998) suggests that a loss-framed message is more effective when a goal-frame is used (i.e. message aiming to promote a single behaviour). Research is required to test whether this finding is replicated for parents choosing to have MMR in the ‘real-world’ setting.

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Using Information Technology to Evaluate Shared Decision Making in a Clinical Setting

Kearing S (1), Clay K (2), Maheu L (2), Collins ED (3), Moore C (3), Llewellyn-Thomas HA (1), O’Connor AM (4), Gallagher S (5), Chambers K (5), and Aman D (5)

(1) Dartmouth Medical School, Center for Evaluative Clinical Sciences, Hanover, NH; (2) Dartmouth Hitchcock Medical Center, Center for Shared Decision Making, Lebanon, NH; (3) Dartmouth Hitchcock Medical Center, Comprehensive Breast Program, Lebanon, NH; (4) University of Ottawa, Faculty of Health Sciences & Faculty of Medicine, Ottawa Health Research Institute, Ottawa, Canada and (5) BioInformatics, Dartmouth Medical School, Lebanon, NH

Background: The purpose of the Center for Shared Decision Making (CSDM) at Dartmouth-Hitchcock Medical Center (DHMC) is to provide patients with decision support. An effective decision support service in a busy clinical setting requires information systems that can meet the unique needs of multiple key players:

- The patient/provider dyad needs to record and summarize an individual’s clinical and decisional data.
- Clinical staff and researchers need a system that permits rapid aggregation and analysis of cohort data.
- The institution that houses the service needs performance measures that can contribute to overall monitoring and quality-assurance.

The objective of this presentation is to demonstrate the computer-based systems used by the CSDM to address these information management and reporting needs.

Methods: Using standard software and hardware, the Center for Shared Decision Making currently uses two distinct applications.

First, the CSDM database (CenterWorks) resides on a Microsoft SQL server® and is generic in scope. It captures a) patients’ demographic characteristics and visit information, b) stage and preferred role, treatment predispositions, and decisional conflict, c) type of decision support provided, and d) satisfaction.

Second, the Comprehensive Breast Program / Center for Shared Decision Making joint project use a web-based system. In this specialized study, longitudinal assessments of medical as well as decision-making data are captured for breast cancer patients.

Results: These systems allow for feedback of clinical and decision process data in real time at the individual level, as well as providing an accessible source of data for research and clinical reporting.

Conclusions: The information-system technology for integrating SDM and clinical care currently exists. The emergent data can yield valuable insights into the patient decision making process, the clinical skills involved in decision support, and the achievement of performance standards. The principles used to guide the design and implementation of the CSDM's electronic information system can be adapted for other clinical shared-decision making initiatives. Illustrative examples demonstrating interactive forms, database design, and sample reports can be presented on laptop computers during the poster session.

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Patient decision-making in clinical depression and reported satisfaction with practitioners

Bunn H, Jacobsen MJ, Whitelaw C, Ritchie L, McIntosh A, Fox J

University of Ottawa, Ottawa Health Research Institute, Royal Ottawa Hospital, Ottawa Hospital

Background: Recent trends suggest the need for increased involvement of psychiatric patients in health care decision-making. However, little is known about their preferences for participation in decision-making, the types of decisions they are making or how satisfaction with practitioners impacts on decision-making.

Methods: Report results of a survey of a convenience sample of 94 patients diagnosed with clinical depression recruited from 2 hospitals in Ottawa, Canada. Survey was based on the Ottawa Decision Support Framework.

Results: The most common decisions were medication related (37%). Participants (58%) reported high levels of decisional conflict due primarily to lack of support and insufficient information. Most participants (98%) expressed interest in being involved in decision-making with 38% wanting to share decision-making with their practitioner. 68% identified psychiatrists and 18% identified nurses as being involved in their decision-making.

Patient dissatisfaction with practitioners correlated with less perceived involvement in decision-making ($p<0.001$), higher levels of decisional conflict ($p=0.009$), higher support needs ($p<0.001$), higher knowledge needs ($p=0.003$), more values conflict ($p=0.016$), less satisfaction with decision-making ($p<0.001$), and lower perceptions of effective decision-making ($p<0.001$).

High levels of decisional conflict were also related to less satisfaction with decision-making ($p<0.001$), and lower perceptions of effective decision-making ($p<0.001$).

Conclusions: Findings have relevance for clinicians who are trying to develop better ways to support psychiatric patients to make more informed decisions. The results of the project will be used to design an intervention to assist mental health practitioners to support patient decision making. The intervention will be tailored to modify the key factors contributing to decisional conflict in clinical depression.

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Early work on the CReDITED decision aid development process

Byers A, Belkora J

University of California, San Francisco, Stanford University

Background: Decision aids continue to proliferate in a variety of health fields as more evaluations demonstrate their value in improving shared decision making. As decision aids are increasingly implemented in software, a general development process that can be used for all types of decision aids, especially computerized decision aids, is needed to ensure quality and efficiency in development. We developed such a process, extending previously proposed processes that have narrower application.

Methods: We drew best practices from the decision aid, project management, product management and software development literature.

Results: We propose the CReDITED development process, consisting of six iterative phases. 1) Charter: articulate the reasons for embarking on the development project; 2) Requirements: determine and describe what stakeholders want; 3) Design: specify a prototype, obtain feedback, and make revisions; 4) Implementation & Testing: produce the decision aid; 5) Evaluation: assess the effectiveness of the tool; 6) Diffusion: distribute and maintain the decision aid. We have preliminarily validated the CReDITED process by using it to guide the development of a breast cancer adjuvant therapy decision aid and to adapt another aid for use with minorities in rural areas.

Conclusions: We have found CReDITED to be valuable in at least three ways. First, it provides a roadmap for development that allows us to budget and allocate resources appropriately. Second, the process allows us to communicate where we have been and where we are heading with stakeholders whose input we need. Third, the process results in higher quality decision aids than our previous efforts because it embodies quality management principles such as building in frequent feedback and opportunities for course correction. We will continue to test CReDITED in other projects and report further refinements.

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Rules-of-Thumb Used for Statin Decision Making: Eliciting Patients' Decision Heuristics

Crouch M, Whitney S

Baylor College of Medicine

Background: Acceptance, persistence, and adherence rates are low for prescribed HMG-CoA reductase inhibitors (statins), despite their demonstrated effectiveness for preventing cardiovascular events. Gigerenzer's work in bounded rationality and decision heuristics suggests that people use rule-of-thumb (mental shortcut) to simplify the complexities of rational decision making. Eliciting and discussing patients' decision heuristics could help care providers better understand patients' frame of reference and decision-making priorities as they try to engage them in shared decision making.

Methods: Audiotaped, semi-structured, individual interviews (20) and focus groups (2) with adult patients with hypercholesterolemia to elicit their attitudes and beliefs about statin therapy. Some were taking or had taken a statin, others had never taken any cholesterol medicine. Qualitative analysis of interview transcripts and recursive discussion of findings identified putative rules-of-thumb (decision heuristics) for deciding about statin therapy.

Results: Almost all interviewees and focus group participants identified concern about adverse side effects from long-term statin therapy as their foremost consideration when deciding about statin therapy. This concern appeared to dominate decision making to a degree that is disproportionate to the low probability of the feared negative outcome. Putative statin decision-making heuristics (rules-of-thumb) identified (in descending frequency of appearance) were: "Avoid Harm-by-Commission", "What, Me Worry?", "Act to Avoid Harm", "Doctor Knows Best", "Natural is Better", "Won't Hurt to Try It", and "What's the Use?"

Conclusions: Many patients regarding statin therapy focus heavily on potential side effects. Consistent with Gigerenzer's work in bounded rationality and decision heuristics, such individuals tend to use "Avoid Harm-by-Commission" or "What, Me Worry?" (about heart attack)" as an overriding rule-of-thumb to simplify the complexities of rational statin decision making. Patients tend to use mental shortcuts (decision heuristics) that allow them to decide about statin therapy quickly and decisively, using a minimal subset of available information. Care providers might improve statin acceptance and persistence by eliciting and discussing patients' preferred decision heuristics in the course of shared decision making. Challenging the erroneous assumptions implicit in certain decision heuristics could potentially alleviate unrealistic or exaggerated patient concerns. Providers attuned to patients' decision heuristics might be able to prompt some patients to use a different prevailing rule-of-thumb or a more deliberative shared decision process.

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Prevention of cardiovascular diseases by means of a decision support tool for sharing the medical evidence with patients, a clustered randomized controlled trial in primary care

van Steenkiste B, van der Weijden T, Stoffers H, Kester A, Timmermans DRM, Rinkens P, Grol R

Department of General Practice, Centre for Quality of Care Research, Care and Public Health Research Institute (CAPHRI), Maastricht University, Maastricht, The Netherlands; VU University Medical Centre, Department of Social Medicine, Amsterdam, The Netherlands; Department of General Practice, Maastricht University, Maastricht, The Netherlands; Centre for Quality of Care Research, Radboud University Nijmegen Medical Centre, The Netherlands; Department of Methodology and Statistics, Maastricht University, Maastricht, The Netherlands

Background: Cardiovascular preventive guidelines recommend optimising patients' health status regarding important risk factors. However, acknowledging patients' (mis)conceptions and preferences in general practice is not optimal. Risk perception seems to be a key factor in motivation for behaviour change.

Objective: to assess the effect of a decision support tool on the patients' risk perception and self-reported lifestyle.

Methods: Design: cluster randomized trial

Participants: 34 general practitioners (GPs). Each GP was instructed to include 30 consecutive patients' with whom cardiovascular risk was discussed.

Intervention: decision support tool: a booklet explaining the patients' absolute cardiovascular risk in 10 years in natural frequencies, including comparative data on other patients. Patients read the booklet at home and were invited to return to discuss their risk and preferences for risk management.

Measurements: appropriateness of risk perception (perceived risk related to actual risk) and self-reported lifestyle regarding smoking, physical activity, alcohol use and obesity. The GPs registered data after each consultation. The patients completed questionnaires at baseline and at 6 months.

Results: In the intervention arm 276 consultations were recorded and 214 in the control arm. In the intervention group 190 (57%) patients returned for a second consultation to discuss their risk. Multi-level regression analysis revealed no significant effect of the intervention on patients' risk perception, but there was an effect on lifestyle. Men in the intervention group significantly increased their physical activity compare to men in the control group (OR 3.8, 95% CI 1.7 – 8.7).

Conclusions: Although the decision support tool was not ruled out in an optimal way and did not affect risk perception, there seems to be a beneficial effect of such tool on the patient's self-reported lifestyle. Further research is needed to confirm these findings.

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Women's decision making needs related to treatment decision for recurrent ovarian cancer

Jolicoeur L (1), O'Connor AM (2), Graham ID (2), Hopkins L (1)

(1) The Ottawa Hospital; (2) The Ottawa Health Research Institute and The University of Ottawa

Background: It is estimated that 2,600 women were diagnosed with ovarian cancer in Canada in 2003 and 1,550 had died of this disease during the year. Despite response rates to primary treatment of between 70 and 80%, 70% will recur within 24months.

The management of advanced ovarian cancer has shifted from a palliative approach to that of a chronic disease due to increasing chemotherapy options for recurrence. Randomized controlled trials have failed to demonstrate clear evidence that any single option provides superior long-term survival, response rates or better quality of life. It has been suggested that in the absence of such evidence, treatment decisions should be based on patient preference.

Objective: To describe the decision making needs of women with ovarian cancer related to treatment of recurrent disease.

