HEALTHCARE

POLICY Politiques de Santé

Health Services, Management and Policy Research Services de santé, gestion et recherche de politique



Volume 1 + Number 2

Interactions: Trade Policy and Healthcare Reform After Chaoulli v. Quebec MARK CRAWFORD

Experiencing Difficulties Accessing First-Contact
Health Services in Canada
CLAUDIA SANMARTIN AND NANCY ROSS

Inclusivity and Dementia: Health Services Planning
with Individuals with Dementia
KYLE WHITFIELD AND SUSAN WISMER

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario SANOBER S. MOTIWALA, SHAMALI GUPTA, MEREDITH B. LILLY, WENDY J. UNGAR AND PETER C. COYTE

Waiting Time for Radiation Therapy in Breast Cancer Patients in Quebec from 1992 to 1998

BERNARD FORTIN, MARK S. GOLDBERG, NANCY E. MAYO, MARIE-FRANCE VALOIS, SUSAN C. SCOTT AND JAMES HANLEY

Perspectives • Decision-Maker Interview
Linkage and Exchange



HEALTHCARE QUARTERLY: Best practices, policy and innovations in the administration of healthcare. For administrators, academics, insurers, suppliers and policy leaders. Edited by Dr. Peggy Leatt, University of North Carolina, Chapel Hill + CANADIAN JOURNAL OF NURSING LEADERSHIP covering politics, policy, theory and innovations that contribute to leadership in nursing administration, practice, teaching and research. Peer reviewed. Edited by Dr. Dorothy Pringle, University of Toronto, Toronto + HEALTHCARE PAPERS: Review of new models in healthcare. Bridging the gap between the world of academia and the world of healthcare management and policy. Authors explore the potential of new ideas. Edited by Dr. Peggy Leatt, University of North Carolina, Chapel Hill. • HEALTHCARE POLICY: Healthcare policy research and translation. Peer reviewed. For health system managers, practitioners, politicians and their administrators, and educators and academics. Authors come from a broad range of disciplines including social sciences, humanities, ethics, law, management sciences, and knowledge translation. Edited by Dr. Brian Hutchison, McMaster University, Hamilton. • ELECTRONIC HEALTHCARE: Best practices, policy and innovations exploring e-models, e-practices and e-products for e-health. For administrators, academics, insurers, suppliers and policy pundits. Edited by Dr. Michael Guerriere, University of Toronto, Toronto and Denis Protti, University of Victoria, Victoria. + LAW & GOVERNANCE: Within the framework of the law and the role of governance providing policies, programs, practices and opinions for the providers, administrators and insurers of healthcare services. Editorial Chair. Dr. Kevin Smith, McMaster University, Hamilton. + HRRESOURCES: Cases, commentary and policy reviews for healthcare clinicians, human resources managers and the policy leaders, insurers, academics, administrators, boards and advisors of all healthcare organizations. Editorial Chair. Dr. Louise Lemieux-Charles, University of Toronto, Toronto. + JOURNAL OF WORLD HEALTH & POPULATION: Best practices, policy and innovations in the administration of healthcare in developing communities and countries. For administrators, academics, researchers and policy leaders. Includes peer reviewed research papers. Edited by Dr. John Paul, University of North Carolina, Chapel Hill. + LONGWOODS.COM: Enabling excellence in healthcare. Providing electronic access to news, information, career opportunities, conference schedules, research, case studies, policy reviews and commentary that cover politics, policy, theory, best practices and innovations in healthcare.

Researchers' Role in Policy Decision-Making: Purveyors of Evidence, Purveyors of Ideas?

N THIS ISSUE OF THE JOURNAL WE PRESENT TWO ESSAYS (LAVIS ET AL. 2005, Greenhalgh and Russell 2005), two commentaries (Pope et al. 2005, Roger 2005) 🗕 and responses from Lomas (Lomas 2005a) and Lavis (Lavis 2005) under the umbrella title Perspectives on Evidence, Synthesis and Decision-Making. Together with Lomas's essay in our inaugural issue (Lomas 2005b), they provide sometimes complementary, sometimes competing, but invariably thoughtful perspectives on how (and to what extent) research and other evidence can be synthesized, presented and received to inform health policy and management decisions.

At the risk of overkill, I now dip my oar in these already busy waters to consider the role of researchers in the decision-making process.

In their commentary, Pope and colleagues make a useful distinction between reviews or syntheses that provide knowledge support and those that offer decision support. The decision support mode engages researchers with policy makers, managers, stakeholders and "experts" in a consideration of policy options. Beyond summarizing and clarifying the relevant evidence, what are the appropriate roles of researchers in this inevitably messy process? They might reasonably be expected to advocate for the research evidence, challenging policies that ignore or defy evidence pointing to a high probability of public benefit or harm. But should the line be drawn there or is it appropriate for researchers to join the policy fray as advocates for ideas, values or policies? Aren't researchers' ideas as good as anyone else's - maybe better if they've been immersed in the policy area under consideration, sometimes for an entire career. On the other hand, researchers' ideas and arguments reflect not just their expertise but their entire life experience and may contain varying degrees of personal or professional self-interest. Wearing the mantle of objectivity, researchers are well positioned to inject their values into policy discussions in the guise of evidence. By becoming advocates for ideas, researchers may debase their currency as purveyors of evidence. Clearly, these are questions that individual researchers, research synthesis teams and those who establish the rules of engagement for a decision support synthesis process will need to address and resolve.

However, as Greenhalgh and Russell (2005) so forcefully point out, conventional evidence – synthesized or not – usually plays a marginal role in policy decision-making. When considered at all, (highly selected) evidence usually enters the process through intermediaries, such as in-house analysts, "experts," advisers, lobbyists, interest groups, journalists or decision-makers themselves. At a recent workshop on conducting and commissioning syntheses for managers and policy makers,* Phil Davies, Deputy Director of the UK Government Social Research Unit, described the "evidence chain" of 55 top UK policy makers. Asked where they turned for guidance, they listed their sources in the following order: special advisers, "experts," think tanks/opinion formers, lobbyists and pressure groups, professional associations, media and constituents/consumers/users. Academics were not even mentioned. In Davies's words, academics are "at the level of plankton" in the evidence chain. The message seems clear. If researchers want to change the world, they need to become "experts." Leaving aside the question of how this metamorphosis occurs – whether by serendipity or design - the dilemma about the proper role of the researcher, described above in the context of the decision support synthesis, emerges once again. However, to the extent that the researcher "expert" provides policy advice informally or behind closed doors, the restraining effect of transparency on the free expression of value-based argument masquerading as evidence is lost. Whether a researcher can achieve and maintain the status of expert while remaining simply a purveyor of, and advocate for, research evidence (and whether such "objectivity" is even possible) remains in doubt.

Having described policy making as the "messy unfolding of collective action, achieved mostly through dialogue, argument, influence and conflict," Greenhalgh and Russell conclude that all's fair in policy making as long as the participants are aware of *and explicit about* how they and others play the game. Accepting this view, the least that can be expected of researchers who actively engage in the policy making process is explicitness about their interests, premises and values.

* Conducting and Commissioning Syntheses for Managers and Policy Makers, November 30 – December 2, Montreal, Quebec. Sponsored by the Canadian Health Services Research Foundation, Canadian Institutes of Health Research and the NHS Service and Delivery Organization R&D Programme.

REFERENCES

Greenhalgh, T. and J. Russell. 2005. "Reframing Evidence Synthesis As Rhetorical Action in the Policy Making Drama." *Healthcare Policy* 1(2): 34–42.

Lavis, J. 2005. "Moving Forward on Both Systematic Reviews and Deliberative Processes." *Healthcare Policy* 1(2): 59–63.

Lavis, J., H. Davies, R. Gruen, K. Walshe and C. Farquhar. 2005. "Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers." *Healthcare Policy* 1(2): 21–33.

Editorial

Lomas, J. 2005a. "Whose Views Count in Evidence Synthesis? And When Do They Count?" Healthcare Policy 1(2): 55–57.

Lomas, J. 2005b "Using Research to Inform Healthcare Managers' and Policy Makers' Questions: From Summative to Interpretive Synthesis." Healthcare Policy 1(1): 55–71.

Pope, C., N. Mays and J. Popay. 2005. "Informing Policy Making and Management in Healthcare: The Place for Synthesis." *Healthcare Policy* 1(2): 43–48.

Roger, R. 2005. "A Decision-Maker's Perspective on Lavis and Lomas." Healthcare Policy 1(2): 49-54.

> BRIAN HUTCHISON, MD, MSC, FCFP Editor-in-chief

Rôle des chercheurs dans la prise de décisions en matière de politiques : fournisseurs de preuves, fournisseurs d'idées?

ans ce numéro de la Revue nous présentons deux articles (Lavis et al. 2005, Greenhalgh et Russell 2005), deux commentaires (Pope et al. 2005, Roger 2005) et des réactions de Lomas (Lomas 2005a) et de Lavis (Lavis 2005) sous le thème « Points de vue sur les preuves, la synthèse et la prise de décisions. » Ajoutés à l'article publié par Lomas dans notre tout premier numéro (Lomas 2005b), ces textes fournissent des points de vue parfois complémentaires, parfois contradictoires, mais toujours très pertinents sur la façon (et la mesure dans laquelle) la recherche et les autres preuves peuvent être synthétisées, présentées et reçues pour informer les décisions sur les politiques de la santé et la gestion.

Au risque de pécher par excès, je vais à mon tour me jeter dans ces eaux déjà fourmillantes d'idées et examiner le rôle des chercheurs dans le processus de prise de décisions.

Dans leur commentaire, Pope et ses collègues font une distinction utile entre les examens et les synthèses qui fournissent un soutien aux connaissances et ceux qui fournissent un soutien aux décisions. Le soutien aux décisions fait participer les chercheurs, les décideurs, les gestionnaires, les intervenants et les « experts » à l'examen des choix possibles en matière de politiques. Outre le fait de résumer et de clarifier les preuves

pertinentes, quels autres rôles appropriés les chercheurs peuvent-ils jouer dans ce processus inévitablement désordonné? On peut raisonnablement s'attendre à ce qu'ils vantent les mérites des preuves fournies par la recherche et à ce qu'ils contestent les politiques qui remettent en cause ou qui ne tiennent pas compte des preuves indiquant une probabilité élevée de répercussions positives ou négatives sur le public. Mais doit-on s'arrêter là ou est-il approprié que les chercheurs se jettent dans la mêlée des politiques en tant que défenseurs d'idées, de valeurs ou de politiques? Les idées des chercheurs ne sont-elles pas aussi bonnes que celles des autres – voire meilleures, surtout si le chercheur travaille dans le domaine en question depuis nombre d'années ou y a passé toute sa carrière. D'un autre côté, les idées et les arguments des chercheurs reflètent non seulement leur expertise mais l'expérience de toute une vie et peuvent donc cacher, à des degrés variables, des enjeux personnels ou professionnels. Portant le manteau de l'objectivité, les chercheurs sont bien placés pour injecter, sous la guise de preuves, leurs propres valeurs dans les discussions sur les politiques. En devenant promoteurs d'idées, les chercheurs peuvent déprécier leur valeur en tant que fournisseurs de preuves. De toute évidence, ce sont là des questions que les chercheurs, les équipes de synthèse de recherche et ceux qui établissent les règles d'engagement pour un processus de synthèse à l'appui des décisions devront aborder et résoudre.

Cependant, comme Greenhalgh et Russell (2005) le soulignent si bien, les preuves traditionnelles – qu'elles soient synthétisées ou non – n'ont habituellement qu'un rôle marginal dans la prise des décisions relatives aux politiques. Lorsqu'on en tient compte, les preuves (hautement sélectionnées) sont généralement intégrées au processus par l'entremise d'intermédiaires comme les analystes internes, les « experts », les conseillers, les lobbyistes, les groupes d'intérêt, les journalistes ou les décideurs eux-mêmes. Lors d'un récent atelier sur la réalisation et la commande de synthèses pour les gestionnaires et les décideurs,* Phil Davies, directeur adjoint de l'unité de recherche sociale du gouvernement du R.-U., a décrit la « chaîne de preuves » de 55 grands décideurs du R.-U. Quand on leur demande vers où ils se tournent pour obtenir des conseils, ils citent leurs sources dans l'ordre suivant : conseillers spéciaux, « experts », « comités des sages », leaders d'opinions, lobbyistes et groupes de pression, associations professionnelles, médias et commettants/consommateurs/utilisateurs. Personne n'a mentionné les universitaires. Comme le dit Davies, les universitaires sont « l'équivalent du plancton » dans la chaîne de preuves. Le message semble clair. Si les chercheurs veulent changer le monde, ils doivent devenir des « experts. » Laissant de côté la question de savoir comment s'opère cette métamorphose – que ce soit par un heureux hasard ou par volonté – le dilemme entourant le rôle adéquat du chercheur, décrit ci-dessus dans le contexte des synthèses appuyant les décisions, émerge à nouveau. Cependant, dans la mesure où l'« expert » chercheur fournit des conseils sur les politiques de façon informelle ou derrière des portes closes, l'effet restreignant de la transparence sur la libre expression d'un argument axé sur la valeur et déguisé en

preuve est perdu. Il reste donc douteux qu'un chercheur puisse acquérir et maintenir le statut d'expert tout en demeurant un simple fournisseur – et un défenseur – de données de recherche (et qu'une telle « objectivité » soit même possible).

Ayant décrit l'élaboration de politiques comme étant « le dévoilement désordonné de mesures collectives, réalisé principalement par le dialogue, l'argument, l'influence et le conflit », Greenhalgh et Russell en viennent à la conclusion que tout est permis dans l'élaboration de politiques, à condition que les participants soient conscients de la façon dont eux et les autres jouent le jeu et qu'ils l'expriment explicitement. Si on accepte ce point de vue, la moindre des choses à laquelle on peut s'attendre des chercheurs qui participent activement au processus d'élaboration de politiques est une expression explicite de leurs enjeux, de leurs principes et de leurs valeurs.

* Réaliser et commander des synthèses pour les gestionnaires et les décideurs, du 30 novembre au 2 décembre, Montréal, Québec. Parrainé par la Fondation canadienne de la recherche sur les services de santé, Instituts canadiens de recherche en santé, et le programme de recherche et de développement du NHS Service and Delivery Organization.

> BRIAN HUTCHISON, MD, MSC, FCFP Rédacteur en chef

RÉFÉRENCES

Greenhalgh, T. et J. Russell. 2005. « Recadrer la synthèse des preuves comme une mesure de pure forme dans le drame de l'élaboration des politiques. » Politiques de santé 1(2): 34-42.

Lavis, J. 2005. « Aller de l'avant avec les examens systématiques et les processus de délibération. » Politiques de santé 1(2): 59-63

Lavis, J., H. Davies, R. Gruen, K. Walshe et C. Farquhar. 2005. « Travailler au sein de la Cochrane Collaboration et au delà de celle-ci pour rendre les examens systématiques plus utiles aux gestionnaires et aux décideurs du domaine des soins de santé. » Politiques de santé 1(2): 21-33.

Lomas, J. 2005a. « De quelles opinions tient-on compte dans la synthèse des preuves? » Politiques de santé 1(2): 55-57.

Lomas, J. 2005b « Utiliser la recherche pour informer les questions des gestionnaires et des décideurs : des synthèses sommatives aux synthèses interprétatives. » Politiques de santé 1(1): 55-71.

Pope, C., N. Mays et J. Popay. 2005. « Informer l'élaboration de politiques et la gestion dans les soins de santé : la place de la synthèse. » Politiques de santé 1(2): 43-48.

Roger, R. 2005. « Point de vue d'un décideur sur les articles de Lavis et Lomas. » Politiques de santé 1(2): 49–54.