Study Method: A descriptive, cross-sectional design based on needs assessment principles using the service receiver approach was used. Data were collected from face to face interviews and health record reviews. A questionnaire was developed based on the Ottawa Decision Support Framework using a standard template developed by Jacobsen and O'Connor (1998). Descriptive and qualitative analyses were performed.

Results: Preliminary results indicate that women did not report experiencing decisional conflict related to decisions for treatment of recurrent ovarian cancer. Women also perceived that they did not have treatment options. Factors influencing decisions included perceptions of the decision, perceptions of others involved in the decision, and resources available to women. In addition, hope appears to be a determinant in the decision making of this patient population.

Conclusions: Women who have made recent decisions about treatment do not report major decisional difficulties. Factors impacting decisions include perception of the decision including hope, perception of others involved in the decision, resources available to women. Prospective studies at the point of decision making are needed to confirm findings.

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Measuring the usability and usefulness of online patient decision aids: A demonstration of methods

Brehaut JC, O'Connor AM, Tugwell P, Lindgaard G, Santesso N, Cranney A, Graham ID

Ottawa Health Research Institute

Background: As the Internet becomes more important for providing health care information to consumers, decision aid developers are increasingly producing or adapting their tools for the Web. To date, however, there has been little systematic effort to discover how best to make use of this medium when providing patient decision support. The computer usability literature distinguishes between usability (easy to use, find, navigate, etc.), and usefulness (the right information for a specific decision maker) of online information. We will demonstrate a number of methods and techniques for studying the usability and usefulness of online patient decision support, in the context of decision support tools developed for patients with musculoskeletal disorders.

Methods: The multimedia presentation will demonstrate a number of qualitative and quantitative techniques, drawn from the computer usability and naturalistic decision making traditions, being used in the Ottawa Patient Decision Support Laboratory. The problems and benefits associated with conducting web-based surveys of decision support users will be discussed, as will the role of expert user evaluations. We will demonstrate how the cognitive walkthrough, a standard usability inspection method used to identify components of a task, can be extended to develop a coding scheme (goals, subgoals, and actions required) against which the performance of individual users can be compared. We will also demonstrate how a portable usability laboratory (or lower-tech, less costly versions thereof) can allow access to a rich variety of data sources, including user session transcripts, experimenter field notes, video of the user, and video screen captures of the user session. Coding this rich variety of information at different levels of fidelity will be discussed and demonstrated.

Conclusions: There has been little work done on how patient decision support can most effectively be presented on the Web. We will demonstrate a variety of empirical methods designed to enable decision support researchers to address this gap in the literature.

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The assessment of depressive patients' involvement in decision making in audiotaped primary care consultations

Loh A, Simon D, Hennig K, Härter M

University Hospital, Department of Psychiatry and Psychotherapy

Background: The involvement of depressive patients in primary care is supposed to enhance treatment acceptance, adherence and clinical outcome. Little empirical information is available about the extent to which it is possible to involve patients who are significantly impaired in their communication and decision-making abilities.

Methods: 20 consultations between depressive patients and 9 General Practitioners were audiotaped. The extent of patient involvement in decision-making was assessed by two independent raters using the OPTION scale. New diagnosed patients with mild and moderate depression were enrolled. In addition, the duration of the communication sequences concerning a set of 6 decision-making skills (problem definition, equipoise, options and risk information, enabling patients to explore, decision making, and review arrangements) was analysed. Interrater concordance was about 67%, and the interrater intraclass coefficient (ICC) was .54.

Results: Analyses of the OPTION scales showed extremely low levels of patient involvement in medical decisions. The means of the OPTION items were between 0.0 (equipoise) and 1.1 (reviewing the decision), in a possible range from 0 to 4 which revealed strong floor effects. The analyses of the duration of the communication in shared decision-making skills showed a wide range between a mean of 762.2 sec (problem definition) and a mean of 0.8 sec (equipoise). The interaction in the remaining skills last between 31.4 and 60.2 seconds. Mean duration of all consultations was 16.1 minute.

Conclusions: Physicians used the majority of their time to identify and define the patient's medical problem. The amount of consultation time requested for each step of the decision making process requires additional research. Further shared decision making interventions should emphasize the importance of a set of different communication skills to enhance General Practitioners' decision making competences.

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Who utilizes decision aids? Findings from a randomized trial of two patient directed prostate cancer screening decision support interventions.

Partin MR, Nelson D, Flood AB, Wilt TJ

The Center for Chronic Disease Outcomes Research at the Minneapolis VA Medical Center, the University of Minnesota, and the Center for the Evaluative Clinical Sciences at Dartmouth Medical School

Background: In the context of a RCT to provide unsolicited decision aids to men eligible for prostate cancer screening, we examined who actually used a pamphlet versus video aid, and how selective utilization affected study outcomes.

Methods: 1152 male veterans age 50+ from 4 VA medical facilities were randomly assigned to: mailed pamphlet, mailed video, or usual care (control). Materials were mailed two weeks prior to primary care appointments, and outcomes assessed by telephone survey one week after appointments. Analyses examined: (1) use of materials by intervention and impact of patient characteristics on use, and (2) the impact of intervention use, adjusting for patient characteristics, on a ten-item knowledge index.

Results: 56% of video and 50% of pamphlet subjects reported using the materials. Who used the pamphlet did not vary by patient characteristics. Use of the video was higher depending on education, previous prostate problems, and family history, and lower with prior abnormal PSA. In intent-to-treat analyses, both the video and pamphlet intervention groups had significantly higher knowledge scores relative to the control group (7.75, 7.45, and 6.97, respectively). Reassigning groups based on use (with non-users moved to the control group) roughly doubled the differences in knowledge scores between both intervention groups and the control group. After adjustments for selective utilization by patient characteristics, the differences in knowledge scores relative to the control group increased by about 50% for both interventions.

Conclusions: Utilization of the interventions was low, and selectivity of utilization varied by the type of aid. While adjusting for whether the materials were used and who used them did not substantively alter our conclusions regarding the impact of the interventions on knowledge, these findings suggest that future efforts to broadly implement decision aids may need to offer a variety of approaches, and incorporate creative strategies to enhance utilization, to reach all population subgroups.

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Assisting Physicians with Decision Making for Children with Motor Coordination Problems

Gaines BR, Egan M, Missiuna C, McLean J, De Laat D

Children's Hospital of Eastern Ontario, University of Ottawa, Canchild Centre for Childhood Disability Research/McMaster University

Background: Children with developmental motor problems present to their doctors, as a riddle in diagnosis and a challenge for management. Approximately 5-6% of school age children display characteristics consistent with 'Developmental Coordination Disorder' (DCD), yet DCD remains a challenging diagnosis to make. This disorder negatively affects a child's ability to successfully complete everyday self-care activities and academic tasks. Children do not 'outgrow' DCD and the impact of continually lagging behind their peers can lead to anxiety, social withdrawal and physical inactivity. Accurate diagnosis is needed to help families to put helpful supports in place for their children, at home, in school and during community activities.

Methods: In this poster we describe our current study that aims to improve primary care management of DCD in the Ottawa area through interdisciplinary education and assessment. A range of knowledge exchange activities are provided including written materials and resources, workshops with small groups of physicians, an interactive website, and academic detailing. As well, an occupational therapist provides physicians with the results of motor, cognitive and functional screening tools to allow shared decision making about whether the child meets the diagnostic criteria for DCD.

Results: Evaluation of the decision making process between the occupational therapist and primary care physicians enrolled in the project is ongoing. Description of the process will include: two case examples of physicians' involvement in project, the academic detailing by the occupational therapist and the resultant shared decision making regarding the diagnostic process.

Conclusions: Interdisciplinary care in the primary health care setting has the potential to enhance primary care for children with motor coordination problems. The successes and lessons learned from the implementation of our model will be highlighted.

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Choice of Risk Representation to Enable Diabetes Decision-Making

Whitt I, Chung JA, Noble K, Vallena A, Alam F, Adams A, Weymiller A, Montori VM

(1) Mayo Clinic College of Medicine, (2) University of Western Ontario, (3) University of Toronto, (4) York University, (5) McMaster University

Background: The most adequate approach to convey risk information to enable informed patient choices is unknown. We set out to test patient understanding of risk information when the risk for common adverse effects of competing hypoglycemic treatments (which agent is associated with greater risk for weight gain, glyburide or metformin, and which agent is associated with greater risk for lower extremity edema, rosiglitazone or metformin) is presented using either natural frequencies (i.e., "of 100 people, 5 will suffer an adverse event"), or ordered faces (a graphical grid of 100 faces, 5 sad and 95 happy).

Methods: We surveyed 139 patients (mean age 54 (SD 16), 51% women, 81% completed high school, mean A1c 7.76 (SD 1.44), normal cognitive function) attending the diabetes clinic at McMaster University. We also assessed whether their understanding with each format was related to participant age, gender, education, or global numeracy (Schwartz-Woloshin tool).

Results:

	Correct in both formats	Natural freq	Ordered faces	Exact P values
All participants (n=139)	105 (76%)	111 (80%)	120 (86%)	0.07
Age>65 (n=35)	25 (71%)	25 (71%)	29 (83%)	0.1
Without complete high school (n=24)	10 (42%)	12 (50%)	17 (71%)	0.2
Innumerate patients (n=107)	74 (69%)	80 (75%)	88 (82%)	0.1

The Table shows no significant differences in risk interpretation between presentation formats. Of the 28 who misinterpreted the natural frequency presentation, 15 (54%) correctly interpreted the ordered faces; of the 19 who misinterpreted the ordered faces, 6 (32%) correctly interpreted the natural frequency presentation. Younger (ANOVA $P=.04$) and numerate participants with complete high school education (both $\text{Chi}^2 P<.0001$) correctly interpreted risk regardless of format (no gender differences).

Conclusions: Among well-educated patients with diabetes, ordered faces and natural frequency presentations of risk yielded similar understanding; ordered faces, a graphical representation, may yield better understanding among the elderly, the less educated, and the innumerate. These results may contribute to the design of decision aids to enhance evidence-based patient choice, particularly among disadvantaged minorities.

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Models for Integrating Decision Support into Clinical Care: The Dartmouth Experience

Clay K (1), Brooks WB (5), Cochran N (4), Collins ED (2), Fowler FJ (7), Mimnaugh D (8), O'Connor AM (3), O'Connor MA (8), Tomek I (6), Weinstein J (6), Abdu W (6), Wennberg J (8), Llewellyn-Thomas HA (8)

(1) Dartmouth Hitchcock Medical Center, Center for Shared Decision Making, Lebanon, NH; (2) Dartmouth-Hitchcock Medical Center, Comprehensive Breast Program, Lebanon, NH; (3) University of Ottawa, Faculty of Health Sciences & Faculty of Medicine, Ottawa Health Research Institute, Ottawa, Canada; (4) Veterans Affairs Medical Center, Section of Ambulatory Care, White River Junction, VT; (5) Dartmouth-Hitchcock Medical Center, Section of General Internal Medicine, Lebanon, NH; (6) Dartmouth-Hitchcock Medical Center, Department of Orthopaedics, Lebanon, NH; (7) Foundation for Informed Medical Decision Making, Boston, MA; (8) Center for the Evaluative Clinical Sciences, Dartmouth Medical School, Hanover, NH

Background: The Center for Shared Decision Making (CSDM) at Dartmouth-Hitchcock Medical Center (DHMC) is applying a consistent set of practice, monitoring, and evaluative principles to the design and implementation of four models for incorporating decision support into clinical practice. These four models are: (1) hospital-based referral center; (2) stand-alone specialty/primary care practices; (3) integration across multiple practices in one hospital; and (4) integration into a network of hospitals.

Methods: (1) The CSDM referral center opened in 1999. Patients are referred to a central location to borrow decision aids (PtDAs) and receive decision support counseling.

(2) Implementation in the Comprehensive Breast Program began in early 2004. In a pre-surgeon appointment, women with invasive breast cancer complete questionnaires - before and after viewing a video-based PtDA about surgical options – capturing decision support needs, knowledge, values, and treatment preferences. Each woman receives a printed summary report, as does her surgeon.

(3) The designs of parallel integrated models of decision support in the Department of Orthopaedics for spine, hip, knee and in Primary Care are under way.

(4) A similar integrated model of decision support in 2 community hospitals is under way.

Results: Data from the breast cancer model imply that "[i]ntegrating decision support with clinical care is operationally feasible and yields benefits for patients and physicians. Overall, the...transition to the new protocol has been nearly seamless...The video and report help prepare...patients and physicians for the initial consultation. With further testing this process can be adapted to a variety of health conditions."

Conclusions: Successful integration of decision support in multiple settings requires flexibility (a process adaptable to the unique characteristics of each site) and consistency (using decision aids and a framework of core decision process quality measures and decision-specific knowledge/values/preferences measures).

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Methods for Integrating Decision Support into Clinical Care: The Dartmouth Experience

Clay K (1), Collins ED (2), Moore C (2), Weinstein J (4), O'Connor AM (3), Jacobsen MJ (3), Llewellyn-Thomas HA (5)

(1) Dartmouth-Hitchcock Medical Center, Center for Shared Decision Making, Lebanon, NH; (2) Dartmouth-Hitchcock Medical Center, Comprehensive Breast Program, Lebanon, NH; (3) University of Ottawa, Faculty of Health Sciences & Faculty of Medicine, Ottawa Health Research Institute, Ottawa, Canada; (4) Dartmouth-Hitchcock Medical Center, Department of Orthopaedics, Lebanon, NH; (5) Center for the Evaluative Clinical Sciences, Dartmouth Medical School, Hanover, NH

Background: There is convincing evidence that patient decision aids (PtDAs) improve decision quality in preference-sensitive clinical situations. However, implementing widespread use in clinical settings remains challenging. Barriers to using PtDAs include a) lack of patient and physician awareness, b) lack of access, and c) lack of motivation and financial remuneration to include decision aids as a standard of care. The Center for Shared Decision Making (CSDM) at Dartmouth Hitchcock Medical Center (DHMC) has piloted a framework for systematically integrating decision support into clinical care.

Methods: The CSDM uses the following stepwise framework:

Identify a clinical champion(s).

Perform needs assessment interviews with clinicians and patients to determine the decision support needs of a clinical section.

Add value for patients and clinicians by improving patient knowledge, gathering data for clinicians about their patients, providing summary report feedback, and using real-time feed forward and practice improvement techniques.

Map the current flow of care to include data capture and decision support tools without adding work in the clinical practice. Use general as well as condition-specific core decision making modules to standardize the process within the institution.

Results: This approach has been implemented in the DHMC Comprehensive Breast Program. It is currently under way in two Orthopaedic specialty sections and two General Internal Medicine practices.

Conclusions: We have successfully integrated decision support into clinical care for breast cancer patients, by designing an automatic process that occurs mostly behind the scenes and results in consistent decision support offered to patients across all providers. Our goal is to incorporate these technologies in other medical and surgical disciplines.

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Breast Cancer Treatment Decision Making: Does the Sisterhood of Breast Cancer Transcend Culture?

Wescott P, Reifler E, Sepucha KR, Park E

The Foundation for Informed Medical Decision Making, Boston, Massachusetts

Background: Disparities in health care for underserved populations have led to the concern that there may be problems in the quality of care and the opportunity for shared decision making available to these patients. We examined whether a decision aid for breast cancer patients should be targeted for different ethnic/racial groups.

Methods: We analyzed the appropriateness of a video tape from the Foundation for Informed Medical Decision Making entitled Early Stage Breast Cancer: Choosing Your Surgery. We conducted 8 focus groups (from March to October 2004) with breast cancer patients who could evaluate the video by reflecting back on their experience of making this decision. These patients came from four demographic groups: African American women, Hispanic women, rural women and a comparison group of white women with some college education, and all had made the surgery decision regarding treatment for early stage breast cancer. All groups were audio-taped and transcribed, and thematic content analysis was performed by 3 coders.

Results: Across demographic groups, we were struck more by similarities than differences. Every group had concerns about getting information that they could trust and that was easy to understand. In general, when differences appeared in how women coped with cancer, sought support, experienced treatment, or responded to the testimony of patients and physicians in our decision aid, individual characteristics were more prominent than group characteristics. One exception was the recognition that translating our tape into Spanish would be of enormous value for Hispanic women whose first language is not English, regardless of their education level. Other than that, there were few major group differences in response to the decision aid and none that would cause us to provide different tapes to different underserved groups. We heard across demographic groups that women identified more with patients who made a decision similar to theirs rather than with patients who happened to be of a similar race or cultural background.

Conclusions: In this study, we found little in the way in which early stage breast cancer patients experience decision making that seemed endemic to their cultural setting. We concluded that decision aids need not be targeted to specific ethnic groups. However, for Hispanic women for whom English is not their primary language, translation of tapes into a patient's first language is needed.

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Information and shared decision making in Dutch prostate cancer patients

Visser AP, Fischer F, Voerman B, Garssen B, Van Anandel G, Bensing J

Helen Dowling Institute: Centre for Psycho-oncology, Utrecht, Onze Lieve Vrouwe Gasthuis (OLVG), Amsterdam, National Institute for Health Service Research (NIVEL)+, Utrecht, NL

Background: Patient centeredness as represented by fitting information provision and shared decision making becomes more and more adopted in medical practice. However, this applies mostly for younger patient groups. The aim of this study was to determine Dutch prostate cancer (PC) patients' involvement in treatment decision making, and their satisfaction with the information supply on disease.

Methods: As part of a larger study on quality of life and psychosocial problems of men with PC, 187 patients, were recruited from 5 hospitals and the Dutch PC patient organisation. We used questions regarding patient satisfaction with information provision and treatment decision making, their role (autonomous, collaborative, passive) patients report to have had, during the decision making process. Furthermore, we investigated whether the patients' role was related to sociodemographic characteristics (age, having a partner, education, employment status) and medical aspects (type of treatment, existence of metastases).

Results: Most patients were satisfied with the information provision concerning the disease, the treatment options and possible side effects. To lesser extent they were satisfied with the information on receiving psychosocial counselling. Most patients felt they had had influence in the medical decision making (autonomous 18%; collaborative 60%; 22% stated that the doctor had made the decision alone. Patients who indicated to have had no

voice in the decision making and those who were unsatisfied with the information provision were less content with the decision making process. Analyses showed that the absence of the partner and being older was associated with less influence in treatment decision making and the discussion of only one treatment option.

Conclusions: Patient participation is associated with greater satisfaction with decision making, however older and single patients with PC tend to be less involved in the decision making process. These groups of patients need more attentions when assessing patient's preferences for involvement in treatment decisions for PC.

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Sexual Health Decision Making: Listening to Thai Youth

Doull M, O'Connor AM, Chuemchit M, Jacobsen MJ, Robinson V, Tugwell P, Sitti-Amorn C

Centre for Global Health, University of Ottawa, Ottawa; Clinical Epidemiology Program, Ottawa Hospital; Institute of Health Research, Chulalongkorn University, Bangkok Thailand.

Background: Globally, the sexual health of adolescents is a significant issue that is often overlooked or examined only from an 'adult' perspective. Through a brief exploratory study we attempted to understand the sexual health decisions that Thai adolescents are faced with, from their own perspective. Understanding the sexual health decisions that adolescents face will allow for the development of interventions that are relevant and responsive.

Methods: The objectives of this project were informed by the goals and needs of the Center for Research and Development of Sexuality Education (CRDSE), Institute of Health Research, Chulalongkorn University, Thailand. Specifically the objectives were: 1) To describe the decision making needs of Thai adolescents in the Bangkok area regarding sexual health decisions; 2) To describe the decision support needs of counsellors working with adolescents in the Bangkok area on issues of sexual health; and 3) To test the decision making needs assessment tools and concepts in Thailand.

The Ottawa Decision Support Framework (ODSF) formed the basis of this exploratory study. A questionnaire was developed based on this framework and administered via interviews to young Thai males and females as well as counsellors working in the area of sexual health in Bangkok, Thailand. A purposive sample (n=18) of adolescents was selected from two Bangkok secondary schools. The counsellor sample (n=10) consisted of counsellors working in the area of adolescent health who had completed the counsellor training program at Chulalongkorn University.

Data were analysed using descriptive statistics. Qualitative analysis was used to group similar responses in thematic categories. The results were then presented as frequencies in each theme or question response category.

Results: Results reveal significant sexual health decision making needs amongst this group of young people as well as a disconnect between the adolescents' perceived needs as identified by the adolescents themselves and by the sexual health counsellors. For example, counsellors identified abortion and issues around sexually transmitted infections and HIV/AIDS as most important whereas adolescents were more concerned about relationship issues, including sexual intercourse.

Conclusions: Despite the conception that young Thai people do not engage in independent decision making because of the traditional nature of the Thai family, the results reveal that in fact adolescents did identify sexual health decisions that they made independently. Thus by listening to adolescents we learned significant lessons that will inform future sexual health counsellor training programs at Chulalongkorn University, Thailand. These lessons include not only topical issues of importance to adolescents but what kind of resources and information they are looking for and who they feel should be involved in their decision making. Listening to adolescents has provided important insights that can now be used in the creation of relevant and useful sexual health interventions in Thailand.

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What information do patients select from an interactive CD-Rom on treatment options in breast cancer?

Molenaar S, Sprangers M, Oort FJ, Rutgers E, Luiten E, Mulder J, de Haes H,

Academic Medical Center, Dutch Cancer Institute, St. Anna Hospital (Geldrop), Medisch Spectrum Twente.

Background: To facilitate shared decision making, effective decision aids have been introduced in health care. How much, and which information patients select from an interactive decision aid on breast cancer was measured, and associations between patients' characteristics and information selection were explored.

Methods: The interactive decision aid was provided to 106 patients after an initial discussion with their surgeon about their diagnosis and treatment options. The information they selected from the program was registered into log files. These log files were analyzed by sociodemographic background, treatment preference, psychological functioning, decisional conflict, and decision style factors.

Results: Patients (n=97; 92%) used the interactive decision aid intensively. On average, patients spent almost 70 minutes searching for information and selected 21 information topics. Overall, treatment related information was clearly more often selected. The interactive format was found to facilitate differences in information selection between subgroups. Age, education, and decision style factors were associated with information selection. Decisional conflict, treatment preference and psychological functioning were not associated with information selection.

Conclusions: To conclude, patients' use of the decision aid may enhance the insight into their decision making process. The interactive breast cancer decision aid was utilized intensively by patients and appears to facilitate a match between patients' information needs and the provision of information.

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Gaps and opportunities in the maternal decision-making needs of HIV-positive women in Africa

Doull M, Robinson V, Cook L, O'Connor AM, Jacobsen MJ, Tugwell P

Centre for Global Health, University of Ottawa, Clinical Epidemiology Unit, University of Ottawa & Ottawa Hospital

Background: The objective of this review is to examine the evidence surrounding current maternal to child transmission interventions and to investigate women's practices and decision making needs regarding these interventions in the sub-Saharan African context. Specifically, attempts were made to identify opportunities and gaps in our knowledge of HIV positive women's decision making and outline areas where decision support activities such as "Health Coach" programs may be appropriate to improve self-care practices and the appropriate utilization of resources.