Volume 1, Number 2 • January 2006

EDITOR-IN-CHIEF

BRIAN HUTCHISON, MD, MSC, FCFP

Professor Emeritus, Departments of Family Medicine and Clinical Epidemiology and Biostatistics, Centre for Health Economics and Policy Analysis, McMaster University

SENIOR EDITORS

FRANÇOIS BÉLAND, PHD
Professor, Department of Health Administration,
Faculté de médicine, Université de Montréal
Member, Groupe de recherche
interdisciplinaire en santé (GRIS)
Co-Director, Groupe de recherche
Université de Montréal-Université McGill
sur les personnes agées

RICK ROGER, MHSA Former Chief Executive Officer, Vancouver Island Health Authority Former Associate Deputy Minister, Saskatchewan Department of Health

EDITORS

LUC BOILEAU, MD, MSC, FRCPC President and Chief Executive Officer, Agence de la santé et des services sociaux de la Montérégie PASCALE LEHOUX, PHD
Associate Professor, Department of Health
Administration, Faculté de médicine,
Université de Montréal,
Member, Groupe de recherche
interdisciplinaire en santé (GRIS)
Canada Research Chair on Innovations in Health

COLLEEN FLOOD, PHD
Associate Professor, Faculty of Law and Department
of Health Policy, Management and Evaluation,
University of Toronto,
Canada Research Chair in Health Law and Policy

JOHN HORNE, PHD
Professor, Department of Community Health
Sciences, University of Manitoba
Former Chief Operating Officer,
Winnipeg Health Sciences Centre

CHAIR, EDITORIAL ADVISORY BOARD

ROBERT EVANS, PHD

Professor, Department of Economics, University of British Columbia Member, Centre for Health Services and Policy Research, University of British Columbia

EXECUTIVE EDITOR

DIANNE FOSTER KENT dkent@longwoods.com

MANAGING EDITOR

REBECCA HART rhart@longwoods.com

COPY EDITOR
FRANCINE GERACI

TRANSLATION
JOSEPHINE VERSACE

PROOFREADERWAYNE HERRINGTON

PUBLISHER

ANTON HART ahart@longwoods.com

DIRECTOR, DESIGN AND PRODUCTION

YVONNE KOO

PRODUCTION

JONATHAN WHITEHEAD

HOW TO REACH THE EDITORS AND PUBLISHER

Telephone: 416-864-9667 Fax: 416-368-4443

ADDRESSES

All mail should go to: Longwoods Publishing Corporation, 260 Adelaide Street East, No. 8, Toronto, Ontario M5A 1N1, Canada

For deliveries to our studio: 18 Eastern Avenue, Toronto, Ontario M5A 1H5, Canada

SUBSCRIPTIONS

Individual subscription rate for one year (online only) is [C]\$100 per year in Canada and [US]\$100 per year elsewhere. Institutional subscription rate for one year (online) is [C]\$450 per year in Canada and [US]\$450 per year elsewhere. Subscriptions must be paid in advance. For subscription information contact Barbara Marshall at telephone 416-864-9667, ext. 100 or by email at bmarshall@longwoods.com For institutional subscriptions, please contact Rebecca Hart at telephone 416-864-9667, ext. 105 or by email at rhart@longwoods.com

> An additional 7% Goods and Services Tax (GST) is payable on all Canadian transactions. Our GST number is R138513668.

EDITORIAL

To submit material or talk to our editors please contact: Rebecca Hart at 416-864-9667, ext. 105 or by email at rhart@longwoods.com

ADVERTISING

For advertising rates and inquiries, please contact Susan Hale at telephone 416-864-9667, ext. 104 or by email at shale@longwoods.com

PUBLISHING

To discuss supplements or other publishing issues contact Anton Hart at 416-864-9667, ext. 109 or by email at ahart@longwoods.com

Healthcare Policy/Politiques de Santé is published four times per year. The journal is published with support from the Canadian Institutes of Health Research's Institute of Health Services and Policy Research. Manuscripts are reviewed by the editors and a panel of peers appointed by the editors.

ISSN No. 1715-6572 Publications Mail Agreement No. 40069375

Return Undeliverable Canadian Addresses to: Circulation Department, Longwoods Publishing Corporation, 260 Adelaide Street East, No. 8, Toronto, Ontario M5A 1N1, Canada

CONTENTS

From the Editor-in-Chief

Researchers' Role in Policy Decision-Making: Purveyors of Evidence,
Purveyors of Ideas?

BRIAN HUTCHISON

THE UNDISCIPLINED ECONOMIST

14 Kafka, New Orleans, the OARs and the KT Boundary

ROBERT G. EVANS

Reverse the flow of Kafka's fable of the Imperial Message and you have the problem of Knowledge Transfer – the message is not getting through.

Perspectives on Evidence, Synthesis and Decision-Making

21

Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers

JOHN N. LAVIS, HUW T.O. DAVIES, RUSSELL L. GRUEN, KIERAN WALSHE AND CYNTHIA M. FARQUHAR

34 Reframing Evidence Synthesis As Rhetorical Action in the Policy Making Drama

TRISHA GREENHALGH AND JILL RUSSELL

43 Informing Policy Making and Management in Healthcare: The Place for Synthesis

CATHERINE POPE, NICHOLAS MAYS AND JENNIE POPAY

- 49 A Decision-Maker's Perspective on Lavis and Lomas
- Whose Views Count in Evidence Synthesis? And When Do They Count? IONATHAN LOMAS
- Moving Forward on Both Systematic Reviews and Deliberative Processes JOHN N. LAVIS

Data Matters

64

Bariatric Surgery in Canada

ALEKSANDRA JOKOVIC, JENNIFER FROOD AND KIRA LEEB Obesity rates for Canadian adults are much higher today than in the past; however, rates of bariatric surgery, a treatment for high-risk severely obese individuals, have not risen in parallel.

Decision-Maker Interview

71 Reflections on Conversations with Robert Bell and Michael Guerriere: What Is Relevant Research? ANTON HART

Linkage and Exchange

80 Knowledge Translation to Advance the Nurse Practitioner Role in British Columbia

MARJORIE MACDONALD, SANDRA REGAN, HEATHER DAVIDSON, RITA SCHREIBER, JANE CRICKMORE, LESLEY MOSS, JANET PINELLI AND BERNADETTE PAULY

Researchers and decision-makers conduct policy-relevant research to guide legislative and regulatory development and the design of a nurse practitioner education program.

Research Papers



90 Interactions: Trade Policy and Healthcare Reform After Chaoulli v. Quebec MARK CRAWFORD

Is it time for Canada to acknowledge the fragile boundary between health and trade policies and strengthen the separation between private and public health insurance?

103 Experiencing Difficulties Accessing First-Contact Health Services in Canada CLAUDIA SANMARTIN AND NANCY ROSS

Canadians without regular doctors and recent immigrants have difficulties accessing first-contact healthcare services. Reports of difficulties in accessing care vary by age, sex and region.

120 Inclusivity and Dementia: Health Services Planning with Individuals with Dementia

KYLE WHITFIELD AND SUSAN WISMER

Effective inclusion requires action at multiple levels by individuals with dementia, care partners, service providers and funding organizations.

135 The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

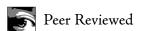
SANOBER S. MOTIWALA, SHAMALI GUPTA, MEREDITH B. LILLY, WENDY J. UNGAR AND PETER C. COYTE

In the past year, several court cases have been brought against provincial governments to increase funding for Intensive Behavioural Intervention (IBI). This economic evaluation examines the costs and consequences of expanding an IBI program.

152 Waiting Time for Radiation Therapy in Breast Cancer Patients in Quebec from 1992 to 1998

BERNARD FORTIN, MARK S. GOLDBERG, NANCY E. MAYO, MARIE-FRANCE VALOIS, SUSAN C. SCOTT AND JAMES HANLEY

A study of surgically treated breast cancer patients in Quebec documents and helps to explain increased waiting times for radiation therapy.



Du rédacteur en chef

Rôle des chercheurs dans la prise de décisions en matière de politiques: fournisseurs de preuves, fournisseurs d'idées?

BRIAN HUTCHISON

L'économiste indiscipliné

14 Kafka, la Nouvelle-Orléans, les OAR et la frontière de l'AC ROBERT G. EVANS

Racontez la fable du message impérial de Kafka en sens inverse et vous avez le problème de l'application des connaissances – le message ne passe pas.

Points de vue sur les preuves, la synthèse et la prise de décisions

- Travailler au sein de la Cochrane Collaboration et au delà de celle-ci pour rendre les examens systématiques plus utiles aux gestionnaires et aux décideurs du domaine des soins de santé

 JOHN N. LAVIS, HUW T.O. DAVIES, RUSSELL L. GRUEN, KIERAN WALSHE
 ET CYNTHIA M. FARQUHAR
- Recadrer la synthèse des preuves comme une mesure de pure forme dans le drame de l'élaboration de politiques
 TRISHA GREENHALGH ET JILL RUSSELL
- Informer l'élaboration de politiques et la gestion dans les soins de santé : la place de la synthèse

 CATHERINE POPE, NICHOLAS MAYS ET JENNIE POPAY
- 49 Point de vue d'un décideur sur les articles de Lavis et Lomas RICK ROGER

- 55 De quelles opinions tient-on compte dans la synthèse des preuves? Et quand en tient-on compte? JONATHAN LOMAS
- 59 Aller de l'avant avec les examens systématiques et les processus de délibération JOHN N. LAVIS

Questions de données

64



La chirurgie bariatrique au Canada
ALEKSANDRA JOKOVIC, JENNIFER FROOD ET KIRA LEEB Les taux d'obésité chez les adultes canadiens sont beaucoup plus élevés aujourd'hui que par le passé; cependant, les taux de chirurgie bariatrique – un traitement pour les personnes très obèses présentant un risque élevé – n'ont pas augmenté au même rythme.

Entrevue avec des décideurs

Réflexions sur des conversations avec Robert Bell et Michael Guerriere : La 71 recherche pertinente : qu'est-ce que c'est au juste? ANTON HART

Liens et échanges

80 Appliquer les connaissances en vue de faire avancer le rôle des infirmières praticiennes en Colombie-Britannique

MARJORIE MACDONALD, SANDRA REGAN, HEATHER DAVIDSON, RITA SCHREIBER, JANE CRICKMORE, LESLEY MOSS, JANET PINELLI ET BERNADETTE PAULY

Des chercheurs et des décideurs effectuent de la recherche liée aux politiques afin de guider l'élaboration de mesures législatives et réglementaires et la conception d'un programme d'enseignement à l'intention des infirmières praticiennes.

Documents de recherche



90 Interactions : les politiques commerciales et la réforme des soins de santé après Chaoulli c. Québec

MARK CRAWFORD

Est-il temps pour le Canada de reconnaître la frontière fragile entre les politiques de santé et les politiques commerciales et de renforcer la séparation entre l'assurancesanté publique et privée?

103 Difficultés d'accès aux soins de santé de première ligne au Canada

CLAUDIA SANMARTIN ET NANCY ROSS

Les Canadiens qui n'ont pas de médecin de famille et les immigrants récents ont de la difficulté à avoir accès à des soins de santé de première ligne. Le signalement des difficultés d'accès aux soins variait selon l'âge, le sexe et la région.

120 Inclusivité et démence : planification des services de santé pour les personnes atteintes de démence

KYLE WHITFIELD ET SUSAN WISMER

L'inclusion efficace exige la prise de mesures, à des paliers multiples, par les personnes atteintes de démence, les partenaires en matière de soins, les fournisseurs de services et les bailleurs de fonds.

Rentabilité de l'étendue des services d'intervention comportementale intensive à tous les enfants autistes de l'Ontario

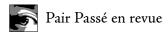
SANOBER S. MOTIWALA, SHAMALI GUPTA, MEREDITH B. LILLY, WENDY J. UNGAR ET PETER C. COYTE

Au cours de la dernière année, plusieurs poursuites judiciaires ont été intentées contre les gouvernements provinciaux en vue d'amener ces derniers à augmenter le financement accordé à l'intervention comportementale intensive (ICI). Cette analyse économique examine les coûts et les conséquences de l'élargissement de la portée d'un programme d'ICI.

Temps d'attente pour la radiothérapie chez les femmes atteintes de cancer du sein au Québec de 1992 à 1998

BERNARD FORTIN, MARK S. GOLDBERG, NANCY E. MAYO, MARIE-FRANCE VALOIS, SUSAN C. SCOTT ET JAMES HANLEY

Une étude menée auprès de femmes atteintes du cancer du sein et qui ont reçu un traitement chirurgical au Québec cherche à expliquer la raison de l'augmentation du temps d'attente pour les traitements de radiothérapie.



International Network of C Integrated Care

7th Annual Integrated Care Conference Integrated Care: The Agony and the Ecstasy April 7-8, 2006, Montreal, Canada

Organizers

International Network of Integrated Care (INIC) www.integratedcarenetwork.org SOLIDAGE Research Group www.solidage.ca PRISMA Research Group www.prisma-qc.ca

The International Network of Integrated Care (INIC) is a non-profit organization that represents researchers, policy analysts, managers and professionals dedicated to the promotion of integrated care leading to better quality, more cost-effective health care.

Keynote Speakers

Philippe Couillard

Minister of Health, Government of Quebec Integrating health and social services to better serve a population: the Quebec experience

Léonard Aucoin

President, InfoVeille Santé What can public health care systems learn from Kaiser Permanente?

Ruud ter Meulin

Professor, Chair of Ethics in Medicine Bristol University, Bristol, UK Market forces and integrated care: how well can they mix?

Chad Boult

Director, Lipitz Center for Integrated Care Professor of Health Policy & Management Johns Hopkins University, Baltimore, Maryland Implementing the chronic care model: the 'guided care' approach to primary care for high-risk elderly patients

David Levine

President and CEO Montreal Regional Health Authority Population based health care management: a model for health reform in Montreal

Conference objectives

- Review of the latest developments in integrated health care drawing on specific international experiences;
- Discuss economic and social factors that influence the efficacy of integrated care;
- Discuss the implementation of integrated care models;
- Present research results leading to novel ideas and developments in integrated care.

Call for Abstracts

Paper and poster submissions are encouraged in the areas of research, policy and practice. See details on the meeting information website.

Abstract deadline is January 30, 2006

Additional meeting information: www.integratedcarenetwork.org

Kafka, New Orleans, the OARs and the KT Boundary

Kafka, la Nouvelle-Orléans, les OAR et la frontière de l'AC

Reverse the flow of Kafka's fable of the Imperial Message and you have the problem of Knowledge Transfer – the message is not getting through.

by ROBERT G. EVANS
Professor of Economics
University of British Columbia
Vancouver, BC

Abstract

The dying emperor in Kafka's tale has sent you a message of great importance, entrusted to his strongest herald. But the throne room, the palace, the city are so huge and so crowded with people that the message can never reach you. Reverse the tale and you have the problem of Knowledge Transfer (KT) – brutally illustrated by the fate of New Orleans. Important information, of unquestioned validity, soundly based in research and easy to understand, simply does not get through to practice. A recent evaluation of the Ottawa Ankle Rules makes the point all too clearly. Indeed, the KT problem is worse than Kafka's. Economically motivated people and organizations actively distort the messages – and try to trip the herald – while grossly oversimplified frameworks of understanding include no language in which the messages can be expressed. "More research" is not the answer.

Résumé

L'empereur mourant du récit de Kafka vous a envoyé un message de la plus haute importance et l'a confié à son plus fidèle messager. Mais la salle du trône, le palais et

la ville sont si vastes et si populeux que le message ne vous parvient jamais. Racontez cette histoire en sens inverse et vous avez le problème de l'application des connaissances (AC) – crûment illustrée par le destin de la Nouvelle-Orléans. Les renseignements importants dont la validité est sans équivoque, qui sont fondés sur des travaux de recherche solides et qui sont faciles à comprendre, n'arrivent tout simplement pas à se frayer un chemin jusqu'à la pratique. Une récente évaluation des « Ottawa Ankle Rules » n'illustre que trop clairement ce point. Le problème de l'AC est en réalité bien pire que celui de Kafka. Les personnes et les organismes ayant des enjeux économiques s'emploient activement à déformer les messages – et à essayer de faire trébucher le messager – tandis que des cadres théoriques trop simplifiés n'incluent aucun langage dans lequel exprimer les messages. « D'autres travaux de recherche » ne sont pas la solution.