Methods: Considering the issue of MTCT and decision making a cascade of decisions was developed around which the literature review and synthesis was structured. The Ottawa Decisional Support Framework was used to assemble evidence of women's decision-making needs and to assess opportunities for reducing decisional conflict surrounding these difficult decisions. A search strategy was developed and various databases such as MEDLINE, EMBASE, PsycINFO were searched. For benefits and harms of each decisional outcome, we considered a Cochrane systematic review the highest level of evidence, followed by other systematic reviews, then randomized controlled trials (RCT).

Results: Several gaps in our knowledge about women's decision making in the context of pregnancy and HIV were identified. The availability of evidence varied for each decision however, significant gaps included: evidence around testing for ones status, advanced directives for self and child, disclosure (specifically the impact of), perceptions of antiretroviral use and data on termination of pregnancies.

Conclusions: Decision making as a concept was generally not addressed in the MTCT literature. Evidence regarding the perceptions of women and other regarding the various decisions was often not available and subsequently an important aspect of MTCT interventions neglected. Incorporating a multi-disciplinary decision-support framework may prove useful to promote women's autonomy and involvement in decision making for their health.

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Conflicts of decision making on prenatal testing in Japan

Arimori N, Aoki M, Horiuchi S, Arita M

St. Lukes College of Nursing, University of Tokyo

Background: The purpose of this study was to identify conflicts of pregnant women's decision making on prenatal testing by using the Japanese version of the Ottawa personal decision guide.

Methods: This is a descriptive study. The subjects were pregnant women seeking genetic counselling in an urban general hospital providing genetic counselling by an obstetrician in Japan. An investigator conducted a consultation by using the Japanese version of the Ottawa personal decision guide after the obstetrician's genetic counselling and collected data on the decisional conflict scale, self-esteem scale and demographics by interview.

Results: As a result, the subjects were 40 women with average age of 36.8 ± 3.4 , and gestation period of 13.4 ± 2.13 weeks. Of 40 women, 30 were primipara while 10 were multi-parous. There were 23 housewives.

At the initial visit, 22 women (55%) have already decided to undergo prenatal testing. As primary causes of hospital visit, older age was reported in 19 cases (48%), the NT value in 5 (13%), family's genetic reason in 5 (13%), after marker testing in 3 (7%), maternal risks in 3 (7%). The total number of options were 58 in the 4th step "comparative study of options" of the Japanese version of the Ottawa personal decision guide.

Advantages of most common "amniocentesis" included "able to know the fetal condition such as chromosomal disorders/21 trisomy by a definite diagnosis" in 25 cases, "able to be relieved if there is nothing wrong" in 11, and "able to be prepared" in 6. The disadvantages were reported as "miscarriage and infections" in 32 cases, "feeling guilty" in 2, "expensive" in 3, "maternal issues including pain" in 3 and "suffer if something is wrong" in 3. The 16 of 32 women made same decision as they have chosen before using balance sheet.

Conclusions: These results suggest that "comparative study of options" in the decision guide is useful for actual decision making.

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Perceptions des participants à l'Université du 3e âge face au Modèle d'Aide à la Décision d'Ottawa (MADÉO)

Blais J, Desmartis M, Légaré F, Turcot-Lemay L

Centre Hospitalier Universitaire de Québec - Hôpital St-François d'Assise - Université Laval

Contexte : Le Modèle d'Aide à la Décision d'Ottawa (MADÉO) vise à promouvoir la participation des patients à la prise de décision. L'étude avait pour objectif d'identifier les perceptions des participants à l'Université du 3e âge face au MADÉO.

Méthodes : Dans le cadre de l'Université du 3e âge, une formation médicale continue sur le MADÉO de 1.5 hres a été adaptée. Avant la conférence, les participants ont complété une Échelle de Conflit Décisionnel (ECD) se rapportant à une décision difficile prise avec leur médecin. Après la conférence, ils ont complété une évaluation dans laquelle on leur demandait d'identifier les forces et faiblesses de la conférence ainsi que les changements qu'ils apporteraient lors d'une prochaine prise de décision avec leur médecin. Selon la nature des données traitées, des analyses statistiques descriptives simples et des analyses de contenu furent réalisées.

Résultats : Ce sont 77 ECD et 84 évaluations qui furent colligées. 63% des participants (âge moyen = $65 \pm X$) rapportait un diplôme d'études universitaires et 75% étaient des femmes. Parmi les éléments les plus fréquemment mentionnées, on retrouve au niveau des forces de la conférence, conférencières et qualité des informations; au niveau des faiblesses de la conférence, aspect technique et statistiques; et au niveau des changements dans la prochaine prise de décision avec le médecin, demander plus d'informations au médecin et augmenter ma participation à la prise de décision en discutant avec mon médecin et en donnant mon opinion.

Conclusions : Il est possible d'adapter une formation médicale continue sur le MADÉO pour un auditoire inscrit à l'Université du 3^{ème} Âge. Celui-ci a le potentiel d'influer sur leur niveau de participation à la prise de décision avec leur médecin.

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Parents' perceived vulnerability and control in preventing an infectious child disease: A large-scale interview study about vaccination

Timmermans DRM, Henneman L, Hirasings R, Van der Wal G

Department of Public and Occupational Health, Institute for Research in Extramural Medicine, VU University Medical Center, Amsterdam, The Netherlands, TNO Prevention and Health, Leiden, The Netherlands

Background: From the time that large-scale national vaccination programs for children existed, there always have been opponents of vaccination, mostly on religious grounds or based on anthroposophical ideas. Other reasons for the ambivalence toward vaccination may lie in parents' appraisal of the risks of vaccination. The aim is to study parents' perceptions of the risks of vaccination and their beliefs about preventing a Meningococcal C infection in relation to their evaluation of the usefulness of vaccination.

Methods: As part of a vaccination catch-up campaign against group-C meningococci, all children in Amsterdam aged 6 to 14 years were invited for vaccination in September 2002. 1763 parents were interviewed after their children were vaccinated.

Results: 20% of the parents perceived the risk of their own child becoming infected before vaccination as lower than that of other children (the 'optimists'), while an equal percentage of parents perceived the risk as higher. Another group of parents (8%) who thought they had some control in preventing the disease, more often considered side-effects of vaccination as being serious than other parents. The latter group and the 'optimists', who differed from other parents regarding educational and ethnic background, evaluated the vaccination campaign as less useful than other parents.

Conclusions: Having a too optimistic view of the susceptibility of their child catching an infectious disease, or thinking to have some control in preventing the disease, seem to be two different lines of reasoning to be more critical towards vaccination. These two groups of parents should be addressed differently when informing them about vaccination in order to positively affect future willingness to vaccinate.

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Implementing Nurse-Mediated Telephone Support for Chronic Conditions in Primary Care Centers Situated in Low Income Communities: Needs of People with Type 2 Diabetes

Lange I, Bustamante C, Vial B, Maturana C, Ferrer L, Sapag J, Araya S, Rojas M, del Mazo I, Mena I, Clavero C, Pantoja T, Urrutia M, Jaimovich S, Tellez A, Valenzuela E, Rojas V, Aguayo E, Luarte M, Duarte E, Borkoski M, Aguilar M, Robinson V, Tugwell P, O'Connor AM

Pontificia Universidad Catolica de Santiago, Chile, Ottawa Health Research Institute, Institute of Population Health, University of Ottawa,

Background: To describe the needs of people with Type 2 diabetes regarding self-management of their health and their potential interest in telephone support.

Methods: A cross-sectional study was conducted with a random sample of 632 clients with type 2 diabetes who were enrolled in the cardiovascular program at three primary health care centers in Puente Alto, Chile. A self administered survey was used at the participants' home including: (1) nationally validated questions (i.e., perception of health, tobacco use, demographics), (2) the Stanford self-care questionnaires (i.e., medication, exercise, use of health services), and (3) questions about use, availability, and utilization of telephone mediated health services.

Results: Only 1 individual available for home interview did not agree to participate. The modal respondent was female, between 46-60 years of age, with 8 or fewer years of education, not working outside the home and diagnosed as diabetics for more than 5 years. Regarding the use of medication, 87% reported using hypoglycemic drugs, 5% insulin, 63% anti-hypertensive medication, and 24% lipid lowering drugs.

The types of major health limitations reported included: poor health (19%); major limitations climbing stairs (39%); major problems with moderate physical effort (28%); much pain with daily activities (14.5%); feeling downhearted and depressed all of the time (44%); and having difficulties with social activities due to physical or emotional health (11%).

Diabetic self-management problems were common: 86% did not monitor their glucose at home; 41-46% reported difficulties following their food plan; 96% were sedentary; 18% used tobacco. Social support to help them manage their diabetes included: spouse/partner [50%]; daughter [41%]; or son [29%].

Participants who were not satisfied with services provided at the health care center mentioned dissatisfaction with: relationship with providers (8%); relationship with administrative personnel (19%); quality of care (20%); waiting time (29%); problems getting there (11%); difficulty making time to go (20%); and costs of transportation (35%). Seventy eight (78%) walked to the primary care center, 7% were hospitalized in the last 4 months, and 36% used urgent care in the last 6 months.

Ninety four percent (94%) of the sample reported access to a telephone, and the types of services they would ask for in a call center would be: appointments (83%); information and support regarding treatment (68%); use of health services (74%); checking before going to emergency room or urgent care (83%); and help with emotional problems (61%). Respondents preferred: both inbound/outbound calls (62%); only inbound calls (15%); only outbound calls (17%); no calls (5%).

Conclusions: A significant number of respondents reported limitations with emotional and physical functioning. Self-management of diabetes is sub-optimal. The respondents are receptive to telephone-mediated support for managing their diabetes, overall health, and the use of health services.

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Involving patients into clinical practice guidelines (CPGs) process: a study by French guidelines developers in the field of oncology

Carretier J (1), Bataillard A (1), Kelson M (2), Fervers B (3)

(1) Federation of the French Comprehensive Cancer Centers, Paris, France; (2) Patient Involvement Unit, National Institute for Clinical Excellence, London.; (3) Centre Léon Bérard, Lyon, France

Background: Patients' preferences are essential in defining optimal cancer treatment because of the uncertain outcomes and important side effects. Their preferences should therefore be integrated in the development process of CPGs. The Standards & Options: Recommendations programme (SOR), run by the Federation of the French Comprehensive Cancer Centres (FNCLCC) has developed CPGs in oncology since 1993. The methodology is based on a literature review and critical appraisal by a multidisciplinary group of experts, with feedback from specialists in cancer care delivery.

Objective: Incorporate patients' views and preferences in the development process of CPGs in oncology.

Methods: 3 steps: 1. Review of the literature and analysis of the experiences in other countries (Patient Involvement Unit (PIU) at the National Institute for Clinical Excellence and Scottish Intercollegiate Guidelines Network).

2. Definition of an approach for the transposition of the methodology to incorporate patients' views and preferences in a French context and design of a pilot study. 3. Accomplishment of the pilot study and assessment of the results.

Results:

1. A literature review had been carried out to identify the different methods of patient's involvement in CPG. The literature describes various methodologies to involve patients in CPG process : patients or patient advocate in the working group, focus group, "one off" meeting, e.g. Each method shows positive input, but some problems have been faced including patient education on technical term and dealing with emotional issues. To complete this review, the researchers involved in this step will shadow the work of the PIU experience.

2. A preliminary feasibility study had been conducted with focus groups of five breast cancer patients to review a guideline draft. In the CPG itself, the patients were satisfied with the presentation of treatment options but asked for a more detailed description of particular side effects. They said the need to give patients information on the full range of treatment options and the importance of patients' participation in treatment decisions should be emphasized

more in the CPG. They considered the fact that the CPG included information on social and psychological aspects was very important, but felt that more information on psychological welfare should be given, and a clear recommendation to offer referral to a psychologist should be made. For the process, they found the scientific information difficult to understand, but considered the clinical algorithms helpful to understand the issues and treatment options. Depending on each patient's experience of their disease, they found reviewing the CPG to be an emotional experience.

3. A piloting committee has been created to deal with scientific, societal and psychological issues of transposing foreign methodology in the French Context. French oncologists, cancer patients associations, a psychologist, a sociologist and a representative from a national health agency compose this committee. Its role is to choose, according to the literature review and experiences, the best method that will be used to test the involvement of French cancer patients in the CPG process.

Conclusions: The preliminary study demonstrates the feasibility of collecting relevant comments and views from French cancer patients, but also the importance for patients to be clearly informed about the purpose and limits of their input in the review.

Accomplishment and assessment of the pilot study will be the next steps of this work. It will propose a common methodological framework thereby providing added value to existing programs. In addition this approach could be used as a model for development of CPGs for other diseases.

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Evaluating the need for a decision support tool for immigrant and refugee women from HIV-endemic countries regarding voluntary testing and counselling (VCT)

Mitra D, Tugwell P, Jacobsen MJ, Pottie K

University of Ottawa, Institute of Population Health

Background: People who emigrate from HIV-endemic countries account for the fastest growing proportion of HIV cases in Ontario, Canada. Longitudinal surveillance also reveals that perinatal HIV infections are disproportionately high in women from HIV-endemic countries. The purpose of this study is to develop and evaluate the effectiveness of a decision aid for reproductive-aged immigrant women from HIV-endemic countries in preparation for voluntary counselling and testing for HIV (VCT). Specifically, the Ottawa Decision Support framework will be used to explicate processes in VCT-related decision making to assist women in making evidence-informed decisions, and sensitize providers to contextual issues involving the decision to test for HIV. This abstract will detail the preliminary stages of the study which explored the feasibility of applying a decision support intervention in this setting and identified current gaps in practice.

Methods: A literature review using electronic databases (MEDLINE, CINAHL & EMBASE) and technical reports published by various governmental and non-governmental organizations (i.e. Health Canada, Ontario Ministry of Health, the University of Toronto, the African Caribbean Counsel on HIV/AIDS) was conducted. Information was also collected through personal correspondence with providers at the Immigrant Health Clinic and anonymous HIV testing centres in Ottawa regarding current practice.

Results: VCT guidelines tailored to the decision making needs of the target group do not exist. National evidence-based illness prevention guidelines for immigrants from developing countries are being developed to optimize culturally appropriate needs-based care. These guidelines include directives for VCT. However, questions about how to maximize acceptability and informed decision-making in relation to VCT remain. Correspondence with service providers in Ottawa revealed significant difficulties in communicating effectively with clients about VCT in a culturally sensitive manner. Therefore, gaps exist in the availability of evidence-based, culturally-appropriate decision making tools for both clients and service providers in this setting.

Conclusions: Few studies link decision making to the uptake of VCT, the entry point to all HIV prevention & treatment options. Mapping decision making concepts onto VCT practices may be crucial in developing effective primary prevention and MTCT-prevention programs, particularly for women at high risk for HIV/AIDS. Next steps for this project include conducting an in-depth needs assessment with service providers and immigrant and refugee

women to inform the development of a VCT decision aid. Pilot testing and evaluation of the tool will also be completed.

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Feasibility of organisational development strategies to implement shared decision making in German health care organisations

Kuch C, Scheibler F, Pfaff H

Department for Medical Sociology, University Hospital of Cologne

Background: The interest in successful implementation of shared decision making (SDM) in health care organisations is increasing. It is argued that interventions aiming at patients and professionals which have been found to be effective have been mainly tested in explanatory trials, their effectiveness in clinical practice shows unsatisfying implementation. The perspective of organisational development could add useful hints for successful implementation of SDM. The aim of this study is to design useful strategies to implement SDM in German health care organisations.

Methods: Firstly two focus group interviews were held with ten health professionals to gain existing needs, barriers and critical factors for success of implementation of SDM in German health care organisations. Secondly organisational development strategies to implement SDM in German health care organisations were gained in three focus groups held with altogether fourteen organisational developers. Thirdly the feasibility and possible benefits of the strategies have been tested and usefully completed: after submitting the strategies semi-structured interviews were held with nine health professionals practicing shared decision making and eight health politicians from government, health insurances and health care organisation alliances.

Results: The main requirements rely on the implementation process, e.g. applying a solution focused approach, encouragement by leaders, participating of practitioners, group culture open to development, awareness of changing role expectations, support learning to perform SDM and to support commitment like prospect of evaluation. They also rely on general conditions like the need of SDM perceived by patients, existing time to perform SDM, funding etc.

Conclusions: It has been shown that the perspective of organisational development can provide useful advice for implementation of SDM in the German health care system. Additionally general conditions derived from society and policy have to be considered. Applying the solution focused approach seems to be promising.

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Themes and Persuasive Devices in US Television Advertising of Prescription Pharmaceuticals

Frosch D

Leonard Davis Institute of Health Economics, Center of Excellence in Cancer Communications Research, University of Pennsylvania

Background: Starting in 1997, and concurrent with the growing promotion of using decision aids to facilitate informed decision making among healthcare consumers, the US population has witnessed an explosion of direct to consumer prescription pharmaceutical advertising (DTCA) on television. A recent estimate suggests the average American television viewer sees more than 30 hours of DTCA per year. Proponents of DTCA argue that ads are creating more informed consumers who can play an active role in healthcare decision-making. While prior work has examined the content of print ads, to date there are no published studies examining themes and persuasive devices used in television ads.

Methods: Primetime television programming (7-11pm) on four network channels was recorded for a period of one month, resulting in 38 unique prescription drug ads. Ads were coded for types of appeals used (e.g., rational, positive, negative), factual information about the target condition provided (e.g., symptoms, cause, who gets the condition), narrative themes (e.g., loss & regaining of control, distress, breakthroughs, appeals to social norms), portrayals of lifestyle and non-pharmacological alternatives, and product benefits.

Results: Preliminary results indicate that a majority (86.4%) of ads use some rational appeal in promoting products, yet only a minority provide information about the cause of a condition (13.6%) or who is likely to get it (9.1%). Loss (54.5%) and regaining of control are frequently used narrative themes, as well as appeals to social norms (77.3%) and breakthroughs (36.4%). No ads mentioned non-pharmacological alternatives as viable treatment options.

Conclusions: The content of DTCA stands in stark contrast to decision-aids, which intend to provide unbiased reviews of options for a given condition that acknowledge inherent uncertainties. In light of high levels of DTCA exposure in the population, physicians can benefit from a better understanding of how ads attempt to shape consumer expectations of healthcare products and services.

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Assessment of breast cancer patient's information needs in France : first step before the implementation of shared decision-making in the medical encounter

Moumjid N (1), Morelle M (1), Brémond A (1), Farsi F (2), Carrère MO (1,3)

(1) GRESAC, LASS, CNRS (FRE 2747), Centre Léon Bérard, Lyon, France; (2) ONCORA Network, France; (3) Claude Bernard University, Lyon 1, France

Background: International literature shows that breast cancer patients have a much stronger desire for information than other patients. To our knowledge, no study, except public opinion surveys, has investigated this question in France. This is why so few data are available on the subject, compared to mainly Anglo-Saxon countries.

Objective: Analyze the information needs of patients newly diagnosed with breast cancer in France.

Methods: In 2002-2003, a retrospective, cross-sectional survey was conducted by the GRESAC (Research Group in Health Economics and Networks in Cancer Care, Regional Cancer Center Léon Bérard), in collaboration with ONCORA (Rhône-Alpes cancer network) and the CHEPA (Center for Health Economics and Policy Analysis, Ontario, Canada) among French patients with newly diagnosed breast cancer. Standardized questionnaires evaluated the information that each patient expected from the different physicians in charge (surgeons, radiotherapists, or medical oncologists).

Results: 238 patients participated in the study (71.4% responders).

The information needs expressed are considerable, though significantly different depending on the topic ($p < 0.0001$). The demand for information on "common" concerns (disease, treatments, treatment-associated risks and/or benefit) is high, compared to more "specific" topics (effect of treatments on sex life, physical appearance, mood, family or social relationship, or patient's self-care ability).

Patients claim that information would help them face fear and uncertainty, understand their disease, prepare for treatments and determine their trust in their doctor. Interestingly, quite a number (62.7%) also say that this would help them in treatment decision-making.

However, patients consider that doctors only insufficiently respond to their information needs. This is particularly true for so-called "specific" topics, and all the more so for young and highly educated patients.

Conclusions: French patients with breast cancer have a strong desire for information. Though our general conclusion is in agreement with international findings, we bring extra information regarding "specific" topics.

If the objective is to implement shared decision-making for breast cancer patients, this study shows that physicians will first have to convey a large amount of information to satisfy patients' information needs even if they tend to underestimate those needs or fail to identify them.

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Shared-decision-making in the medical encounter: French physicians' point of view in breast cancer

Nguyen F (1,2), Moumjid N (1), Brémond A (1), Carrère MO (1,2)

(1) GRESAC, LASS, CNRS, FRE 2747; (2) Claude Bernard University, Lyon, France

Background: We do not know what physicians' usual practice of decision-making (DM) is since few studies have been conducted on this topic.

Objectives: To find out: 1) Usual practice of DM reported by French physicians; 2) main physicians' characteristics linked with their usual practice of DM.

Methods: A cross-sectional survey questionnaire was mailed to eligible oncologists treating breast cancer patients in a cancer network in France. This survey was part of a collaborative project initiated by the CHEPA (McMaster University) and the Hamilton Supportive Cancer Unit.

Physicians reported their socio-demographics, professional characteristics and perceptions of their patients' wishes to participate to the DM process. Among four clinical examples they indicated the one best representing their usual practice of DM:

Paternalism: Physician dominates the DM process.

Some sharing: Information is shared between the physician and the patient but the physician is the sole decision-maker.

Informed decision-making: Physician provides information to the patient but the patient is the sole decision-maker.

Shared decision-making (SDM): Patient and physician shared participation in every step of the DM process.

We present here the results related to surgeons' responses.

Results: 73 questionnaires (among 113) were fulfilled by surgeons and analysed.

The majority (57%) declared that they practice some sharing, being mostly men, more than 50 years old.

21% said they practice paternalism, treating very few cancer patients, thinking patients do not want to participate to the DM process.

Only 22% said they practice SDM, being mostly women, with twenty years of experience, treating mainly cancer patients.

Lastly, none chose the informed decision-making example.

Conclusions: Most of Canadian physicians (69% of surgeons) said they adopt a SDM approach, but, in France, most of physicians (57% of surgeons) said they rather practice some sharing: allowing their patients to ask all the questions they want, they want to remain the sole decision-maker. DM practice is associated to physicians' demographics, professional characteristics and perception of their patients' wishes to participate to the DM process.