An Imperial Message

The Emperor – so they say – has sent a message, directly from his death bed, to you alone, his pathetic subject, a tiny shadow that has taken refuge at the farthest distance from the imperial sun. He ordered the herald to kneel down beside his bed and whispered the message in his ear. He thought it was so important that he had the herald speak it back to him. He confirmed the accuracy of the verbal message by nodding his head. And in front of the entire crowd of those witnessing his death – all the obstructing walls have been broken down, and all the great ones of his empire are standing in a circle on the broad and high-soaring flights of stairs – in front of all of them he dispatched his herald.

The messenger starts off at once, a powerful, tireless man. Sticking one arm out and then another, he makes his way through the crowd. If he runs into resistance, he points to his breast, where there is a sign of the sun. So he moves forward easily, unlike anyone else. But the crowd is huge; its dwelling places are infinite. If there were an open field, how he would fly along, and soon you would hear the marvellous pounding of his fist on your door. But instead of that, how futile are all his efforts. He is still forcing his way through the private rooms of the innermost palace.

Never will he win his way through. And if he did manage that, nothing would have been achieved. He would have to fight his way down the steps and, if he managed to do that, still nothing would have been achieved. He would have to stride through the courtyards, and after the courtyards through the second palace encircling the first, and then again, through stairs and courtyards, and then, once again, a palace, and so on for thousands of years. And if he finally burst through the outermost door – but that can never, never happen – the royal capital city, the centre of the world, is still there in front of him, piled high and full of sediment. No one pushes his way through here, certainly not someone

with a message from a dead man. But you sit at your window and dream of that message when evening comes. (Translated by Ian Johnston, Malaspina College–University, Nanaimo, BC)

Reverse the flow of Kafka's fable and you have the problem of Knowledge Transfer (KT). You, the humble researcher beyond the outer fringe of power, have a message of great importance for the emperor. The message is crystal clear, and the (living) emperor needs and would very much want to hear it. But so crowded is the public discourse with other issues, other priorities, other people's messages, that it is impossible for your message to get through. Human rationality is bounded, and your message is outside the boundary. Which brings us to New Orleans.

"Just Because I Don't Care ..."

From the perspective of KT, what is most interesting about the drowning of New Orleans is not the disaster itself, nor the slow and fumbling response, nor even the gathering of commercial vultures as the event reaches the end of its media life. Rather, it is that the disaster was so predictable and so widely and accurately predicted. From sophisticated computer simulations and engineering studies, to articles in high-end magazines – *Scientific American, National Geographic* – the message was spelled out unambiguously in letters 10 feet tall.

Nor was that message at all difficult to understand. The various interacting natural and human processes that made New Orleans a disaster waiting to happen may be complex and subtle, but the central points do not require advanced training. Much of New Orleans is below sea level, some nearly 20 feet below. The city has survived behind levees that were known to be inadequate to withstand a major hurricane. The Gulf of Mexico is a major hurricane track. When (not if) a hurricane hit, the city would be drowned. There would be great loss of life, massive disruption of lives and colossal property damage. One did, it was, and there was.

If the ultimate test of good science is successful prediction, then the analysis of New Orleans' predicament was very good science. The KT was a complete and utter failure. But that failure cannot be charged to the messenger, or to the message. The message was clear, and the heralds tried their best. But the streets of the capital, the courtyards and corridors of the palace, and especially the throne room, were thronged, jammed tight with people and their uncountable multitudes of concerns. Whatever message receptor sites there might have been were already occupied. (The arteries of imperial power, suggests Morris Barer, were clogged with fatter pork.) The herald and his portentous message could not get through.

Rowing Against the Current

Now let's narrow the focus and consider another clear and unambiguous message: orders of magnitude less dramatic than the destruction of a city, but nonetheless with powerful implications for KT in healthcare. Over a decade ago, a research team at the Ottawa Civic Hospital (Stiell et al. 1992, 1994) generated and began to disseminate the Ottawa Ankle Rules (OARs). These constituted a rigorously developed and extensively tested algorithm for diagnosing ankle injuries in the Emergency Department (ED) that permits clinicians to rule out fractures through a simple (and small) set of careful observations. Radiography, the standard response to ankle injury, was – in a high proportion of presenting cases – simply unnecessary.

Injured ankles make up a significant share of ED workload; universal implementation of these rules could thus reduce radiology load and costs, as well as saving patient and clinician time. Perhaps more important, the development of such a simple and successful clinical decision rule (CDR) held out the prospect of a much broader array of similar CDRs, a program that the Ottawa team have subsequently taken up with vigour.

And the result?

These rules are transforming the approach to the assessment of these injuries and, after training, can be used by clinicians from a range of backgrounds (including medical, nursing and paramedic staff), in both hospital and community settings. (Heyworth 2003)

But in 1999, Cameron and Naylor told a different story from Ontario:

Although participants gave highly positive appraisals of the Ottawa Ankle Rules and the educational sessions, there was no reduction in the use of ankle radiography for the 10 hospitals that received the educational sessions. ... Even when a dissemination strategy is well received and involves a widely accepted clinical guideline, the impact on behaviour in clinical practice may be small.

Or, indeed, nil. So the recently published study of uptake by the Ottawa group (Brehaut et al. 2005) should not be a total surprise. Their survey of a sample of ED physicians found that while 99.2% reported familiarity with the OARs, "82.4% had not reviewed the rules in months or years, and only 30.9% were able to correctly [sic] remember the components of the rule."

Perhaps it is just as well that "only 42.2% reported basing their decisions to order radiography primarily on the rule," though that is exactly the purpose for which the OARs were designed and are very effective. 89.6% reported applying the OARs (very rarely consulting memory aids) "always" or "most of the time." But most applied these rules in combination with other clinical observations. Unfortunately, these observa-

tions were "non-rule factors that are not related to the presence of a fracture ... and factors that add no more predictive value over and above the rule."

These findings essentially repeat the message of Jonathan Lomas and his colleagues (1989): "Do practice guidelines guide practice?" Well, no. Lomas et al. surveyed Ontario clinicians to determine their responses to the SOGC guidelines for caesarian section, guidelines motivated by rates of intervention that were generally agreed to be excessive. They then matched (with subjects' permission) responses with actual practice as reflected in OHIP billing. Briefly, a majority of respondents said that they knew of the guidelines, agreed with them and followed them in practice. But in fact, they did not. Inappropriate interventions continued unabated.

The point of this excursion into CDRs is not to bash ED clinicians, but to suggest a parallel between these two egregious examples, from radically different settings, of complete failure of knowledge transfer. In both cases the message was simple, clear and about as solidly grounded in evidence and analysis as one could hope. Both messages were consequential and were widely disseminated within the relevant communities, and their implications for "What is to be done?" were direct and unambiguous. Nothing happened.

"Do I Have the Party to Whom I Am Speaking?"

We now have a nice, new Canadian journal of health policy. KT is both part of its purpose and part of its subject matter. But Kafka's story implies that simply (!) generating sound research findings with clear policy implications and disseminating them widely may nonetheless achieve nothing. (Bit of a nihilist, Kafka was, but that's one way to avoid disappointment.)

Health researchers' messages, of course, address not one emperor but several different "policy maker" communities. The experience with the OARs, however, underlines heavily a point made long ago by Lomas, that every clinician is a policy maker. Clinical policy, the sum and resultant of day-to-day decisions, is at least as significant for health system performance as is the "high policy" of politicians, senior bureaucrats and administrators – and even, occasionally, judges. (A.P. Herbert's character Albert Haddock argues that a judgment of the House of Lords is equivalent to an act of God because it, too, is something that "no reasonable man could have expected.")

Official policies can have a powerful impact on the context of clinical policy, but their effects, for good or ill, ultimately flow through clinical decisions. Have we implicitly written off direct communication with clinicians as "not our department" – or perhaps wholly ineffective in the absence of substantial contextual change? Do we then bet our chips solely on reaching non-clinicians?

At the journal's launch, though, Paul Jacobson argued rather vigorously that our journal will not reach even those official policy makers who are really critical for effec-

tive KT. A broadened conversation with health administrators and bureaucrats remains within a shared framework of understanding. Our messages may be clear, sound and well understood within that community, but the real levers of power are elsewhere – in the hands of politicians and senior finance officials who are outside our conversation.

Their absence was powerfully illustrated by Lavis et al. (2003) in surveying the penetration within federal and provincial bureaucracies of current concepts of population health. Those ideas were widely disseminated and had been taken up across health, social services and labour ministries – but not in finance. What could fiscal policy possibly have to do with population health? Some thought that the survey had been sent to them in error.

Lavis's findings reinforce Kafka's point. The failure of KT was not traceable to a confused message or to inarticulate messengers. People in other ministries "got the message" with no apparent difficulty, and members of finance departments are surely, on average, no less intelligent. Why has nothing gotten through?

Kafka's hordes have, I think, their analogy in the powerful and elaborately articulated framework of understanding peculiar to economics and predominant in finance departments and the business community generally. Such frameworks provide a filter for information, defining what is and particularly what is not to be attended to. Conventional economic analysis, especially as practised in North America, provides "off-the-shelf" explanations generated from *a priori* theory for both the determinants of health and the dynamics of healthcare systems. These typically incorporate little, if any, knowledge of the actual subject matter and are correspondingly grossly oversimplified when not just plain wrong.

Findings from health services research, solidly rooted in the real world of health and healthcare, do not fit into the predetermined conceptual categories of the conventional economic framework – no receptor sites – so in a real sense cannot be heard. They *can* be heard by those working within alternative, much looser and more flexible frameworks of understanding – but they are generally farther from the throne.

Research Be Damned! We're Trying to Make a Buck!

Worse, the crowd in the throne room includes some – small in numbers, perhaps, but very heavily resourced – with a strong economic interest in blocking or distorting the messages from research and substituting self-serving myths. The pharmaceutical industry is the most notorious example, but private insurers have an obvious interest in undermining universal public coverage. No private payment, no private insurance. Commercial diagnostic enterprises can be indifferent to OAR-type decision rules, only so long as they have no effect. Imagine the impact on costs, and on health policy generally, if all access to MRI had to be justified by some explicit, evidence-based prospect of improved patient outcomes.

All cost savings are threats to someone's income. For publicly traded corporations, a reduction in expected future earnings translates directly into reduced share values. Remember Nortel – capital markets are brutally unforgiving.

Demand creates its own supply, and these commercial interests have supported the growth of a specialized private disinformation industry – "liars for hire" would be impolite, call them marketers by other means – to promote public policies furthering those corporate interests and to deflect or discredit threatening research findings. All perfectly normal, in a for-profit world. These activities have little or no penetration among the health research community, but have been very effective in exploiting the intellectual vulnerability of those pre-conditioned to hear their selective, simplistic and grossly distorted messages. The *Chaoulli* decision provides a spectacular example, but any randomly selected product of standard economics training should serve as well.

The "(K) retaceous-Tertiary (KT) Boundary" refers not to knowledge transfer, but to a thin layer of iridium-enriched clay marking a discontinuity between these geological periods. It is generally interpreted as the consequence of a really bad day in the Yucatan. The crossing of this KT boundary was a decisive break in evolutionary history. But the Age of Mammals, previously a bunch of evolutionary no-hopers, would have been impossible without the elimination of the dinosaurs. While they remain in place – unexamined habits of thought and behaviour, fed and reinforced by entrenched economic interests – KT will be a dubious battle.

REFERENCES

Brehaut, J.C., I.G. Stiell, L. Visentin and I.D. Graham. 2005 (October). "Clinical Decision Rules in the Real World': How a Widely Disseminated Rule Is Used in Everyday Practice." *Academy of Emergency Medicine* 12(10): 948–956.

Cameron, C. and C.D. Naylor. 1999. "No Impact from Active Dissemination of the Ottawa Ankle Rules: Further Evidence of the Need for Local Implementation of Practice Guidelines." *Canadian Medical Association Journal* 160(8): 1165–1168.

Heyworth, J. 2003 (February 22). "Ottawa Ankle Rules for the Injured Ankle: Useful Clinical Rules Save on Radiographs and Need to Be Used Widely." Editorial. *British Medical Journal* 326: 405–406.

Lavis, J.N., S.E. Ross, G.L. Stoddart et al. 2003 (April). "Do Canadian Civil Servants Care about the Health of Populations?" *American Journal of Public Health* 93(4): 371–379.

Lomas, J., G.M. Anderson, K. Domnick-Pierre et al. 1989. "Do Practice Guidelines Guide Practice?" New England Journal of Medicine 321(19): 1306–1311.

Stiell, I.G, G.H. Greenberg, R.D. McKnight et al. 1992. "A Study to Develop Clinical Decision Rules for the Use of Radiography in Acute Ankle Injuries." *Annals of Emergency Medicine* 21: 384–390.

Stiell, I.G, R.D. McKnight, G.H. Greenberg et al. 1994. "Implementation of the Ottawa Ankle Rules." *Journal of the American Medical Association* 271: 827–832.

Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers

Travailler au sein de la Cochrane Collaboration et au delà de celle-ci pour rendre les examens systématiques plus utiles aux gestionnaires et aux décideurs du domaine des soins de santé



by John N. Lavis, Md, Phd

Member, Centre for Health Economics and Policy Analysis Associate Professor, Department of Clinical Epidemiology and Biostatistics Associate Member, Department of Political Science McMaster University, Hamilton, Canada

HUW T.O. DAVIES, PHD

Director, Centre for Public Policy and Management Professor, School of Management University of St. Andrews, St. Andrews, Scotland

RUSSELL L. GRUEN, MB BS, PHD, FRACS

Fellow in Trauma Surgery and Critical Care, Harborview Medical Center and University of Washington, Seattle, USA Associate Professor, Menzies School of Health Research, Darwin, Australia

KIERAN WALSHE, PHD

Director, Centre for Public Policy and Management Professor of Health Policy and Management Manchester Business School, Manchester, England

CYNTHIA M. FARQUHAR, MD, MPH, FRANZCOG Professor, Department of Obstetrics and Gynaecology University of Auckland, Auckland, New Zealand

Abstract

Participants in the Cochrane Collaboration conduct and periodically update systematic reviews that address the question, "What works?" for healthcare interventions. The Cochrane Library makes available quality-appraised systematic reviews that address this question. No coordinated effort has been undertaken to conduct and periodically update systematic reviews that address the other types of questions asked by healthcare managers and policy makers, to adapt existing reviews to highlight decision-relevant information (including the factors that may affect assessments of a review's local applicability) or to facilitate their retrieval through a "one-stop shopping" portal. Researchers interested in evaluating new methodological developments, health services and policy researchers interested in conducting and adapting systematic reviews, and research funders all have a role to play in making systematic reviews more useful for healthcare managers and policy makers.

Résumé

Les participants à la Cochrane Collaboration effectuent et mettent périodiquement à jour des examens systématiques qui abordent la question : « Qu'est-ce qui fonctionne? » pour les interventions en matière de santé. La Cochrane Library met, à la portée du public, des examens systématiques dont la qualité a été évaluée et qui traitent de cette question. Aucun effort coordonné n'a été entrepris pour effectuer et mettre périodiquement à jour des examens systématiques qui traitent des autres types de questions que posent les gestionnaires et les décideurs; pour adapter les examens existants afin de mettre en relief les données pertinentes pour la prise de décisions (y compris les facteurs susceptibles d'influencer les évaluations de l'applicabilité d'un examen à l'échelle locale); ou pour faciliter leur extraction par l'entremise d'un « guichet unique. » Les chercheurs désireux d'évaluer les nouveaux développements méthodologiques, les chercheurs en politiques qui veulent réaliser et adapter des examens systématiques, ainsi que les bailleurs de fonds de travaux de recherche ont tous un rôle à jouer pour rendre les examens systématiques plus utiles aux gestionnaires et aux décideurs du domaine des soins de santé.

making by providing research-based responses to important questions about health systems (Davies et al. 2000; Lavis et al. 2004). Systematic reviews offer four advantages to potential target audiences outside the research community, the first two of which apply primarily to reviews that address questions about "what works." First, the likelihood of being misled by research evidence is lower with a systematic review than with an individual study (Eggar et al. 2001). Second, confidence in what can be expected from an intervention is higher with a systematic review than with an individual study (Eggar et al. 2001). Third, drawing on an existing systematic review constitutes a more efficient use of time because the research literature has already been identified, selected, appraised and synthesized in a systematic and transparent way (Lavis et al. 2005). Fourth, a systematic review can be more constructively contested than an individual study because debates can focus on appraisal and synthesis rather than on the reasons that one study was identified and selected over others (Lavis et al. 2005).

The Cochrane Collaboration is an international, not-for-profit and independent organization, dedicated to making up-to-date, accurate information about the effects of healthcare interventions readily available worldwide by promoting the search for evidence and producing and disseminating systematic reviews. The Cochrane Library provides one-stop shopping for quality-appraised reviews that address the question "What works?" – both those reviews produced according to the quality standards of the Cochrane Collaboration and those that have been quality-appraised by two independent raters. (The Cochrane Library also provides one-stop shopping for health technology assessments, which typically build on systematic reviews, and economic evaluations.)

The Cochrane Collaboration's Effective Practice and Organization of Care (EPOC) Review Group has as its major focus the promotion of systematic reviews of health system interventions (McAuley et al. 2003). An EPOC review draws on randomized controlled trials or (in their absence) controlled before/after studies and interrupted time-series studies to address a question about the effectiveness of an intervention (i.e., "What works?"). EPOC faces challenges, however, in ensuring that reviews address questions relevant to healthcare management and policy making, developing methods and quality standards to assess complex health system interventions, highlighting factors that may influence the local applicability of reviews and adapting the presentation of reviews to enhance their usefulness for managers and policy makers.

No coordinated effort akin to the Cochrane Collaboration has been undertaken to address questions other than "What works?," and no "one-stop shopping" portal akin to the Cochrane Library has been developed to make available quality-appraised

reviews that address a broader array of questions. Healthcare managers and policy makers are interested in the most effective solutions to the most burdensome health problems, the most effective ways to fit these solutions into complex health systems and the most effective ways to bring about desired changes in health systems (Lavis et al. 2004). But in addition to asking questions about effectiveness (does changing X change Y?), they also ask questions about cost-effectiveness (is X_1 more cost-effective than X_2 in achieving a one-unit change in Y?), relationships (is X associated with Y?), mechanisms (how are X and Y linked, or why does changing X change Y?) and meanings (how have X or Y been viewed or experienced?). In recent years a variety of new approaches have been developed to conduct and update systematic reviews that address this broader array of questions.

In this paper we outline some ways in which the production and updating of systematic reviews (i.e., the future flow of systematic reviews), the adaptation of the global stock of systematic reviews and the development of improved retrieval mechanisms for systematic reviews could enhance the usefulness of systematic reviews for healthcare managers and policy makers. In so doing we highlight how health services and policy researchers can work both within the Cochrane Collaboration to address questions about "what works" and beyond it to address other questions. We envision a future in which all health services and policy researchers register their reviews (as do Cochrane reviewers) to avoid unnecessary duplication and most regularly update at least one systematic review. We also envision a future in which research funders support production, adaptation and retrieval processes to ensure that systematic reviews are available when healthcare managers and policy makers need them to inform their decision-making.

Conducting and Updating Systematic Reviews

Of the five elements of a systematic review -(1) an explicit question, (2) an explicit description of the search strategy, (3) an explicit statement about what types of research evidence were included and excluded, (4) a critical examination of the quality of the studies included in the review and (5) a critical and transparent process of interpretation of the findings of the studies included in the review - we focus particularly on posing questions (element 1), selecting studies (element 3) and synthesizing studies (element 5), as well as on the role of healthcare managers and policy makers in these three steps.

We begin with involving healthcare managers and policy makers in the systematic review because their inclusion has the potential to influence many elements of the process. We offer three reasons for augmenting the stock of investigator-driven systematic reviews with reviews that involve healthcare managers and policy makers. First, a systematic review of the factors that influenced the use of research evidence

in healthcare policy making identified that individual-level interactions between researchers and healthcare policy makers increased the prospects for research use in policy making (Lavis et al. 2005). Second, an analysis of websites of research funders, producers/purveyors of research and journals that include healthcare managers and policy makers among their target audiences found that such linkage and exchange processes are rare (Lavis et al. 2005). Third, involving managers and policy makers in the systematic review could enhance the public accountability of researchers when they derive take-home messages from research, which is a type of accountability that has been noticeably lacking (Black 2001).

We now turn to the first element of a systematic review – an explicit question. As we have already pointed out, healthcare managers and policy makers ask questions about the most effective solutions to the most burdensome health problems, the most effective ways to fit these solutions into complex health systems or, more generally, to design health systems (i.e., governance, financial and delivery arrangements) and the most effective ways to bring about desired changes in health systems. While Cochrane's EPOC Review Group is focused in part on the effectiveness of such governance, financial and delivery arrangements, the scale of its effort does not yet match the scale (or complexity) of the task at hand. Moreover, while the EPOC Review Group is also focused in part on the most effective ways to bring about desired changes in health systems, its efforts need to be expanded beyond interventions targeted at health professionals to include change-management strategies at the level of organizations.

Healthcare managers and policy makers also ask questions about the cost-effectiveness of alternative approaches to achieving particular outcomes, relationships between factors and outcomes, mechanisms through which factors may affect outcomes and the meanings ascribed to particular factors and outcomes. In recent years new approaches have been developed to conduct and update systematic reviews that address this broader array of questions (Dixon-Woods et al. 2005; Mays et al. 2005). Most involve relatively minor alterations to established approaches, but one is substantively different in that it takes a more iterative approach to the development of the question as the systematic review progresses (Pawson et al. 2005). The arguments in favour of allowing the question to be refined and revised are that this approach is more likely to yield new ways of thinking and, when informed by interactions with healthcare managers and policy makers, is more likely to yield reviews relevant to the decisions they face. The arguments against allowing the question to change are that this approach requires either a great deal of resources or "cutting corners" in subsequent steps, and that it introduces bias into what would otherwise be an approach that strives to minimize bias.

We now turn to the third element of a systematic review – an explicit statement about what types of research evidence were included and excluded. Here we again highlight the one substantive change that has been advocated by some of those who

produce systematic reviews for healthcare managers and policy makers: drawing a purposive sample of studies for review rather than reviewing all eligible studies. This proposal often goes hand in hand with the proposal to allow the question to change as the systematic review progresses, in part because drawing a sample of studies reduces the resources required for an iterative approach. Drawing a purposive sample of studies would also be consistent with the qualitative methods used in some approaches to synthesizing studies. The arguments against purposive sampling are that it could introduce bias and, in the long run, reduce the pressure to improve the retrievability of health services and policy research.

Finally, we turn to the fifth element of a systematic review – a critical and transparent process of interpretation of the findings of the studies included. The new approaches that have been developed to conduct and update systematic reviews that address the broader array of questions asked by healthcare managers and policy makers often differ most profoundly in how research findings are synthesized (Dixon-Woods et al. 2005). The approaches range from techniques that are largely qualitative and interpretive (e.g., thematic analysis) to those that are largely quantitative and integrative (e.g., Bayesian meta-analysis). A recent review of these approaches concluded with a call for their further development and refinement in coordinated and well-evaluated ways (Dixon-Woods et al. 2005).

Adapting Systematic Reviews

Even if the future flow of systematic reviews were modified in ways that enhance their relevance to healthcare managers and policy makers, substantial efforts would still be needed to adapt the global stock of reviews in ways that enhance their usefulness. Two potential adaptations involve changes to the types of information profiled in a systematic review. First, information about the harms (or risks) and costs of interventions (not just the benefits), the uncertainty associated with estimates and any differential effects by subgroup would be needed in order to provide healthcare managers and policy makers with decision-relevant information. Second, information about the contextual factors that may affect a review's local applicability would be needed in order for managers and policy makers to decide whether to give serious consideration to the decision-relevant information. The other potential adaptation involves developing user-friendly "front ends" for reviews that would allow rapid scanning for relevance and then graded entry to highly relevant reviews.

Providing three types of decision-relevant information – harms (or risks) and costs (not just benefits), uncertainty and differential effects by subgroup – was universally supported as a way to enhance the usefulness of systematic reviews by the healthcare managers and policy makers who were interviewed about these possibilities (Lavis et al. 2005). Highlighting the uncertainty associated with estimates would be

relatively straightforward. But providing information about harms (or risks) would require greater emphasis on examining in primary studies the harms (or risks) associated with interventions (GRADE Working Group 2004). Providing information about the costs of interventions, not just the benefits, would require additional efforts to identify such costs as well as a broader consideration of economic issues in systematic reviews, a topic being examined by the Campbell and Cochrane Economics Methods Group (C&CEMG 2005). Moreover, describing any differential effects by subgroup would need to be approached with caution, given prevailing concerns about subgroup analyses (Oxman and Guyatt 1992).

Providing information about the contextual factors that may affect a review's local applicability is perhaps even more important and challenging. Commonalities in human biology mean that a prescription drug will often work the same way in different populations. Differences in health systems mean that an intervention that works in one organization or jurisdiction may not work the same way in another, and systematic reviews may not contain studies that were conducted in a healthcare manager's organization or a policy maker's jurisdiction. One approach to helping managers and policy makers decide whether to give serious consideration to a systematic review is to highlight features of the intervention and the contexts in which it was employed that would influence assessments of the review's local applicability. Such features may include the relative importance of the health problem, relevance of outcome measures, practicality of the intervention, appropriateness of the intervention and its cost-effectiveness (Gruen et al. 2005).

A second approach to assisting managers and policy makers with assessments of the local applicability of a systematic review is to equip them with a tool to conduct such assessments (Lavis et al. 2004). The one existing tool includes four questions: (1) Could it work, or are there important differences in the structural elements of health systems that mean an intervention could not work in the same way as in the jurisdictions where the research was done? (2) Will it work, or are there important differences in the perspectives and influence of those health system stakeholders who have the political resources to influence decisions that mean an intervention will not be accepted or taken up in the same way, and does the health system face other challenges that substantially alter the potential benefits and harms (or risks) of the intervention? (3) What would it take to make it work, or can power dynamics and on-the-ground realities and constraints be changed in the short to medium term, and what are the prospects for making this happen? (4) Is it worth it or is the balance of benefits and harms (or risks) classifiable as net benefits, trade-offs, uncertain trade-offs or no net benefits, and are the incremental health benefits from incorporating the intervention among the mix of interventions provided worth the incremental costs?

Developing user-friendly "front ends" for reviews that allow rapid scanning for

relevance and then graded entry constitute a third and very different type of adaptation process. One example of such a format is one page of take-home messages, a three-page executive summary that summarizes the full report, and a 25-page report, as well as a longer technical report, if necessary (Canadian Health Services Research Foundation 2001). Interviews with healthcare managers and policy makers suggest that presenting systematic reviews using something like a 1:3:25 format is preferred over current approaches. However, an analysis of websites suggests that reports using a graded-entry format are rare (Lavis et al. 2005). Presumably, either the one- or three-page summary should follow a structured format. Structured abstracts are an innovation developed by those conducting clinical research (Haynes et al. 1990).

Improving Retrieval Mechanisms for Systematic Reviews

Even if the global stock and future flow of systematic reviews were modified in ways that enhance their relevance and usefulness to healthcare managers and policy makers, substantial efforts would still be needed to improve retrieval mechanisms. For systematic reviews to be helpful, managers and policy makers need to be able to access them when they need them. Three retrieval mechanisms are commonly used: (1) searching the Cochrane Library, (2) using the systematic review option in a PubMed clinical query (National Center for Biotechnology Information 2005) and (3) copying and pasting the best available search strategies (bmj.com 2005; Montori et al. 2004) into a PubMed query. These mechanisms have not yet been tested for systematic reviews of health services and policy research, for systematic reviews that address questions other than "What works?" or for databases other than Medline.

More importantly for healthcare managers and policy makers, the user-friendly "front ends" of systematic reviews could be made available through an online database that could be searched using keywords that make sense to managers and policy makers and that is linked to the full reviews when they are available through other quality-appraised sources, such as the Cochrane Library. The Health Evidence Network (WHO Regional Office for Europe 2005) provides a database targeted at healthcare policy makers; however, the evidence summaries are not always based on systematic reviews.

Towards Shared Ground and Further Debate

There is a great deal of shared ground in the perspectives of those advocating for an increased focus on systematic reviews as a way to provide research-based responses to important questions about health systems. For example, there is widespread agreement that the reviews should collectively (not necessarily individually) address a variety of questions relevant to healthcare managers and policy makers (including

"What works?"). It is also generally agreed that methods should be systematic, transparent and appropriate to the question(s) asked; that new methods should be subject to evaluation (e.g., allowing the question to change once the review has been started, selecting a purposive sample of studies rather than all eligible studies and using different approaches to synthesizing eligible studies); and that the resulting products should be adapted to the needs of managers and policy makers (Sheldon 2005).

However, there are also some important differences of opinion (Lomas 2005). Some would argue that the Cochrane Collaboration's highly specified and routinized methodologies are appropriate to questions of "what works" for healthcare interventions such as drugs and procedures, but are likely to work less well and provide fewer useful insights when used to tackle a broader range of questions concerning complex organizational and policy interventions. But there are many areas of cross-over between these two research domains. For example, many social scientists also ask questions about "what works" - witness the Campbell Collaboration, which is focused on social, behavioural and educational interventions (rather than healthcare interventions) and the many social scientists working within the Cochrane Collaboration itself. In clinical research, too, there is a long tradition of examining mediating and moderating variables (including context). We would argue that the important point is that those who want to see healthcare managers and policy makers make better use of research in their decision-making should aim to learn from the considerable experience and accumulated expertise of the Cochrane Collaboration, while recognizing that its methods and approaches may need to be adapted and revised. These and other differences in perspective should be subject to further debate.

We summarize in Table 1 some dimensions of that debate where we believe that legitimate and important differing perspectives exist. In some cases we might expect a greater consensus to emerge, as experience of conducting systematic reviews on health system interventions accumulates; in other areas, the tensions will resolve differently contingent on the managerial or policy questions being asked. Health services and policy researchers could learn the hard way how best to conduct systematic reviews and not benefit from the experience of those who have grappled with similar challenges in other methodological and disciplinary domains, but few of us would argue that such an approach would be either sensible or a justifiable use of scarce research resources. Participants in the Cochrane Collaboration are likely to welcome and benefit themselves from the opportunity to tackle the challenges unique to producing and regularly updating systematic reviews for healthcare managers and policy makers.

Implications for Researchers and Research Funders

As the health services and policy research community begins to pay serious atten-

TABLE 1. Some differing perspectives about producing and adapting a systematic review

ISSUE

PERSPECTIVES

Developing a partnership for producing and adapting a systematic review

Should we engage with managers and policy makers at the start and end of the review process to set the question and interpret the findings, but let the methodological expertise of the researchers lead the intervening process; or, should we aim for a more iterative and continuing engagement throughout the review?

Framing the question for a systematic review

Should we address a focused question where we can do a good review, but risk its not speaking to many of the issues that managers and policy makers want it to tackle; or, should we tackle a broad question that is highly relevant but involves considerable methodological challenges?