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Décision informée dans le dépistage du cancer du sein au sein de la Francophonie

Brémond A (1), Moumjid N (1), Soler P (2), Légaré F (3), Major D (4), Brisson J (4), Lepage C (5)

(1) GRESAC, LASS, CNRS (FRE 2747), Centre Léon Bérard, France; (2) Registre des Cancers du Sein du Rhône, France; (3) Université Laval, Québec; (4) Institut National de Santé Publique du Québec; (5) Direction de la Santé Publique, Québec

Contexte : La participation du patient et de l'utilisateur à la décision de santé est vue comme une procédure permettant de diminuer l'asymétrie d'information et de pouvoir entre les professionnels de santé et le patient/l'utilisateur. La participation de ces derniers à la décision médicale vise à améliorer leur information et à respecter leur autonomie en les impliquant dans les décisions de traitement, de soins, ou de prévention, dans la mesure où elles sont susceptibles d'affecter leur bien-être.

Le projet présenté a pour objectif général de mesurer l'impact sur le taux de participation au dépistage du cancer du sein d'un outil d'information et d'aide à la décision fondé sur les données actuelles de la science et élaboré avec des femmes ayant et des femmes n'ayant pas l'expérience du dépistage du cancer du sein comparativement à l'information fournie en routine sur le dépistage. Le projet vise donc à observer une différence de participation en fonction de l'information reçue.

Outre la possibilité potentielle de fidéliser des femmes qui ont participé une fois au dépistage, ce projet offre de façon plus intéressante la possibilité de permettre aux femmes de prendre une décision (participer ou non au dépistage) conforme à leurs préférences. Il permettra enfin de comprendre les raisons des choix effectués et d'analyser la satisfaction des femmes par rapport au processus d'information et d'aide à la décision.

Méthodes : Une hypothèse souvent exprimée, mais jamais vérifiée, consiste à dire que l'attitude des femmes vis-à-vis du dépistage varie largement en fonction du contexte culturel. La diversité des milieux culturels dans la présente étude proposée (rural/urbain, deux pays différents que sont la France et le Canada (Québec)) devrait permettre de tester cette hypothèse grâce à une homogénéité de la présentation du dépistage.

Il s'agira d'un essai prospectif randomisé conduit dans chaque pays comparant deux modalités d'information des femmes éligibles pour le dépistage du cancer du sein.

Les femmes du groupe témoin recevront l'information distribuée en routine. Les femmes des groupes « action » recevront un outil d'information et d'aide à la décision élaborée par les équipes de recherche. Au cours de l'analyse les taux de participation de chaque groupes seront mesurés tandis qu'un questionnaire qualitatif étudiera les raisons des choix effectués.

Résultats : Ce projet en cours de constitution ne permettra pas de fournir des résultats lors du colloque en juin prochain.

Conclusions : Même si ce projet ne permettra pas de fournir des résultats en juin prochain, sa présentation nous semble importante car elle vise à 1) montrer aux personnes présentes que des projets d'envergure et avec un impact réel en terme de politique de santé publique peuvent être conduits dans la Francophonie; 2) susciter des réactions et collaborations sur ce thème et sur d'autres au sein de la francophonie, l'un des objectifs de la session francophone organisée.

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Participation des patientes à la décision thérapeutique dans la prise en charge initiale du cancer du sein : Développement et évaluation préliminaire d'un protocole d'aide au partage de la décision médicale

Meunier A (1), Moumjid N (1,2), Brémond A (1,2), Mignotte H (1), Faure C (1), Carrère MO (1,2)

(1) Centre Léon Bérard, Lyon, France; (2) GRESAC, LASS, CNRS (FRE 2747), Lyon, France

Contexte : Depuis une vingtaine d'années, les patients expriment le désir d'une meilleure information et d'une plus grande implication dans la décision thérapeutique. En France, la volonté de transférer aux patients une information de qualité est réelle et la participation du patient aux choix thérapeutiques est mentionnée dans la loi relative aux droits des malades et à la qualité du système de santé (2002).

Objectif : Elaborer et évaluer, un processus d'aide au partage de la décision thérapeutique dans le cancer du sein.

Méthodes : Des outils d'aide au partage de la décision médicale et destinés aux patientes (guides d'entretien, tableaux de décision, documents d'information) ont été élaborés.

Depuis Janvier 2004, 166 patientes ont intégré cette étude, lors de leur prise en charge pour traitement d'un cancer du sein. Après information des résultats des examens, les différentes options thérapeutiques sont exposées à la patiente pour le geste chirurgical puis pour la décision de traitement adjuvant. Le programme thérapeutique est ensuite établi en accord avec la patiente.

Le vécu de cette nouvelle démarche est évalué à travers des questionnaires remis aux patientes.

Résultats : Pour les médecins, c'est un exercice nouveau, dans lequel il n'est pas aisé de taire ses propres convictions afin d'être à l'écoute des interrogations ou des affirmations de la patiente.

Le point de vue spécifique d'une patiente sera développé à travers un témoignage, puis nous présenterons l'analyse préliminaire des questionnaires remplis par les patientes.

Conclusions : Il s'agit de la première étude réalisée en France développant un processus complet d'aide au partage de la décision médicale. Ce processus a profondément modifié le mode d'information et de décision des praticiens participants à l'étude. L'analyse du vécu des patientes, exprimant souvent leur crainte mais aussi leur satisfaction d'être restées actrices de leur traitement, semble essentielle.

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Decision Making for Stage I Seminoma: A 15-Year Review

Samant R, Alomary I, Gallant V

Ottawa Hospital Regional Cancer Centre and University of Ottawa

Background: Stage I testicular seminoma is a highly curable malignancy among young men. Historically adjuvant radiation has been considered standard but recent studies suggest that initial surveillance, and reserving radiotherapy for recurrences, is also reasonable. Therefore, we decided to evaluate treatment among Stage I seminoma patients at our Centre.

Methods: A retrospective chart review of all Stage I seminoma patients treated from 1989 to 2003 was performed to evaluate management of patients post-orchietomy. Also a survey of radiation oncologists was performed to determine their perspectives on current management approaches for these patients.

Results: A total of 150 patients were identified with 71% receiving adjuvant radiotherapy while 29% were placed on surveillance. The 5-year relapse rate was 21% among the surveillance group compared to none in the radiotherapy group, but the 5-year overall survival was 100% regardless of the treatment approach used. There has been a significant increase in the use of surveillance over the time period studied. All the physicians currently recommend both observation and adjuvant radiotherapy as reasonable management options and most have been doing so since the late 1990's. The approach that most physicians claim to use for management was discussing the options and giving their own recommendations but letting the patient decide.

Conclusions: The increasing use of surveillance for Stage I seminoma patients suggests that there is now more shared decision making than in the past. This is most appropriate for a disease where the overall cure rate is excellent regardless of the initial treatment used, and patient preferences are key to the decision-making process.

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Developing Patient Competencies Through the Use of Health Coaching Methodology

Powers A, Rapp L, Erramuzpe K

Health Dialog, Inc.

Background: Much research has focused on the development of shared decision-making communication skills with healthcare professionals, but in order to promote and increase patient participation in the shared decision making process, patients need to develop competencies in this area. Recent studies reveal that patients perceive changing their communication behavior with health care providers will disrupt rapport and affect their quality of care. (Towle et al. 2003) Health professionals recognize the importance of patient participation and attempt to actively elicit their points of view but are not always successful.

At Health Dialog, Inc. Health Coaches, who are healthcare professionals, collaborate to improve patient competencies through transference of the knowledge, communication skills, and self-confidence necessary for active participating in their health care management.

The development of patient competencies in the decision –making process has been demonstrated with the utilization of specially trained Health Coaches.

Methods: Providing evidence based information, helping patients formulate key questions for provider visits, and encouraging individuals to explore their own problem solving process, are methods in which Health Coaches develop the competencies necessary for patients to become effective healthcare participants.

Satisfaction surveys were conducted by an independent research company with patients who spoke with a Health Coach and patients who had not. Data was compared between the two groups.

Results: In survey results, 71% of participants rated their ability to communicate with their providers as “much better” or “better”, as a result of working with a Health Coach. In addition over 60% of those surveyed felt they were more confident in discussing questions and concerns with their providers after speaking with a Health Coach.

In addition, 80% of patients surveyed reported that they spoke with their providers about the concerns they had discussed with the Health Coach.

Conclusions: The intervention of professionals trained in the Health Coaching Methodology positively impacts the patient-provider relationship.

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Evaluation of an Education Program to Enhance Decision Support at a Health Call Center

Powers A, Rapp L, O'Connor AM, Stacey D, Jacobsen MJ, Kearing S, Erramuzpe K

Health Dialog, Inc

Background: Many studies support the importance of patient participation in decisions about their health.

Some decisions are straightforward with clear benefits that outweigh harms other decisions are more complex with no “best choice” for everyone. The benefits and harms are either unknown due to a lack of research or there is a need to weigh the benefits against the harms. Therefore, the best choice depends on how a person values the benefits, harms, and scientific uncertainty. These are called “preference-sensitive” decisions. Research shows that people making preference-sensitive decisions often have difficulty and need help. Without decision aids and health coaching, there is over-use of expensive surgical options that informed patients don't value. The aim of this study is to evaluate the effect of continuing education on the quality of decision support provided by health coaches for callers facing preference-sensitive decisions.

Methods: Descriptive, before and after-intervention comparison.

1. Baseline Assessment of the Quality of Health Coaches' Decision Support. Health coaches were asked to respond to one call from a simulated caller, according to usual practice. Calls from the simulated patient presented preference-sensitive scenarios of unclear values or inadequate support. Documentation was recorded in the training database and calls were audio taped.
2. Health coaches were assigned to participate in a modified decision support education program. This training uses standardized self-learning, testing and feedback from an auto-tutorial, and a shorter group workshop time.
3. One month later, there will be a repeat of a simulated call. Coaches fielding a values scenario at baseline will receive a values scenario; coaches fielding a pressure scenario at baseline will receive a pressure scenario. Documentation will be recorded in the training-database and calls will be audio taped.

Results: Study is in progress. Data is currently being collected and analyzed

Conclusions: The results of this study may be used to improve health coach phone efficiency, improve quality of patient calls, streamline health coach training initiatives, and improve decision support to individuals faced with preference sensitive-decisions.

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What Do Patients Think of Video-Based Decision Aids “Downstream”? A Telephone Debriefing Process

O'Connor MA (1), Kearing S (1), Maheu L (2), Fowler FJ (3)

(1) Dartmouth Medical School, Center for Evaluative Clinical Sciences, Hanover, NH; (2) Dartmouth Hitchcock Medical Center, Center for Shared Decision Making, Lebanon, NH; (3) Foundation for Informed Medical Decision Making Inc., Boston, MA

Background: Since 1998, the Center for Shared Decision Making (CSDM) at Dartmouth-Hitchcock Medical Center (DHMC) has provided individuals with evidence-based patients' decision aids (PtDAs). The CSDM's resources include 16 video-based PtDAs produced by the Foundation for Informed Medical Decision Making (FIMDM). We know that effective PtDAs help patients: a) to understand their condition, the therapeutic options, the options' potential benefits and harms, b) to clarify their personal preferences, and c) to collaborate with their physician in arriving at an informed, preference-based choice. However, little is known about patients' longer-term impressions

about these video-based PtDAs. The study purpose was to test the feasibility of using telephone interviews to gather these impressions.

Methods: A subset of patients receiving FIMDM video-based PtDAs provided consent to receive a follow-up telephone call within 1 month of viewing. A semi-structured qualitative interview guide was used to obtain feedback on: whether patients viewed the PtDA at the right time in their care pathway, how the PtDA affected their treatment preference, and how the PtDA affected subsequent discussions with their physician.