Conducting a systematic review

Should we aim for a review process that is highly specified, routinized, methodologically sound and transparent, but which might be difficult to adapt to a broad question and heterogeneous literatures; or, should we have a more flexible and adaptable review process that can be tailored to fit the question, but risk being less robust, demonstrably rigorous and transparent?

Adapting a systematic review

Should we develop a review process that contributes to a global stock of systematic reviews on which all managers and policy makers can draw and that highlights information that can inform assessments of local applicability and develop (or leave to others to develop) a separate local adaptation process; or, should we combine production and local adaptation processes by incorporating both research evidence and information about managers' and policy makers' experiences and assessments of their local context?

tion to systematic reviews, now is the time for researchers who are interested in the methodology of systematic reviews or knowledge transfer and exchange to address a number of key issues in the production and adaptation of systematic reviews:

- evaluating alternative approaches to involving healthcare managers and policy makers in the systematic review process;
- evaluating alternative approaches to addressing the different types of questions asked by healthcare managers and policy makers, with a particular focus on such

Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers

issues as the trade-offs involved in allowing the question to change as the systematic review progresses, drawing a purposive sample of studies for inclusion rather than reviewing all eligible studies and using different approaches for synthesizing research findings;

- evaluating alternative approaches to providing information about the contextual factors that may affect a review's local applicability;
- evaluating alternative approaches to developing user-friendly "front ends" for reviews, with a particular focus on the optimal structured format for these "front ends"; and
- evaluating alternative approaches for retrieving systematic reviews of health services and policy research and systematic reviews for questions other than "What works?"

Much of this research could be conducted in conjunction with the Cochrane Collaboration. In pursuing this research agenda, care will need to be taken to identify both similarities and differences between healthcare managers and policy makers. For the purposes of this paper, we have considered them together; however, sometimes their differences may warrant a differentiated approach.

Health services and policy researchers who are interested in conducting and adapting systematic reviews for healthcare managers and policy makers can proceed with a number of key activities:

- involving healthcare managers and policy makers in the systematic review;
- working with Cochrane's EPOC Review Group to increase the scale of its efforts devoted to systematic reviews of the effects of governance, financial and delivery arrangements;
- working with Cochrane's EPOC Review Group to expand the scope of their
 efforts devoted to systematic reviews of the effects of interventions to bring about
 change in health systems (i.e., include change-management strategies at the level
 of organizations, not just interventions targeted at health professionals);
- providing decision-relevant information in systematic reviews, with a particular focus on information about the harms (or risks) and costs of interventions (not just the benefits), the uncertainty associated with estimates and any differential effects by subgroup;
- developing something akin to the Cochrane Collaboration for questions other than "What works?"; and
- providing information about the contextual factors that may affect a review's local applicability.

Research funders could support the activities of researchers who are evaluating

new methodological developments and health services and policy researchers who are conducting and adapting systematic reviews. The latter may require substantial investments in regularly undertaking priority-setting processes to identify emerging questions that could be addressed with systematic reviews (Lomas et al. 2003), the commissioning of "scoping" reviews to identify what types of full systematic reviews are warranted to address priority questions, and the training of health services and policy researchers to conduct and adapt systematic reviews. A single research funder, or a consortium of research funders, could also play a role in improving the retrievability of health services and policy research (randomized, controlled trials did not become easy to identify in Medline by chance alone) and in making available the user-friendly "front ends" of systematic reviews through an online database. For research funders who take seriously their role to make research more useful to healthcare managers and policy makers, systematic reviews offer tremendous opportunities.

ACKNOWLEDGMENTS

This paper was first prepared as a background paper for the first Harkness Fellows in Health Care Policy Alumni Conference, which was co-sponsored by the Commonwealth Fund, the Nuffield Trust and the Health Foundation, and was held at the Pennyhill Park Conference Centre, Bagshot, England, July 17–19, 2005. John Lavis receives salary support as the Canada Research Chair in Knowledge Transfer and Uptake.

Correspondence may be directed to: John N. Lavis, McMaster University, HSC-2D3, 1200 Main St. West, Hamilton, ON, Canada L8N 3Z5; tel.: +1-905-525-9140 (ext. 22907); fax: +1-905-529-5742; email: lavisj@mcmaster.ca; Web: www.researchtopolicy.ca.

REFERENCES

Black, N. 2001. "Public Accountability: One Rule for Practitioners, One for Scientists?" *Journal of Health Services Research and Policy* 6(3): 130–132.

bmj.com. 2005. "E-Table 1. PubMed Translation of Ovid Search Strategies to Retrieve Systematic Reviews from MEDLINE." Retrieved December 6, 2005. http://bmj.bmjjournals.com/cgi/content/full/bmj.38336.804167.47/DC1.

Campbell and Cochrane Economics Methods Group (C&CEMG). 2005. Retrieved December 6, 2005. http://www.med.uea.ac.uk/research/research_econ/cochrane/cochrane_home.htm.

Canadian Health Services Research Foundation. 2001. "Reader-Friendly Writing – 1:3:25." Retrieved December 6, 2005. http://www.chsrf.ca/knowledge_transfer/pdf/cn-1325_e.pdf.

Davies, H.T.O., S.M. Nutley and P.C. Smith. 2000. What Works? Evidence-Based Policy and Practice in Public Services. Bristol, United Kingdom: The Policy Press.

Dixon-Woods, M., S. Agarwal, D. Jones, B. Young and A. Sutton. 2005. "Synthesising Qualitative and Quantitative Evidence: A Review of Possible Methods." *Journal of Health Services Research and Policy* 10(1): 45–53.

Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers

Egger, M., G.D. Smith and K. O'Rourke. 2001. "Rationale, Potentials, and Promise of Systematic Reviews." In M. Egger, G.D. Smith and D.G. Altman, eds. Systematic Reviews in Health Care: Meta-Analysis in Context (2nd ed.). London: BMJ Books.

GRADE Working Group. 2004. "Grading Quality of Evidence and Strength of Recommendations." British Medical Journal 328: 1490-1494.

Gruen, R.L., P.S. Morris, E.L. McDonald and R.S. Bailie. 2005. "Making Systematic Reviews More Useful for Policy-Makers." Bulletin of the World Health Organization 83(6): 480–481.

Haynes, R.B., C.D. Mulrow, E.J. Huth, D.G. Altman and M.J. Gardner. 1990. "More Informative Abstracts Revisited." Annals of Internal Medicine 113(1): 69-76.

Lavis, J.N., H.T.O. Davies, A.D. Oxman, J.-L. Denis, K. Golden-Biddle and E. Ferlie. 2005. "Towards Systematic Reviews That Inform Health Care Management and Policy-Making." Journal of Health Services Research and Policy 10 (Supplement 1): S1:35-S1:48.

Lavis, J.N., F.B. Posada, A. Haines and E. Osei. 2004. "Use of Research to Inform Public Policymaking." The Lancet 364(9445): 1615–1621.

Lomas, J. 2005. "Using Research to Inform Healthcare Managers' and Policy Makers' Questions: From Summative to Interpretive Synthesis." *Healthcare Policy* 1(1): 55–71.

Lomas, J., N. Fulop, D. Gagnon and P. Allen. 2003. "On Being a Good Listener: Setting Priorities for Applied Health Services Research." Milbank Quarterly 81(3): 363-388.

Mays, N., C. Pope and J. Popay. 2005. "Systematically Reviewing Qualitative and Quantitative Evidence to Inform Management and Policy-Making in the Health Field." Journal of Health Services Research and Policy 10 (Supplement 1): S1:6-S1:10.

McAuley, L., J.M. Grimshaw and M. Zwarenstein. 2003. "Scope of EPOC Is Clarified." British Medical Journal 327: 106.

Montori, V.M., N.L. Wilczynski, D. Morgon and R.B. Haynes. 2004. "Optimal Search Strategies for Retrieving Systematic Reviews from Medline: Analytical Survey." British Medical Journal 330: 1-6.

National Center for Biotechnology Information. 2005. "PubMed Clinical Queries." Retrieved December 6, 2005. http://www.ncbi.nlm.nih.gov/entrez/query/static/clinical.html.

Oxman, A.D. and G.H. Guyatt. 1992. "A Consumers' Guide to Subgroup Analyses." Annals of Internal Medicine 116: 78-84.

Pawson, R., T. Greenhalgh, G. Harvey and K. Walshe. 2005. "Realist Review - A New Method of Systematic Review Designed for Complex Policy Interventions." Journal of Health Services Research and Policy 10 (Supplement 1): S1:21-S1:34.

Sheldon, T.A. 2005. "Making Evidence Synthesis More Useful for Management and Policy-Making." Journal of Health Services Research and Policy 10 (Supplement 1): S1:1-S1:5.

World Health Organization Regional Office for Europe. 2005. "Health Evidence Network (HEN)." Retrieved December 6, 2005. http://www.who.dk/hen>.

Reframing Evidence Synthesis As Rhetorical Action in the Policy Making Drama

Recadrer la synthèse des preuves comme une mesure de pure forme dans le drame de l'élaboration de politiques

by TRISHA GREENHALGH
Professor of Primary Health Care
University College London
London, England

JILL RUSSELL Lecturer in Primary Health Care University College London London, England

Abstract

This paper presents a novel conceptualization of policy making as social drama. The selection and presentation of evidence for policy making, including the choice of which questions to ask, which evidence to compile in a synthesis and which syntheses to bring to the policy making table, should be considered as moves in a rhetorical argumentation game and not as the harvesting of objective facts to be fed into a logical decision-making sequence. Viewing policy making as argument does not mean it is

beyond rationality - merely that we must redefine rationality to include not only logical inference and probabilistic reasoning, but also the consideration of plausibility by a reasonable audience. We need better evidence, but we also urgently need better awareness by policy makers of the language games on which their work depends.

Résumé

Cet article présente une nouvelle conceptualisation de l'élaboration de politiques en tant que drame social. La sélection et la présentation des preuves servant de base à l'élaboration de politiques, y compris le choix des questions à poser, des données à compiler dans une synthèse et des synthèses à amener à la table d'élaboration de politiques devraient être considérées comme faisant partie d'un jeu d'arguments rhétoriques et non comme une collecte de faits objectifs qui iront alimenter un processus logique de prise de décisions. Le fait d'envisager l'élaboration de politiques comme un argument ne signifie pas qu'elle est dénuée de rationalité, mais simplement que nous devons redéfinir la rationalité pour y inclure non seulement l'inférence logique et le raisonnement probabiliste, mais également la plausibilité aux yeux d'un auditoire raisonnable. Nous avons besoin de meilleures preuves, mais il existe aussi un besoin urgent de sensibiliser les décideurs aux jeux de langue dont dépend leur travail.

ightharpoonup he Cochrane Collaboration was built on a myth – that the judgments required for evidence synthesis are fundamentally technical ones, achieved through the skilled application of tools of the trade such as protocols, data extraction sheets, methodological checklists and evidence hierarchies. Quality in Cochrane reviews is assured by the robustness of the protocol, the exhaustiveness of the data extraction and the ruthlessness with which "methodologically inferior" studies were rejected.

In the evaluation of simple clinical interventions (such as drug therapies), this myth approximates reality so closely that it is entirely appropriate to operate as if the world were actually thus. But the world of policy making is not one of transferable and enduring scientific truths, nor is it exclusively (or even predominantly) concerned with "what works," and the systematic review movement must adapt accordingly (Lomas 2005; Lavis et al. 2005a). In this paper, we argue that the first step in this process is to change the way we conceptualize the policy making process.

Policy making – which might be defined as the authoritative exposition of values - is about defining and pursuing the right course of action in a particular context, at a particular time, for a particular group of people and with a particular allocation of resources. Policy making is about making and implementing collective ethical judgments. Most of us are painfully aware that "evidence," as the evidence-based medicine movement would define it, fits obliquely and sometimes very marginally into this process. But if evidence is marginal, what is central?

Sociologist Judith Green (2000) undertook a detailed ethnographic study of the work of multi-professional Accident Alliances in the United Kingdom. Her fieldwork demonstrated that in establishing credibility for a proposed course of action in accident prevention policy, advocates drew judiciously (and often very eloquently) upon a variety of sources, including professional expertise, local knowledge, appeals to common sense and personal experience. Research evidence on "what works" was rarely crucial to the case. For example, while randomized trial evidence unequivocally supports the efficacy and cost-effectiveness of hip protectors worn by frail elderly people in the prevention of fall-related injury, the policy making decision turned on the argument that "padded knickers" were seen as unpopular and even comical by patients and staff in nursing homes.

This example – in which a randomized trial reported in the language of risk prevention ("hip protectors") was displaced from its perch atop the evidence hierarchy by a rhetorical trope ("padded knickers") designed to draw the audience's attention away from issues of risk and towards those of individual dignity and self-determination – vividly illustrates that the "evidence" for policy making is not sitting in journals ready to be harvested by assiduous systematic reviewers. Rather, it is dynamically created through the human interaction around the policy making table – and, probably more significantly, the lobbying, campaigning and interpersonal influencing going on in the back rooms and corridors leading up to official policy making meetings.

Before we set any rules about what sort of systematic review policy makers need, we must understand in more detail what policy making is. Policy making is not a series of decision nodes into which evidence, however robust, can be "fed," but the messy unfolding of collective action, achieved mostly through dialogue, argument, influence and conflict and retrospectively made sense of through the telling of stories (formally in the minutes of meetings and informally in personal accounts of who said what and how, and how people reacted) (Birch 1997; Czarniawska 2004; Fischer and Forester 1993; Majone 1989; Stone 1997; Young et al. 2002).

We propose that the selection, compilation, presentation, negotiation, contestation and reframing of evidence as part of the "stuff happening" of policy making can usefully be construed as social drama – that is, as a real, enacted story in which all concerned, whether they want to or not, become actors (Turner 1980). Furthermore, the policy making stage is a slippery one, fraught with ambiguity, unpredictability and multiple interpretations. Playing one's part in it can be a frustrating experience – one that lobbyists and the media understand far better than the humble systematic reviewer.

On this stage, the protocols, checklists and hierarchies that are set so securely in

stone in the Cochrane Handbook can crumble to dust or be distorted at will by the skilled or passionate orator. In social drama, personal testimony ("anecdotal evidence") is a uniquely authentic and powerful force. In a recent high-profile litigation in the United States against Dow Chemical, falsely blamed for a link between silicon breast implants and connective tissue disorders, one witness successfully refuted a library of epidemiological evidence by pointing to her own evident rheumatological disorder and proclaiming "I am the evidence" (Angell 1996).

The concept of evidence as rhetorically constructed on the social stage so as to achieve particular ends for particular people raises an important question (to which we have for too long assumed the answer to be "yes"): to what extent should policy making be driven by evidence? (Sanderson 2003). The very expression "evidence-based policy making" suggests that there are technical solutions to what are essentially political problems – an assumption that, some have argued, devalues democratic debate and plays down the ethical, moral and political ambiguities and dilemmas inherent in the lived reality of planning, implementing and evaluating in social-political life (Hammersley 2001; Schwandt 1997, 2000).

The normative goals of evidence-based practice (finding out what works and then implementing it) are closely aligned with those of the new public management (defining explicit performance outputs and promoting efficiency and cost-effectiveness) (Webb 2001; Hammersley, 2001). Critics of this approach argue that what matters is not merely "what works" but what is appropriate in the circumstances and what is agreed to be the overall desirable goal (Sanderson 2003; Dobrow et al. 2004).

Here's a provocative question: is the "methodological fetishism" of which the Cochrane Collaboration has been accused an extreme example of the politicization of science by the new managerialists? MacLure (2005) has argued that systematic review

assumes that evidence can be extracted intact from the texts in which it is embedded, and "synthesised" in a form that is impervious to ambiguities of context, readers' interpretations of writers' arguments (i.e. bias). Most significantly of all, systematic review systematically degrades the central acts of reviewing: namely, reading and writing, and the unreliable intellectual acts that these support, such as interpretation, argument, and analysis. By replacing reading and writing with an alternate lexicon of scanning, screening, mapping, data extraction, and synthesis, systematic review tries to transform reading and writing into accountable acts. It tries to force their clandestine operations – the bits that happen inside people's heads – or in the incorporeal gaps between decoding and comprehension, thought and expression – up into plain view, where they can be observed, quality-controlled and stripped of interpretation or rhetoric.

Perhaps, then, clarity, transparency, explicitness, reproducibility and other virtues held dear by the Cochrane community have more to do with the discourse of accountability than with the essential quality of the judgments they are assumed to underpin. Deborah Stone (1997) believes that much of the policy process involves debates about values masquerading as debates about facts and data: "The essence of policy making in political communities [is] the struggle over ideas. Ideas are at the centre of all political conflict. ... Each idea is an argument, or more accurately, a collection of arguments in favour of different ways of seeing the world."

Stone's work, and other critiques of the evidence-into-policy model, shift the challenge of "synthesizing evidence for policy making" from a scientific-rationalist frame (ensuring that "objective" evidence is available in an easily assimilable format and in a timely manner to policy makers) to a rhetorical-interpretive frame (acknowledging that all evidence is, and must remain, value-laden and will be rhetorically and judiciously brought to bear in the contact sport of policy development) (Fischer and Forester 1993; Majone 1989; Stone 1997). In this latter perspective, there is no "view from nowhere," so systematic reviewers might as well give up looking for it:

As politicians know only too well but social scientists too often forget, public policy is made of language. Whether in written or oral form, argument is central in all stages of the policy process. ... Argumentation is the key process through which citizens and policymakers arrive at moral judgments and policy choices. ... Each participant [in policy debates] is encouraged to adjust his view of reality, and even to change his values, as a result of the process of reciprocal persuasion. (Majone 1989)

Whereas the technical model of policy making ("evidence into practice") sees group decision-making as a sequence of logical moves to weigh evidence and reach a single, "rational" course of action, the argumentation model proposes (a) that someone presenting evidence to others tailors the presentation to what he or she believes the audience will find persuasive and (b) that what we will accept as evidence depends on what we have already agreed (what has been established or accepted among the team so far) and what we consider to be an acceptable link between the two states (Crawshay-Williams 1957; Toulmin 1958; Perelman and Olbrechts-Tyteca 1971; van Eemeren et al. 1996).

The roots of argumentation theory lie in Aristotle's philosophical treatises on *analytic* (logical argument using premises based on certain knowledge), *dialectic* (debating moves to argue for and against a standpoint) and *rhetoric* (influencing by reference to laws, documents, etc. or by appeal to emotions, authority or previously acceded premises). Most modern-day scientists (including those in the evidence-based medicine movement) hold that "rationality" is restricted to analytic argument. But for the

ancient Greeks, all three dimensions of argumentation were seen as rational, and a respectable scholar was expected to achieve competence in all of them. As the "padded knickers" example illustrates, it is neither "unscientific" nor "biased" to employ rhetorical techniques to get an audience to frame a problem in a new light.

In analytic logic, "evidence" might be thought of as that which is provably true (as in, "Socrates is a man; all men are mortals; therefore, Socrates is mortal") or probably true (in the sense of Bayesian notions such as odds ratios, effect estimates and confidence intervals). But in rhetorical argument, the bounds of rationality extend to what is plausibly true - that is, "evidence" is whatever will convince a reasonable audience.

... "Socrates is a man; all men are mortals; therefore, Socrates is mortal" ... the bounds of rationality extend to what is plausibly true - that is, "evidence" is whatever will convince a reasonable audience.

In their polemical work, The New Rhetoric, Perelman and Olbrechts-Tyteca (1971: 45) showed that rhetorical argumentation techniques persuade by increasing the "intensity of adherence among those who hear it in such a way as to set in motion the intended action." There are, of course, implicit agreements within particular audiences, expressed by their shared language (e.g.,

jargon, professional practices) and the initiation required to join such a group. There are also "preferable premises" - that is, values, value hierarchies and loci (preferences of one abstraction over another, which are the basis of value hierarchies). All these form what are known as the audience's points of departure.

Taking account of points of departure, the arguer uses rhetorical schemes, such as association or dissociation. Association brings together through metaphor or analogy elements that were seen as separate ("we value the input of independent experts; X is an independent expert"). Dissociation does the opposite; it separates elements previously assumed to be part of a whole (as in "that peer reviewed journal' was actually published by the pharmaceutical industry"). Argumentation can be viewed as a performance of "regulated disputation" held according to agreed rules of engagement. Fallacies (that is, things an audience rejects in an argument) are seen as the non-adherence to these agreed rules (van Eemeren et al. 1996). Any argument can be systematically deconstructed to expose the use of rhetorical devices such as association and dissociation, and to expose the (unwritten) rules that the audience uses to accept (as rational) or reject (as fallacious) the conclusions and recommendations made by different players.

Applying these concepts to policy making, Schon and Rein (1990) have suggested that difficult policy making tasks should be faced by acknowledging that controversy is inherent in such work. The way to deal with this inherent and irreducible messiness is not to produce more rigorous, more relevant, less ambiguous, more timely or more appealingly presented evidence but for policy makers to develop a better awareness of their own behaviour as players in the argumentation game.

... difficult policy making tasks should be faced by acknowledging that controversy is inherent in such work. The way to deal with this inherent and irreducible messiness is to develop a better awareness of their own behaviour as players in the argumentation game.

Reflection on the underlying differences that lead to frustrations and conflicts – differences of backgrounds, values, norms and on what constitutes evidence (the points of departure) and therefore what follows as acceptable conclusions or actions (rules of engagement) – is a critical step for managers and policy makers in moving

towards a new rationality of policy making (that is, one in which a linear link between evidence and policy is explicitly rejected, and in which the skills of argumentation are acknowledged, promoted and reflected upon rather than dismissed as underhand, biased or "anecdotal").

Jeremy Grimshaw, who heads the Cochrane Collaboration's Effective Practice and Organization of Care Group, has recently lamented that despite 30 years' research, we still lack a generalizable evidence base to inform management and policy making (Grimshaw et al. 2004), but his proposed solution – that we should do more of the same research, only bigger and better – is naive. There *never will be* a "generalizable evidence base" on which managers and policy makers will be able to draw unambiguously and to universal agreement, and however hard we strive for methodological rigour in systematic review, there never can be a policy that is unambiguously "evidence-based."

Where does this leave us? The "new systematic review methodology" – pragmatic, pluralistic, context-sensitive and cutting its cloth according to local resources, needs, contexts and timescales – is an important epistemological breakthrough. Disseminating its principles, and raising awareness of the growing range of tools and techniques available to the methodologically discerning reviewer (Dixon-Woods et al. 2005; Lavis et al. 2005b; Pawson et al. 2005; Greenhalgh et al. 2005; Lomas 2005), is a high priority. But equally important is the task of disabusing the healthcare community of the misconception that policy making is, or ever could be, "evidence-based" in the way this term is conventionally construed.

A more fruitful, and certainly more original, use of research funding would be to promote and evaluate the training of policy making teams in the art of rhetoric, and particularly in what Schon (1990) has called "frame reflective awareness," designed to ensure that the players in the policy making drama acknowledge and take account of their respective points of departure. Making explicit the values and premises on which each side has built its case will not only highlight "evidence gaps" more systematically but will also generate light rather than heat at the policy making table.

ACKNOWLEDGMENTS

We are grateful to Janet McDonnell and Emma Byrne for many critical discussions and insights that influenced the ideas in this paper.

Correspondence may be directed to Prof. Trisha Greenhalgh, Department of Primary Care and Population Sciences, University College London, 403 Holborn Union Building, Highgate Hill, London N19 5LW; email: p.greenhalgh@pcps.ucl.ac.uk.

REFERENCES

Angell, M. 1996. "Evaluating the Health Risks of Breast Implants: The Interplay of Medical Science, the Law, and Public Opinion." New England Journal of Medicine 334: 1513-1518.

Birch, S. 1997. "As a Matter of Fact: Evidence-Based Decision-Making Unplugged." Health Economics 6: 547-559.

Crawshay-Williams, R. 1957. Methods and Criteria of Reasoning: An Inquiry into the Structure of Controversy. London: Routledge & Kegan Paul.

Czarniawska, B. 2004. Narratives in Social Science Research. London: Sage.

Dixon-Woods, M., S. Agarwal, D. Jones, B. Young and A. Sutton. 2005. "Synthesising Qualitative and Quantitative Evidence: A Review of Possible Methods." Journal of Health Services Research Policy 10: 45-53.

Dobrow, M.J., V. Goel and R.E. Upshur. 2004. "Evidence-Based Health Policy: Context and Utilisation." Social Sciences and Medicine 58: 207-217.

Fischer, F. and J. Forester. 1993. The Argumentative Turn in Policy Analysis and Planning. Durham, NC: Duke University Press.

Green, J. 2000. "Epistemology, Evidence and Experience: Evidence Based Health Care in the Work of Accident Alliances." Sociology of Health and Illness 22: 453-476.

Greenhalgh, T., G. Robert, F. Macfarlane, P. Bate, O. Kyriakidou and R. Peacock. 2005. "Storylines of Research in Diffusion of Innovation: A Meta-narrative Approach to Systematic Review." Social Sciences and Medicine 61: 417-430.

Grimshaw, J.M., R.E. Thomas, G. MacLennan, C. Fraser, C.R. Ramsay, L. Vale et al. 2004. "Effectiveness and Efficiency of Guideline Dissemination and Implementation Strategies." Health Technology Assessment Report 8(6): 1–72.

Hammersley, M. 2001. Some Questions about Evidence-Based Practice in Education. Leeds: University of Leeds Annual Conference of the British Educational Research Association.

Lavis, J., H. Davies, R. Gruen, K. Walsh and C. Farquar. 2005a. "Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers." *Healthcare Policy* 1(2): 21–33.

Lavis, J., H. Davies, A. Oxman, J.L. Denis, K. Golden-Biddle and E. Ferlie. 2005b. "Towards Systematic Reviews That Inform Health Care Management and Policy-Making." *Journal of Health Services Research Policy* 10 (Supplement 1): 35–48.

Lomas, J. 2005. "Using Research to Inform Healthcare Managers' and Policy Makers' Questions: From Summative to Interpretive Synthesis." *Healthcare Policy* 1(1): 55–71.

MacLure, M. 2005. "'Clarity bordering on stupidity': Where's the Quality in Systematic Review?" *Journal of Education Policy* 20: 393–416.

Majone, G. 1989. Evidence, Argument and Persuasion in the Policy Process. New Haven, CT: Yale University Press.

Pawson, R., T. Greenhalgh, G. Harvey and K. Walshe. 2005. "Realist Review – A New Method of Systematic Review Designed for Complex Policy Interventions." *Journal of Health Services Research Policy* 10 (Supplement 1): 21–34.

Perelman, C. and L. Olbrechts-Tyteca. 1971. *The New Rhetoric: A Treatise on Argumentation*. Notre Dame, IN: University of Notre Dame.

Sanderson, I. 2003. "Is It 'What Works' That Matters? Evaluation and Evidence-Based Policy-Making." Research Papers in Education 18: 331–345.

Schon, D. and M. Rein. 1990. Frame Reflection: Towards the Resolution of Intractable Policy Controversies. New York: Basic Books.

Schwandt, T. 1997. "Evaluation As Practical Hermeneutics." Evaluation 3: 69–83.

Schwandt, T. 2000. "Further Diagnostic Thoughts on What Ails Evaluation Practice." *American Journal of Evaluation* 21: 225–229.

Stone, D. 1997. Policy Paradox: The Art of Political Decision Making. New York: Norton.

Toulmin, S.A. 1958. The Uses of Argument. Cambridge: Cambridge University Press.

Turner, V. 1980. "Social Dramas and Stories about Them." Critical Inquiry 7: 141–168.

van Eemeren, F., R. Grootendorst and F. Snoeck Henkemans. 1996. Fundamentals of Argumentation Theory. Mahwah, NJ: Lawrence Erlbaum Associates.

Webb, S. 2001. "Some Considerations on the Validity of Evidence-Based Practice in Social Work." British Journal of Social Work 31: 57–79.

Young, K., D. Ashby, A. Boaz and L. Grayson. 2002. "Social Science and the Evidence-Based Policy Movement." *Social Policy and Society* 1: 215–224.

Informing Policy Making and Management in Healthcare: The Place for Synthesis

Informer l'élaboration de politiques et la gestion dans les soins de santé : la place de la synthèse

by CATHERINE POPE, PHD
Reader in Health Services Research, School of Nursing & Midwifery
University of Southampton, England

NICHOLAS MAYS, FFPH
Professor of Health Policy, Health Services Research Unit
Department of Public Health and Policy
London School of Hygiene and Tropical Medicine
London, England

JENNIE POPAY, BA, MA
Professor of Sociology and Public Health
Institute for Health Research
University of Lancaster, England

Abstract

Research synthesis has an important role supporting the transfer of knowledge between researchers and healthcare decision-makers. But if our goal is to make knowledge more useable and context specific, then extending the scope of systematic reviews or producing syntheses with policy makers and managers may be insufficient. Dialogues, partnerships and reinterpretations of evidence in context will help us achieve this goal.

Résumé

La synthèse de recherche a un important rôle de soutien à jouer dans le transfert des connaissances entre les chercheurs et les décideurs du domaine des soins de santé. Toutefois, si nous voulons rendre les connaissances plus utilisables et plus spécifiques au contexte, l'élargissement de la portée des examens systématiques ou la production de synthèses en collaboration avec les décideurs et les gestionnaires peuvent ne pas suffire. Les dialogues, les partenariats et la réinterprétation des preuves en contexte nous aideront à atteindre ce but.

debates about how to make research evidence available and useful to healthcare managers and policy makers. Both papers argue that the relatively well-developed methods for systematic reviewing – used, for example, within the Cochrane Collaboration – do not address the "broader contextual factors of the managers' and policy makers' world" (Lomas 2005: 59). Lavis et al. suggest that managers and policy makers ask more complex questions that go beyond "What works?" (i.e., questions of effectiveness) and include questions about relationships, mechanisms and meaning. Lavis et al. call for a better repository of knowledge, in essence adapting and extending the Cochrane Library's systematic reviews, to make it more suited to the needs of policy makers and managers. Lomas adds a further twist to this argument by suggesting that the synthesis of research knowledge for policy makers and managers requires different kinds of input (notably, from interpretive social science) and a closer partnership between researchers and managers/policy makers.

So, What's Wrong with Systematic Reviews?

Before we rush into a program of synthesis, it is worth pointing out that many synthesis methods are emerging – the techniques (how to do it) and definitions (what it is) are being developed (Mays et al. 2005; Dixon-Woods et al. 2005). Lomas differentiates summative and interpretive approaches to synthesis. He argues that summative approaches centre on questions of effectiveness, while interpretive approaches are more closely allied to the needs of policy makers and managers. Unfortunately, this implies that policy makers and managers do not need summative accounts. We would suggest that effectiveness reviews may be a necessary, but not sufficient, aid to policy makers and management (they still need to know "what works"). Moreover, there are examples of Cochrane-style systematic reviews aimed at exactly the broad, complex policy-type questions that both Lomas and Lavis et al. identify (Garcia et al. 2002; Harden et al. 2004). There is a danger, in overstating the distinction between summa-

tive and interpretive approaches, that we ignore the usefulness of particular types of review (i.e., systematic reviews of effectiveness) and the presence of interpretive work within existing systematic reviews.

At present, policy makers and managers are accused of failing to utilize research evidence. This charge gives rise to an impression that they exist in an evidence-free vacuum.