Results: Over a year's time, 155 patients were interviewed. Most patients (130; 84 %) had selected a particular therapeutic option by the time of contact. A majority (109; 70%) reported they had received the PtDA at the right time in their care trajectory. About half (78; 50%) reported that the PtDA affected their preferences regarding the therapeutic options (40% indicated a treatment preference before watching the video, while 77% indicated a preference after the video). However, a majority (87; 56 %) reported that they had not had an opportunity to discuss the PtDA with their doctor.

Conclusions: Telephone interviews about patients' impressions after an experience with a video-based PtDA are feasible. This data-collecting strategy can reveal noteworthy patterns (such as impact of PtDA on treatment preference or gaps in post-PtDA discussions with physicians), and could be adapted to address focused research questions (such as decisional regret, or the transfer of decision skills to new situations).

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Predicting Downstream Effects of High Decisional Conflict: Meta-analyses of the Decisional Conflict Scale

O'Connor AM, Sun Q, Laupacis A, Man Son Hing M, Dodin S, Feldman-Stewart D, Siminoff L, Morgan M, Murray E

Ottawa Health Research Institute

Background: The Decisional Conflict Scale (DCS) is a useful clinical tool in assessing the health care consumers' decisional needs. However, the exact predictive ability of the DCS is unknown. This thesis was to examine the DCS as a proxy measure for patients' knowledge level and as a predictor of downstream effects of high decisional conflict, specifically, decision delay, discontinuance of chosen option, and decisional regret.

Methods: Meta-analyses with individual data from 10 clinical trials using the following statistics: descriptive statistics, correlation analysis and logistic regression

Results: Patients' knowledge deficit has a fair association with the uninformed subscale of the DCS (OR 3.10; 95% CI 1.58-6.05). Patients' decisional delay has a very strong association with the DCS (OR 23.81; 4.66-121.51). Patients' discontinuance of chosen treatment has a varied association with the DCS, very strong for change from status quo (OR 59.37; 4.09-861.05) and fair for change from active treatment (OR 3.39; 1.42-8.00). Patients' decisional regret has a strong association with the DCS (OR 5.52; 3.35-9.12).

Conclusions: When clinicians assess a patient's decisional conflict after counselling, and they find the decisional conflict is low, they can be reasonably assured that the likelihood of downstream decision delay, change from the status quo, or decisional regret will be low. However, low scores on the uninformed scale do not guarantee the patient is well informed; they need to validate the patients' understanding with some follow-up questions. Moreover, the likelihood of discontinuing active treatment even with low decisional conflict is also a possibility.

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Supporting informed parental decision-making in relation to the MMR vaccine: A systematic review

Jackson C, Cheater FM

School of Healthcare, University of Leeds, Baines Wing, Leeds, UK

Background: Controversy in the UK over the safety of the combined measles, mumps and rubella (MMR) vaccination has led to a reduction in vaccination rates(1). Reliance on health professionals alone to provide information appears to have limited impact on informing parents' decisions about MMR. An alternative approach

would be an expert-informed but parent-led intervention (2). This research aims to identify and assess the effectiveness and appropriateness of parent-led interventions to support informed parental decision-making in relation to the MMR vaccine.

Methods: The project is supported by a Department of Health (UK) Public Health Initiative Award and comprises two phases. First, a systematic review is being conducted. Review questions include: (a) What are the decision support needs of parents attempting to make an informed decision about child health? (b) What are the decision support needs of young people / adults attempting to make an informed health decision for which there is controversy? (c) How effective and appropriate are existing decision support strategies in these contexts? (4) How effective and appropriate are peer-led health interventions for young people and adults? The review findings will inform an exploratory trial to compare a parent-led intervention with usual family practice MMR policy to support informed parental decision-making for MMR.

Results: The project is ongoing. This paper will present findings of the systematic review including identifying decision support needs and the format of a parent-led intervention for testing in the exploratory trial.

Conclusions: Implications for childhood vaccination policy and practice will be discussed.

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Patient involvement in treatment choices for End Stage Renal Failure: a systematic review.

Winterbottom A, Bekker H, Conner M, Mooney A

University of Leeds (Winterbottom, Bekker and Conner), St James University Hospital (Mooney)

Background: Policy encourages patients with chronic conditions to be involved in the management of their condition. It is unclear if patients with end stage renal failure (ESRF) are involved in the management of their conditions and/or treatment choices.

Aim: to examine patients' involvement in decision making about treatment choices for end stage renal failure.

Methods: Design: systematic review of primary empirical evidence.

Search Strategy: Medline and PsycInfo were searched; the search terms were 'decision making and renal'; 'decision making and dialysis' and 'decision making and transplant'; and 941 articles about physician choices, quality of life, reviews and case studies were excluded.

Results: 14/955 articles met the review criteria; six employed qualitative methods. The studies' design, methods and research aims were too heterogeneous to enable a statistical synthesis. Findings were integrated under four themes:

Information provision - there was little consistency in the way information was provided about treatment options; it is unclear what patients need to enable involvement in their care.

Patient participation - few studies assessed patient participation; no clear patterns emerged from the data but patients hold different beliefs about involvement in treatment choices.

Decision making cognitions – few studies assessed patient's reasons for treatment choices; however, reasoning about transplant choices appears to involve different attributes to cognitions about dialysis.

Study rigour – research quality of both qualitative and quantitative studies was poor; only two studies employed a validated measure (SF 36; Decisional Self Efficacy Scale; Spitzer QOL Index); six were informed by theory, only two explicitly assessed decision making.

Conclusions: There is a dearth of rigorous evidence describing patients' choices about their treatment choices and the types of interventions that may facilitate involvement in their illness management. As ESRF patients are faced

with numerous difficult care decisions, theoretically informed studies are essential to improving services in accord with current policy guidelines.

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Decision Making about Joining a Prostate Cancer Chemoprevention Trial

Myers R, Delmoo E, Iacono R, Lang C, Chelnik K, Kash K, Hubert C, Keenan K, Hirsch I

Thomas Jefferson University, Philadelphia, PA

Background: Approaches for facilitating shared decision making about participation in clinical trials are needed. Decision counseling was used to help men make an informed choice about joining the Negative Biopsy Trial, or NBT (CA77789), a prostate cancer chemoprevention trial. In the trial, men with a recent negative prostate biopsy result are randomly assigned to a daily placebo, 200 mcg selenium, or 400 mcg selenium in pill form and, subsequently, are tested regularly to determine selenium effects.

Methods: The urology department of a major teaching hospital in Philadelphia identified 39 white and 23 African American men who were eligible for the NBT. Initially, the men were offered a decision counseling session about the trial. In this face-to-face session, a trained nurse described the NBT. Then, the nurse followed a protocol designed to help men identify decision factors (pro and con) and domains (cognitive, affective, social), rank the top three factors in terms of importance, and weigh factor influence via pair-wise comparison. The nurse then entered factor weights into a pre-programmed PDA and computed a trial participation preference score (0.0–1.0). After interpreting the score to the patient (score level is positively associated with preference to participate), the nurse elicited a decision. Univariable analyses were performed to determine if preference scores differed for men who decided to and not to join the trial.

Results: Twenty-four (40%) men underwent decision counseling and 38 (60%) declined counseling. Fifteen counselled men decided to join and nine decided not to join the NBT. Mean preference scores differed significantly ($p=0.0002$) for the two groups (0.687 and 0.384, respectively). Cognitive factors exerted the strongest influence on decision making in both groups (65.1% and 57.9%, respectively).

Conclusions: Many men were receptive to decision counseling about the NBT. Decision counseling can facilitate shared decision making about clinical trial participation.

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Training mental health workers in adherence therapy: a cluster randomised controlled trial

Gray R, Robson D

Institute of Psychiatry, Kings College, London.

Background: Adherence therapy is a structured pragmatic intervention that aims to promote shared decision making between clinician and people prescribed antipsychotic medication. The therapy is based on motivational interviewing and cognitive behaviour therapy and has evolved from compliance therapy. The key therapeutic techniques therapists' use are exchanging information, developing discrepancy and effectively dealing with resistance. There are five key interventions to adherence therapy: problem solving; a medication timeline, exploring ambivalence, discussing beliefs about medication and using medication in the future. The aim of the therapy is to achieve concordance about medication between the patient and clinician. It is unclear if mental health workers can deliver this intervention in day-to-day clinical practice.

Methods: A cluster RCT. 234 patients and 49 mental health workers were recruited to the trial. Mental health workers were randomised to receive training in adherence therapy or a control training intervention. The primary outcome was relapse.

Results: Preliminary results will be presented.

Conclusions: Adherence therapy training is acceptable to mental health workers.

310**Ethical stakes in screening workers exposed to beryllium: usefulness of a risk management framework**

Poulin M

Institut national de santé publique du Québec

Background: Inhalation of beryllium dust or particles can cause chronic beryllium disease (CBD) or beryllium sensitization (BeS). Among 100% exposed workers, approximately 2.6% will be sensitized. Among the sensitized workers, 2% will develop CBD. Problem: In the Québec medical community, physicians were divided on the adequacy of the BeLPT as a screening procedure.

The case for screening: 1) Advanced CBD is not curable. 2) Morbidity and mortality of CBD could be reduced if the disease is detected at an early stage. 3) Removal from exposure to beryllium could stop or slow down the disease. 4) BeLPT improves the early detection of CBD.

The case against screening: 1) No study has proven that screening reduces the morbidity and mortality of the disease. 2) There is non negligible intra and inter laboratory test variability. 3) There is the possibility of false positive results requiring further invasive testing without benefits to the workers. 4) Some workers with positive tests may lose their job. 5) There appears to be problems in getting an insurance policy after a positive test.

Methods: How to solve the problem?

We reviewed the literature, we discussed with experts and we held symposiums. We also put together experts in the fields of epidemiology, respiratory diseases, public health and occupational health. We finally applied a risk management framework organised around seven principles: empowerment, equity, openness of mind, scientific rigour, primacy of health protection, prudence and transparency.

Results: Application of the framework:

Scientific rigour: Screening cannot be recommended because the major criteria required to implement such a program are not met. Empowerment: Both the benefits and risks of screening should be discussed with the patient before testing. Some workers may gain benefits while others are likely to be harmed by screening and its subsequent consequences. Patients should then take their own decision.

Prudence: Considering the present uncertainties around the test, we cannot be categorically for or against screening of the workers.

Conclusions: The risk management framework was useful to reach a consensus between the parties. This allowed us to consider certain ethical stakes not identified at the beginning of the process. It permits the worker to take his own decision without pressure: the test is available and he decides to take it or not.

311**Prototyping a User Interface for Collaborative Intelligence-Based Ethical Decision Support in NICU**

Yang L (1), Ou Y (1), Walker CR (3), Frize M (1,2)

(1) School of Information Technology and Engineering, University of Ottawa; (2) Department of Systems and Computer Science, Carleton University; (3) Department of Neonatology, Children's Hospital of Eastern Ontario

Currently there are many approaches to solving ethical dilemma in the neonatal intensive ward; however, there is limited consensus on best clinical practices in neonatal intensive treatment selection. In cases where the patient is threatened with imminent death, medical professionals strive to collaborate with parents to solve complex medical and bioethical sensitive problems. Clinicians and parents alike require consistent information presented in a structuralized framework to allow them to share realistic expectation to move through the difficult process. There are indications that the appropriate use of information systems technologies, such as web-based communication tools, can improve this type of decision process, which may lead to better quality of care and wellbeing for patients and patient families. We developed a web-based decision support tool to facilitate the collaboration between the clinicians and the parents via the communication components. The application employs two sections, clinicians' workspace and parents' workspace, which adaptively deliver high quality patient information to the perspective

users. It also allows them to share and communicate their thoughts and expectations of the treatment. With hospital information systems and network infrastructure support, this system can be integrated with telehealth applications, allowing parents to participate in the care decisions for their infants regardless of physical separation from the infants or temporal limitations of visiting hours. We tested an initial prototype of the tool at a local tertiary hospital, the Children's Hospital of Eastern Ontario. The review consisted of acceptability and usability evaluation by a team of experts in the clinical field, including neonatologists, residents, clinical nurse specialists, bed side nurses, and social workers.