For us a more important distinction, inspired by the pioneering work of Jack Dowie (2001, 2002), is the difference between reviews or syntheses providing knowledge support and those providing decision support. Lavis et al. focus on the problem of providing knowledge support. They

argue that methods used by the Cochrane Collaboration need to be extended to make reviews more generalizable in order to answer the kinds of questions that policy makers and managers ask. We would further argue that a range of types of review and interpretive and summative syntheses (such as narrative synthesis, meta-ethnography and cross-case analysis, described in Mays et al. 2005) have the potential to provide the kinds of knowledge support that Lavis et al. recommend.

The decision-support approach is distinct from knowledge support because it seeks to go beyond research synthesis and to take on some of the tasks entailed in the decision-making process, for example, incorporating weightings that represent values or judgments. Summative and interpretive approaches might have a place early in this process, as in a literature review of qualitative and quantitative studies to make the inferences that inform a Bayesian analysis. In an example of this approach, findings from qualitative research about parents' reasons for having their children immunized (or not) were used to inform a statistical analysis of the factors that influenced this behaviour (Roberts et al. 2002). For policy makers and managers, this approach provided a more comprehensive picture of the potentially important factors than would have been available if only effectiveness data had been included.

Partnerships

Both Lomas (2005) and Lavis et al. (2005) make compelling arguments for moving away from researcher-driven knowledge translation towards co-production of knowledge and a partnership between managers/policy makers and researchers. At present, policy makers and managers are accused of failing to utilize research evidence. This charge gives rise to an impression that they exist in an evidence-free vacuum. Clearly, managers and policy makers do use evidence. What they don't do so often is use the

particularized kinds of evidence that some researchers recognize (e.g., systematic reviews). As Burns points out (2005: 53), these decision-makers have little tradition of using the library. But they utilize intelligence from a variety of sources, including formal research evidence, albeit in an adapted form. One of the reasons for this is that researchers often do not provide evidence that is timely and accessible to policy makers and managers (Popay in press).

At the heart of Lomas's paper is a plea for closer relationships between policy making and management ... We need to think about making the dialogue between researchers and policy makers/managers work ... Some of the current difficulties in getting knowledge into policy and management practice relate to presentation. At a very basic level, there is a strong case for "jargon-busting" – avoiding discipline- or profession-specific terminology and acronyms, and encouraging the use of "plain English" or French (e.g., the Plain

English Campaign) to get our messages across. Lavis et al. champion the 1:3:25 report format pioneered by the Canadian Health Services Research Foundation (CHSRF). This format has proved useful, but there is a danger in becoming over-prescriptive and assuming that standardized formats are a quick fix for knowledge translation. At the heart of Lomas's paper is a plea for closer relationships between policy making and management. Reports in 1:3:25 format, or a larger Cochrane Library with policy-relevant add-on reviews, will not deliver this. We need to think about making the dialogue between researchers and policy makers/managers work (Elliott and Popay 2000). Inevitably, this dialogue will consider making and re-making partnerships in local contexts. One way might be the process adopted by the CHSRF Policy Synthesis Program (CHSRF 2000) whereby researchers and policy makers/managers meet to discuss the content and format of reviews and syntheses. These kinds of critical conversations help to establish what it is that both sides want from the partnership.

There are emerging methods for synthesis that can contribute to the dialogue between research and policy making and management. Synthesis can promote knowledge transfer, but it is not simply an advance on other kinds of literature reviewing; rather, it is a key aspect of this broader activity. Some synthesis approaches allow the inclusion of forms of evidence, such as qualitative research, which have previously been considered too small-scale or too contextualized to inform policy making or management. Others have the potential to become mixed-method approaches, enabling the inclusion of evidence from qualitative and quantitative research and from non-research sources.

Decision support requires a different kind of engagement. It is likely that any synthesis or review would require serious adaptation to meet the demands of decisionmakers. It may not be possible to use existing reviews or syntheses for this purpose. In many ways, decision support requires an even closer partnership between research and policy making or management.

Challenges

There are issues that neither Lomas (2005) nor Lavis et al. (2005) address about who should engage in this business of knowledge translation. We need to recognize the different skills required for different approaches – summative or interpretive, knowledge or decision support. The development of transparent, formalized methods for systematic reviewing has enabled researchers from a variety of backgrounds (clinical/nonclinical, research/informatics) to undertake such reviews. Contemporary work developing methods for synthesis suggests that these approaches may require discipline- or methodologically specific expertise (e.g., work on meta-ethnography has highlighted the need for expertise in qualitative methods).

Decision support is quite different from reviewing or synthesis and, again, requires appropriate skills. Engagement with decision-making processes is likely to require input from a team, extending beyond a partnership between researchers and policy makers/managers to include other types of decision-makers, stakeholders and experts.

The Way Ahead

At the heart of the debate about informing policy making and management in healthcare is a paradox: the more we attempt to make knowledge useable and context specific, the more difficult it becomes to draw on a repertoire of reviews or a stock of knowledge. Both Lomas (2005) and Lavis et al. (2005) emphasize that, in the business of policy making and management, context matters. What they are both arguing for in their different ways - Lavis et al. with their extended version of the Cochrane Collaboration and Lomas with his call for co-produced research synthesis – is for knowledge that is relevant. Ultimately, there may well be a place for new forms of research synthesis, as well as for systematic reviews, in informing management and policy, but local partnerships, critical dialogues and reinterpretation in context will be what make a difference in the world of healthcare management and policy making.

Correspondence may be directed to: Catherine Pope, Reader in Health Services Research, School of Nursing & Midwifery, University of Southampton, Highfield, Southampton SO17 1BJ, United Kingdom; tel.: +44 (0)2380 598293; fax: +44 (0)2380 598308; email: cjp@soton.ac.uk.

REFERENCES

Burns, A. 2005. "Recognising the Needs and Roles of Key Actors." *Journal of Health Services Research and Policy* 10 (Supplement 1): 53–54.

Canadian Health Services Research Foundation (CHSRF). 2000. < http://www.chsrf.ca>.

Dixon-Woods, M., S. Agarwal, D. Jones, B. Young and A. Sutton. 2005. "Synthesising Qualitative and Quantitative Evidence: A Review of Possible Methods." *Journal of Health Services Research and Policy* 10: 45–53.

Dowie, J. 2002. "Research Implications of Science-Informed, Value-Based Decision Making." European Journal of Oncology Library 2: 1–9.

Dowie, J. 2001. "Towards Value-Based, Science-Informed Public Health Policy: Conceptual Framework and Practical Guidelines." Background paper for *The World Health Report* 2002. Geneva: World Health Organization.

Elliott, H. and J. Popay. 2000. "How Are Policy Makers Using Evidence? Models of Research Utilisation and Local NHS Policymaking." *Journal of Epidemiology and Community Health* 54(6): 461–468.

Garcia, J., L. Bricker, J. Henderson, M.-A. Martin, M. Mugford, J. Nielson and T. Roberts. 2002. "Women's Views of Pregnancy Ultrasound: A Systematic Review." *Birth* 29: 225–250.

Harden, A., J. Garcia, S. Oliver, R. Rees, J. Shepherd, G. Brunton and A. Oakley. 2004. "Applying Systematic Review Methods to Studies of People's Views: An Example from Public Health Research." *Journal of Epidemiology and Community Health* 58: 794–800.

Lavis, J., H. Davies, R. Gruen, K. Walshe and C. Farquhar. 2005. "Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers." *Healthcare Policy* 1(2): 21–33.

Lomas, J. 2005. "Using Research to Inform Healthcare Managers' and Policy Makers' Questions: From Summative to Interpretive Synthesis." *Healthcare Policy* 1(1): 55–71.

Mays, N., C. Pope and J. Popay. 2005. "Systematically Reviewing Qualitative and Quantitative Evidence to Inform Management and Policy-Making in the Health Field." *Journal of Health Services Research and Policy* 10 (Supplement 1): 6–20.

Plain English Campaign. No date. Retrieved December 8, 2005. http://www.plainenglish.co.uk/ introduction.html#Anchor-Wha-35253>.

Popay, J. (ed.). In press. Moving Beyond Effectiveness: Methodological Issues in the Synthesis of Diverse Sources of Evidence. London, UK: National Institute for Health & Clinical Excellence.

Roberts, K.A., M. Dixon-Woods, R. Fitzpatrick, K.R. Abrams and D.R. Jones. 2002. "Factors Affecting the Uptake of Childhood Immunisation: A Bayesian Synthesis of Qualitative and Quantitative Evidence." *Lancet* 360: 1596–1599.

A Decision-Maker's Perspective on Lavis and Lomas

Point de vue d'un décideur sur les articles de Lavis et Lomas

by RICK ROGER, MHSA
Co-Director, Centre for Health Care Management,
University of British Columbia, Vancouver, BC

Abstract

Advancement in research synthesis, so well articulated and advocated by Lomas (2005) and Lavis et al. (2005), is a necessary but not sufficient development for the systematized use of research in managerial practice. Although significant progress in the use of evidence-based approaches can be witnessed, enriching efforts need to progress within both the management and research communities. Contextualized by direct experience with harm reduction approaches to population health improvement, this commentary offers propositions concerning the nature of the researcher/decision-maker interchange, arguing for a pronounced strengthening of involvement and activity at all levels in the service delivery system.

Résumé

Les progrès réalisés dans la synthèse des preuves, si bien articulés et présentés par Lomas (2005) et Lavis *et al.* (2005), sont un développement nécessaire mais insuffisant pour assurer une utilisation systématique de la recherche dans le travail des gestionnaires. Bien qu'on observe des progrès significatifs dans l'utilisation des méthodes

fondées sur les preuves, davantage d'efforts doivent être déployés pour promouvoir cette utilisation au sein des communautés de gestion et de recherche. Contextualisé par une expérience directe dans les méthodes axées sur la réduction des préjudices en ce qui a trait à l'amélioration de la santé de la population, ce commentaire offre des propositions concernant la nature de l'échange entre chercheurs et décideurs et préconise un accroissement prononcé de la participation et des initiatives à tous les paliers du système de prestation de services.

Allocation of Resources to Improve Heath," organized by the Milbank Memorial Fund with a supporting grant from the Robert Wood Johnson Foundation, was held June 14–16, 2000, in New York City. Work of the Vancouver/ Richmond Health Board in support of socially marginalized residents attracted attention, and I was invited as regional CEO to participate on a panel discussing housing as a health status determinant. The conference, attended by 22 academic and healthcare policy makers from the United States, Canada, the United Kingdom and New Zealand, was dedicated to the well-established but still debated contention that investments in the health sector alone may not be sufficient to improve population health (Robert Wood Johnson Foundation 2002).

Armed with documentation on the Health Board's rationale and decision-making process, I attempted to establish that a positive health impact had been achieved through a multifaceted approach involving not only housing and the purchase and regeneration of derelict hotels, but also policing, direct services provision, increased support of funded community service organizations, a variety of partnership efforts and funded (drug-using) consumer involvement. Somewhere buried in the Milbank archives will be the report of the conference with a paraphrase of my remarks: "Several things were attempted to improve population health in the downtown eastside of Vancouver; something worked; Mr. Roger has no idea what."

Suitably humbling, but also instructive, this account illustrates prevailing policy development dynamics, contextualizing the managerial reaction to the deliberations of Lomas (2005) and Lavis et al. (2005) in the first and current issues of *Healthcare Policy*. Confronting the gap between the idealized use of research in policy development and current realities, both authors recognize that healthcare managers and decision-makers do not function solely within the simple world of "What works?" The policy making environment is more a function of "What combination of interventions works where, for which sub-populations, in which environmental circumstances, in which combinations, administered at what rate of intensity, over which period of time and in what order?" Complexity of this nature defines the decision-making role in

regional health services delivery where the relations between cause and effect are often only retrospectively coherent.

"Gaelic poetry for deaf seagulls," the construct engendered when the precision of research design and expression demanded by peer-reviewed research conflicts with the functional applicability and degree of generalizability expected of the research ...

Lomas and Lavis et al. lay out both diagnostic journeys examining the methods of research development and synthesis - and remedial journeys contemplating improvements that might be "bootstrapped" from existing methodological approaches and established relationships. In both instances, researcher effectiveness is the focus, and the remedial journey is presented from the perspective of the research community.

Policy making and managerial contingents are considered rather more as destinations for the research effort than as fellow travellers as knowledge is gained. We learn from these papers that managers and host organizations will certainly function as entry points, signposts and way-stops, but hardly as road engineers or route-masters. And while there is nothing intrinsically wrong with this perspective - a little expertise can be a dangerous thing in the wrong circumstances - the obligations of policy makers are underplayed as part of the solution set that is advanced in both papers.

Colleagues in the forest industry and the biological sciences sector deploy a welltravelled phrase to portray the interchanges at issue: "Gaelic poetry for deaf seagulls," the construct engendered when the precision of research design and expression demanded by peer-reviewed research (and that sanctioned by the systematic review process) conflicts with the functional applicability and degree of generalizability expected of the research product (Larkin and Pallister 1976; Baskerville 1997). From any health services management perspective, the movement towards "user-friendly" and easily retrievable "poetry" so well described in these papers is of unquestionable value. There is a parallel argument, however, that the "hearing" or reception ability of the management community also needs attention. Deaf seagulls are not well positioned to inform the research agenda or to introduce research into practice.

Lavis and his co-authors (2005) record activities recommended for health services and policy researchers interested in shaping the products of their efforts for healthcare managers and policy makers. A counterpart list for managers might also be advanced, including:

- cultivation of ongoing relationships with established and emerging researchers;
- disciplined efforts to involve the research community as new initiatives are contemplated, well in advance of the implementation stage and with follow-through as implementation progresses;
- joining the conversation in areas of interest, recalling the ultimate accountability of researchers, policy makers and journalists to the person "serving coffee in the doughnut shop" (Waddell et al. 2005);
- opening organizations to scrutiny, accepting that occasional embarrassment can be the source of inspiration and improvement;
- encouraging developmental efforts inside organizations, learning how to understand and appreciate research;
- development of staff exchanges and secondments between and among research organizations, delivery organizations and knowledge brokering organizations;
- managing the opportunity to broker connections and knowledge exchange between researchers in different areas of specialization;
- involvement in those peer-review activities structured with a "decision-maker" component contributing to research effectiveness, learning how researchers critique one another;
- encouraging communities of practice within and without organizations, activating opportunities for learning at organizational boundaries;
- modelling the way for others in the use of research; sparking evidence, challenging the status quo; and
- following the lead of some of the best-regarded healthcare leaders, writing and recording personal and organizational research and development efforts.

Hearing-assisted "seagulls" will help shape the research agenda towards the shared goal of improved system performance.

What, then, are the lessons to be learned and applied from the Vancouver experience recounted earlier? Four working propositions help frame the thinking stimulated by the comments of Lomas (2005) and Lavis et al. (2005):

- Proposition 1: Migration or outright changes in the question(s) under review should be expected in the context of the researcher—policy maker interchange. Vancouver's downtown eastside initiative started as a response to escalating HIV infection rates among intravenous drug users, but quickly progressed to a focus on drug overdose deaths. Neither researchers nor managers had the luxury of "fixing the question" as the Vancouver/Richmond Board responded to pressures for encompassing approaches.
- Proposition 2: The "what are the issues around doing Y" form of question articulated by Lomas (2005: 58) and expanded by Lavis et al. (2005) in the Cochrane con-

text is of prime importance and should not be discounted as researchers address issues of interest to managers. Externalities (anticipated or not) are consequential in the public policy process. The Vancouver/Richmond Board, the Board's predecessor organizations and its successors have all faced significant challenges in the implementation of harm-reducing approaches to population health improvement.

Proposition 3: While intriguing and potentially useful in some respects, the macrolevel, integrated source of answers to questions contemplated in both papers is unlikely to add much value to policy developers involved in the introduction and management of significant changes in priorities or in delivery arrangements. The need for program evolution does not manifest in discrete, individually measurable steps. Partners involved in the Vancouver initiative could not stage policing meas-

The need for program evolution does not manifest in discrete, individually measurable steps.

ures in a different time or location from the housing or street service measures. Systematic reviews would have assisted in the roll-out of components more than in the shaping of the overall agenda.