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A Clinical Center For Shared Decision Making: The First Five Years

Llewellyn-Thomas HA, Clay K, Mimnaugh D

Center for the Evaluative Clinical Sciences, Dartmouth Medical School, Dartmouth College, Hanover, NH;
Dartmouth-Hitchcock Medical Center, Lebanon, NH

Background: The Center for Shared Decision Making (CSDM) at Dartmouth-Hitchcock Medical Center (DHMC) is the world's first hospital-based clinic designed to provide patients facing close-call, preference-sensitive health care choices with a systematic yet individualized decision support service.

Methods: At the CSDM, patients are "triaged" to 4 different levels of intensity of decision support. Walk-in/referred patients (Level 3) receive condition-specific (PSA screening, elective back surgery, breast/prostate cancer) decision aids (DAs), then complete evaluative questionnaires about the service.

Results: In the first 5 years, >1500 patients received Level 3 support. The post-DA questionnaires indicate:

Uncertainty: Fewer patients are unsure of their treatment preference (21%), compared with before (30%).

Comprehension: Positive subjective evaluations range from 84% (options' risks) to 92% (overall comparisons of the options).

Values Clarification: Positive subjective evaluations range from 74% (options' risks) to 78% (options' benefits).

Making a Choice: 86-87% report enough support/free of social pressure; 68% have enough advice; 57% are sure about what to choose, while 32% remain uncertain.

Decision Process: The service helped patients to organize thoughts (90%); consider pros and cons (92%); identify questions to ask (90%); consider their involvement in decision making (91%); prepare to make a better decision (88%).

Anticipations: The service helped them to know what to expect at their next visit (72%); anticipate improved use of clinic time (69%); anticipate smoother visits (73%); and anticipate better communicate with their MD (91%), without negatively affecting the relationship with their MD (89%).

Conclusions: a) Patients "triaged" to a particular level of decision support can provide data assessing their perceived quality of that support.

b) These quality assessments imply that: i) across a wide range of diagnostic groups, patients respond favorably to a systematic approach to decision support; and ii) sub-groups of patients may benefit from more intensive decision support (e.g., the 32% who are still "uncertain").

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Development of a Decision Support Tool for Malaria Chemoprophylaxis: Needs Assessment and Validation Study

McCarthy AE, Daniel VJ, Jacobsen MJ, O'Connor AM

Division of Infectious Diseases, Ottawa Hospital General Campus, University of Ottawa

Background: Annually, over one million Canadians visiting malaria endemic areas are at risk of malaria. Despite national guidelines and the availability of three equally effective chemoprophylaxis regimens for chloroquine-

resistant *Plasmodium falciparum* (CRPF) areas, there continues to be reports of 400-1000 new malaria cases and one to three deaths each year. The purpose of this research project was to develop and validate a decision support tool (DST) to assist travel medicine to providers more comprehensive malaria prevention advice and decision support for clients travelling to CRPF areas.

Methods: As an initial step, an assessment of the needs or determinants of the decision was required, through a needs assessment of an international expert in travel medicine, to identify gaps in current resources and practices to determine the decision support needs of practitioners assisting travellers to choose the optimal chemoprophylaxis for CRPF areas. The results were then used to develop an evidence-based malaria DST based on the Ottawa Decision Support Framework. Validation included review by decision-making experts, travel medicine practitioners, and clients with recent travel experience to CRPF areas.

Results: 1. Needs Assessment - The two decisions identified by the practitioners as the most difficult for travellers to CRPF areas were whether to take chemoprophylaxis and which drug to take. The practitioners felt that an evidence-based DST would be of value in assisting travellers make a decision consistent with their beliefs and values. Such a DST would increase compliance and ultimately increase traveller empowerment and confidence regarding their decision. A web-based tool would be useful and, ideally, should be utilized prior to the practitioner visit, at home or in the waiting room. 2. Validation - The majority of practitioners would be comfortable offering the DST to clients, felt that it would be effective in increasing travellers' knowledge regarding malaria and assist in the decision regarding chemoprophylaxis. The DST would complement their usual approach and help them to tailor counselling to travellers needs. The perceived barriers to implementation included an increase in counselling time, a need for reorganization of the practice setting and coping with the complexity of the information. Client satisfaction was high with the vast majority strongly recommending the DST for travellers. The DST met the standard expected by the decision making experts at the Ottawa Health Research Institute and has been formatted for their website.

Conclusions: The DST shows promise in preparing clients for travel to CRPF areas. A reduction in malaria infections and mortality is considered to be a reasonable expectation

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Women's Perspectives on Genetics: Understanding, Expectations, and Values

Potter B, Boland I, Chorny Y, O'Reilly N, Graham ID, Cappelli M, Coyle D, Walker M, Wilson BJ

University of Ottawa

Background: This project explores what women understand about genetics, how they relate it to their own life, and the values they hold about the appropriate use of genetic technologies. Since pregnant women are routinely offered tests designed to identify fetal anomalies, mothers with young children have been chosen as a study population likely to have considered issues of wider relevance for genetic testing.

Methods: The participants are an inclusive sample of women who gave birth at the Ottawa Hospital between 1994 and 2004, identified on a post partum unit and from an obstetrics database. Semi-structured interviews are being conducted to provide insights into women's decision-making about prenatal testing, their views about hypothetical decisions regarding other genetic tests, and their values related to genetics in health care. On-going thematic analysis allows for an evolving range of issues to be explored. Approximately 72 women will be interviewed.

Results: To date, approximately 55 interviews have been completed. Key themes that have emerged cover: factors that influence the perceived personal value of actual or hypothetical genetic tests (perceived benefits of information as an end in itself or as a means for intervention, perceived burdens of having genetic information, perceptions of risk, family considerations, underlying values); contributors to decision-making processes (style of information-seeking, social networks and shared experiences, self-reflection); and the complexity of societal considerations (value of equity of access to services, recognition of health system resource issues, concerns about societal discrimination).

Conclusions: Women discuss values and attributes that they would take into account in making a personal decision about genetic testing, yet often emphasize the rights of others to make different choices. Participants also demonstrate an appreciation of the complexity of decision-making at a societal level. The findings will inform efforts to improve care and to engage the public effectively in policy decision-making.

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Patient Willingness to Take Teriparatide

Fraenkel L, Gulanski B, Wittink D

Yale University School of Medicine, VA Connecticut Healthcare System

Background: The objective of this study was to determine how much benefit patients expect teriparatide to confer over bisphosphonates before agreeing to perform daily injections over taking a pill once a week.

Methods: We recruited postmenopausal women and men over the age of 65 who had recently undergone bone densitometry and were found to have either a T score less than -2.5 or had a Fracture Index (FI) of ≥ 6 . Consenting patients completed an Adaptive Conjoint Analysis (ACA) questionnaire to determine their treatment preferences. We performed simulations based on women's values for route of administration, absolute reduction in risk of hip and vertebral fractures over 10 years, and risk of adverse effects, to estimate each individual respondent's treatment choice.

Results: The first 87 participants are included in the analyses (81% participation rate). The study sample included 86 women and 1 man, median age 74 (range 51 to 87); 96% White; 46% married; and 69% had at least some college education.

An increasing number of subjects preferred teriparatide over bisphosphonates as its efficacy increased (see figure below). There was no association between age, level of education, or health status and willingness to take teriparatide; nor was there an association between absolute fracture risk and preference for teriparatide. However, subjects with an excessively high perceived risk of future fracture were more likely to accept daily subcutaneous injections compared to subjects with a lower perceived risk of future fracture (55% versus 17%, chi sq test $p=0.001$).

Conclusions: Subjects at risk for future osteoporotic fractures are willing to take teriparatide over bisphosphonates, but most demand efficacy advantages greater than expected from available data. Willingness to take teriparatide is much greater among patients' with an excessively high perceived risk of future fracture compared to those with more accurate perceptions of fracture risk.

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The Ottawa Panel Evidence-Based Clinical Practice Guidelines (EBCPGs) for Post-Stroke Physical Rehabilitation Interventions - A Decision Aid for clinicians

Brosseau L, Laferrière L, Wells GA, The Ottawa Expert Panel Members

University of Ottawa

Background: The purpose is to present the results of a structured and rigorous methodology in the development of EBCPGs for selected rehabilitation interventions in the treatment of stroke patients and present how detailed recommendations can assist with clinical decisions.

Methods: The Ottawa Panel of experts was formed by a group of health professionals specialized in rehabilitation post-stroke. The EBCPGs are derived from evidence found in randomized controlled trials (RCTs). Comparative controlled trials method, using Cochrane collaboration methodology, was chosen to minimize bias since it outlines a systematic approach to literature search, study selection, data extraction and data synthesis. Based on the Philadelphia Panel, a 15% difference between outcomes for intervention groups in RCTs is chosen as a clinically important difference. Clinically important benefit ($\geq 15\%$) and statistical significance are necessary for a grade A recommendation. Patient-important outcomes are presented under the following subgroups: Intensity of rehabilitation, Therapeutic Exercises, Task Oriented Training, Sensory Intervention, Biofeedback, Gait training, Balance Training, Constraint-Induced Movement therapy, Treatment of Shoulder Subluxation, Electrical Stimulation, Transcutaneous Electrical Nerve Stimulation, Therapeutic Ultrasound and Acupuncture.

Results: The EBCPGs has a total of 350 recommendations ranging from Grade A to D with over 70 at Grade A level of evidence. Feedback will be provided on this methodology taking into consideration the large amount of recommendations reviewed.

Conclusions: An overview will be given on how detailed recommendations can be used in clinical practice.

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3rd International Shared Decision Making Conference – Evaluation Questionnaire

Please evaluate each of the sessions and the overall conference using the following scale and circling the appropriate number:
 1 = strongly disagree (or poor) 3 = neutral or average 5 = strongly agree (or outstanding)

	Met stated objectives	Content relevant to conference theme	Presentation clear and well organized	Presenters answered questions well
TUESDAY JUNE 14, 2005				
Keynote: Jonathan Lomas	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Guest: Donald Kemper	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Parallel Session 1	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
WEDNESDAY, JUNE 15, 2005				
Keynote: J A Muir Gray	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
IPDAS Collaboration	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Poster Session 1	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Parallel Session 2	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Parallel Session 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Poster Session 2: International Session	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Open For a	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
THURSDAY, JUNE 16, 2005				
Keynote: Cathy Charles	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Debate	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Poster Session 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Parallel Session 4	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Parallel Session 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Parallel Session 6	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
OVERALL CONFERENCE				
				Overall Rating
The conference met my expectations				1 2 3 4 5
The conference met the objectives as outlined on the website				1 2 3 4 5
The conference was well organized				1 2 3 4 5
The on campus residence accommodations were comfortable				1 2 3 4 5
There was sufficient opportunity for discussion and questions				1 2 3 4 5
The conference content was relevant				1 2 3 4 5
The conference was of educational value				1 2 3 4 5
Suggestions for future conference topics/themes:				
Comments:				



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