We had access to information on how best to respond to the AIDS epidemic; we knew something of the merits of outpatient versus inpatient approaches to the treatment of addicted populations; and we had research-informed perspectives on the need for housing. Systematic approaches could have improved our understanding, but no integrating synthesis would or could have been expected to respond fully to the interlaced agenda and the accompanying needs for research guidance.

Proposition 4: Researchers and policy makers have moved beyond denial as respective roles are contemplated. The next step is to learn together (perhaps the hard way, as suggested) how best to conduct and disseminate the findings of systematic reviews. In the research context, mistakes were made in Vancouver. Surrounded by well-regarded researchers, Board members and staff did utilize local expertise, but not with the degree of commitment needed for enduring partnership. More could have been learned; rapid-response capacity emulating the "client-contractor" situation set out by Lomas (2005: 60) could have been established; and the CEO could have been more convincing in New York!

In the summer of 1987, the organizers of "Connections 88," a symposium dealing with research and public policy on aging and health, asked for "views from the field" concerning barriers to the use of research. Seeking input from executive-level officials

through an interview and survey approach, 15 detailed responses were received from British Columbia through Ontario. While knowing little of developing approaches to "theme analysis" taking shape in research literature at that time, I recorded a significant degree of skepticism among the respondents; there was not much hope for the evolution of research-informed policy development (Roger 1989). Most decision-makers would agree that the role of research in policy has steadily advanced over the intervening decade and a half, with the development of capacity at all levels of the system. Canada may indeed be "leading the charge in exploring new ways of doing synthesis for healthcare managers and policy makers" (Lomas 2005: 56). Lavis and colleagues (2005), while adopting a differentiated perspective, join Lomas in the sensible ordering of ideas needed for further advancement, enabling the effective deployment of resources now in place. Full realization of potential gains will require constructive efforts in both the research and decision-making communities.

Correspondence may be directed to: Rick Roger, email: rroger@shaw.ca.

REFERENCES

Baskerville, G.L. 1997. "Gaelic Poetry for Deaf Seagulls; Encore." Forestry Chronicles 70: 562-564.

Larkin, P. and A.E. Pallister. 1976. "Gaelic Poetry for Dead Seagulls: An Essay on Research Funding." Issues in Canadian Science Policy 2: 3–11.

Lavis, J., H. Davies, R. Gruen, K. Walshe and C. Farquhar. 2005. "Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers." *Healthcare Policy* 1(2): 21–33.

Lomas, J. 2005. "Using Research to Inform Healthcare Managers' and Policy Makers' Questions: From Summative to Interpretive Synthesis." *Healthcare Policy* 1(1): 55–71.

Robert Wood Johnson Foundation Grant Results Report. 2002. "National Spending on Health Care May Be Too Narrowly Allocated." Retrieved November 21, 2005. http://www.rwjf.org/portfolios/resources/grantsreport.jsp?filename=030887.htm%iaid=141.

Roger, R. 1989. "Profession without Practice: An Administrator's Perspective on Barriers Restricting the Use of Research in Public Policy." In S.J. Lewis (ed.), *Aging and Health: Linking Research and Public Policy*. Chelsea, MI: Lewis Publishers pp. 379–390.

Waddell, C., J. Lomas, J. Lavis, J. Abelson, C.A. Shepherd and T. Bird-Gayson. 2005. "Joining the Conversation: Newspaper Journalists' Views on Working with Researchers." *Healthcare Policy* 1(1): 123–139.

Commentary: Whose Views Count in Evidence Synthesis? And When Do They Count?

De quelles opinions tient-on compte dans la synthèse des preuves? Et quand en tient-on compte?

by JONATHAN LOMAS

Chief Executive Officer

Canadian Health Services Research Foundation

Ottawa, ON

Abstract

Four recent pieces in *Healthcare Policy* reveal some disagreement on when and how to involve decision-makers in the process of evidence synthesis. This commentary proposes varying roles for researchers versus managers or policy makers at each of three different stages of synthesis and at the actual point of decision. It also raises the issue of how poorly current processes accommodate the broader conception of evidence held by most managers and policy makers.

Résumé

Quatre récents articles publiés dans *Politiques de santé* révèlent un certain désaccord quant au moment et à la façon d'amener les décideurs à participer à la synthèse des preuves. Au lieu de faire participer les gestionnaires ou les décideurs, ce commentaire propose de varier les rôles joués par les chercheurs à trois différentes étapes de la synthèse et au moment de la décision elle-même. Il soulève aussi la question de l'incapacité des processus actuels de tenir compte de la conception plus vaste des preuves qu'ont la plupart des gestionnaires et décideurs.

NCLUDING MY OWN ARTICLE IN THE LAST ISSUE, HEALTHCARE POLICY HAS now published four views on research synthesis for managers and policy makers. As Lavis and colleagues (2005) point out, there is much upon which we agree. For instance, there is no argument that the task, while demanding transparency and bias reduction, is different from that of summarizing research for clinicians; or that context is crucial in determining ultimate applicability; or that the questions are about more than "what works." However, the fun of sorting out the issue of synthesis for managers and policy makers lies in debating the differences – in working through the challenge of the best way to improve evidence-informed decision-making.

How much should researchers compromise in their conception of "evidence"? And how much should decision-makers compromise in theirs, when it comes to synthesizing evidence for decision-making?

On this score, there appears to be some disagreement among the four authors published in *Healthcare Policy*, particularly about the relative roles for researchers on the one hand and managers or policy makers on the other. In my earlier article (Lomas 2005), I saw them as equal partners in a co-production role throughout the process. Lavis and colleagues (2005) – and, for a knowledge rather than decision-support synthesis, Pope et al. (2005) – seem to see decision-makers as adjunct input to a researcher-dominated exercise. Greenhalgh and Russell (2005) put policy makers in the driver's seat, opening an avenue for researchers' input, while decision-makers control the traffic lights at all the major junctions.

We have probably all been guilty of too much shorthand on this. In all likelihood, the relative roles of researchers and decision-makers (whether managers or policy makers) should change with the stage of the process.

At the initial stage of summarizing the research – the systematic review stage or knowledge support synthesis – the researcher plays the lead role with a lot of help from the decision-maker in formulating (and potentially re-formulating) the question. At the stage of extracting implications from the summarized research – defining the key general messages – the researcher still takes the lead, but is aided by the decision-maker. At the stage of creating recommendations for policy or management – advising on action for a specific context – the decision-maker takes the lead, tempered by the researcher's caution around evidence. Finally, the manager or policy maker must actually make the decision – alone, but with help from whatever "dialogue," "argumentation" or other political processes are used.

An illustration of this approach at work is provided by a synthesis process that was successfully concluded recently by a Quebec research collective using very similar relative roles as those described above through the different stages (Pineault et al. 2005). This process recognizes that summing up the research evidence is more

than a checklist exercise and requires interpretation, largely by researchers. But it also recognizes that, coming from the other direction, there is interpretation by decisionmakers as they sum up the relevant "colloquial evidence" from their context (Lomas et al. 2005). Evidence-informed decision-making is finding a way to synthesize the two forms of evidence - "science" from the researchers and "colloquial knowledge" from the decision-makers.

Researchers and decision-makers have to meet halfway for this task in what Greenhalgh and Russell (2005) describe as "a new rationality of policy-making ... in which the skills of argumentation are acknowledged, promoted and reflected upon rather than dismissed as underhand, biased or 'anecdotal." The compromise on what counts as "evidence" for the synthesis cannot all be on the side of the decision-maker; researchers' evidence can inform but should not determine the decision. Perhaps the way forward is to find a way for decision-makers' evidence to be incorporated into science - the "new rationality" - rather than our historical drive to fit science into decision-making.

Correspondence may be directed to: Jonathan Lomas, Chief Executive Officer, Canadian Health Services Research Foundation, 1565 Carling Avenue, Suite 700, Ottawa, Ontario K1Z 8R1; tel. 613-728-2238; email: jonathan.lomas@chsrf.ca.

REFERENCES

Greenhalgh, T. and J. Russell. 2005. "Reframing Evidence Synthesis As Rhetorical Action in the Policy Making Drama." Healthcare Policy 1(2): 34–42.

Lavis, J., H. Davies, R. Gruen, K. Walshe and C. Farquhar. 2005. "Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers." Healthcare Policy 1(2): 21-33.

Lomas, J. 2005. "Using Research to Inform Healthcare Managers' and Policy Makers' Questions: From Summative to Interpretive Synthesis." *Healthcare Policy* 1(1): 55–71.

Lomas, J., T. Culyer, C. McCutcheon, L. McAuley and S. Law. 2005. "Conceptualizing and Combining Evidence for Health System Guidance." Retrieved December 6, 2005. .

Pineault, R., D. Tousignant, P. Roberge, P. Lamarche, D. Reinharz, D. Larouche, G. Beaulne and D. Lesage. 2005. "Research Collective on the Organization of Primary Care Services in Quebec." Summary report. Retrieved December 6, 2005. http://www.chsrf.ca/research_themes/pdf/ summary_report_e.pdf>.

Pope, C., N. Mays and J. Popay. 2005. "Informing Policy Making and Management in Healthcare: The Place for Synthesis." Healthcare Policy 1(2): 43–48.

a journal with a distinguished history

W ORLD HEALTH & POPULATION

provides a forum for researchers and policy makers worldwide to publish original research, reviews and opinions on health and population related topics. The journal encourages the conduct and dissemination of applied research and policy analysis from diverse international settings. Its stated goal is to explore ideas, share best practices and enable excellence in healthcare worldwide through publishing contributions by researchers, policy makers and practitioners.

worldhealthandpopulation.com

Founding Editor in Chief Sager Jain, PhD University of North Carolina at Chapel Hill Editor in Chief John E. Paul, PhD University of North Carolina at Chapel Hill

Editorial Advisory Board

Peggy Leatt, PhD University of North Carolina at Chapel Hill Daniel L. Goetz RTI

Karen B. Allen, MA, MSc, PhD UNICEF Eastern and Southern Africa Regional Office Amir A. Khaliq, PhD University of Oklahoma Health Sciences Center

François Béland, PhD Université de Montréal, Sandra G. Leggat, PhD La Trobe University

Adelsteinn Brown, DPhil University of Toronto

Lutchmie Narine, PhD University of North Carolina at Charlotte

Francois Champagne PhD Université de Montréal Bernardo Ramirez, MD INTECH

Wen Chen, Ph.D., M.D.,

Amal C. Sjaaf, MD, DrPH University of Indonesia

Fudan University

Sattar Yoosuf, MD World Health Organization, South East Region

Jean-Louis Denis, PhD Université de Montréal,

> David Zakus, BSc, MES, MSc, PhD Global Health Education Consortium

William H. Dow, PhD University of California, Berkeley

Moving Forward on Both Systematic Reviews and Deliberative Processes

Aller de l'avant avec les examens systématiques et les processus de délibération

by John N. Lavis, Md, Phd

Member, Centre for Health Economics and Policy Analysis Associate Professor, Department of Clinical Epidemiology and Biostatistics Associate Member, Department of Political Science McMaster University, Hamilton, Canada

Abstract

Systematic reviews are increasingly seen as helpful "knowledge support" for managers and policy makers, and deliberative processes are starting to be seen as promising, locally contextualized "decision support." Increases to the flow of systematic reviews should be complemented by efforts to facilitate the retrieval, and adapt the presentation, of the available stock of systematic reviews. Research and other evidence should be combined in transparent ways to facilitate cross-context learning. The challenge for managers and policy makers in moving forward will be to avoid the confusion that comes from the branding of both systematic reviews and deliberative processes.

Résumé

De plus en plus, les examens systématiques sont considérés comme étant utiles au « soutien des connaissances » pour les gestionnaires et les décideurs, et les processus de délibération commencent à être perçus comme étant susceptibles de constituer un « soutien aux décisions » localement contextualisé. L'augmentation du nombre d'examens systématiques devrait être complétée par des mesures visant à faciliter l'extraction et à adapter la présentation du stock actuel d'examens systématiques. La recherche et les autres preuves devraient être combinées de manière transparente afin de faciliter l'apprentissage transcontextuel. Le défi pour les gestionnaires et les décideurs qui veulent aller de l'avant sera d'éviter la confusion découlant de la définition des examens systématiques et des processus de délibération.

ore than two years into an initiative addressing how to enhance the usefulness of systematic reviews for healthcare managers and policy makers, we've come a long way. Systematic reviews are increasingly seen as helpful "knowledge support" for managers and policy makers (Pope et al. 2005). Deliberative processes, which provide opportunities for managers and policy makers to grapple with the local implications of systematic reviews, as well as the many other types of evidence on which they draw to inform their decision-making, are starting to be seen as promising, locally contextualized "decision support" (Lomas et al. 2005; Pope et al. 2005). I highlight here two potential lessons for managers and policy makers that have come from my participation in this initiative.

Make Use of the Existing Stock of Reviews While Supporting the Future Flow of Reviews

Managers and policy makers often work to timelines of days and weeks, not months and years. Timing or timeliness is one of only two factors that emerged with some consistency in a systematic review of the factors that increased the prospects for research use by policy makers (Lavis et al. 2005b). Three processes could each partly address the challenge of timing/timeliness: (1) facilitating the retrieval of systematic reviews that address the full range of questions asked by managers and policy makers (Lavis et al. 2005a); (2) adapting the presentation of systematic reviews so that they can be more easily scanned for relevance, decision-relevant information, and factors that would influence assessments of local applicability (Lavis et al. 2005a); and (3) engaging managers, policy makers and others in helping to identify researchable aspects of managerial and policy challenges that could be explored through systematic reviews

over time frames of six months to three years (Lavis et al. 2005a; Pope et al. 2005).

Relying *only* on a flow of highly context-sensitive systematic reviews seems wasteful and risky. A systematic review can help managers and policy makers think differently about the challenges they face (i.e., it can support conceptual uses of research) even if differences in the precise focus of studies or in the context in which they were conducted mean that a review cannot help them directly solve a particular problem (i.e., it can't always support instrumental uses of research). As well, there are hundreds or thousands of managerial contexts in a jurisdiction as diverse as Canada. And time frames of six months to three years can be a lifetime in politics. Elections, cabinet shuffles, departmental reorganizations, interest group campaigns, opinion poll volatility and unexpected events mean that priorities can change rapidly. Moreover, identifying the need for a systematic review can be a way of "kicking the issue into the long grass" (i.e., it can be used to delay action, which has been called a symbolic use of research).

Look for Transparency in Approaches to Combining Research and Other Types of Evidence

Managers and policy makers draw on research and many other types of evidence to inform their decision-making (Lavis et al. 2004; Lomas et al. 2005). One general category of approaches to facilitate this process is to solicit the other types of evidence by engaging those locally involved in or affected by a decision (1) in the systematic review process (e.g., setting the context, establishing the question or interpreting the results), (2) in a research study that examines their views and experiences in parallel with the review or (3) in a deliberative process that draws on the systematic review as one input among many. Because interactions between researchers and policy makers constitute the second of two factors that emerged with some consistency in a systematic review of the factors that increased the prospects for research use by policy makers (Lavis et al. 2005a), the first and third approaches could also increase the prospects that the review would be used. All three approaches still allow for the production of a systematic review that can be used as an input to decision-making by those who work in different contexts from those locally engaged through one of the approaches. Merging research and other types of evidence in less than transparent ways complicates cross-context learning.

The second general category of approaches is to conduct a systematic review of studies that examine the views and experiences of individuals, like those locally involved in or affected by a decision, and to do so in parallel with or as part of a review that addresses another question, such as which interventions are most effective or how and why a particular intervention works. Managers in one jurisdiction may be just as interested in learning about the views and experiences of managers and

patients in other jurisdictions who are struggling with similar challenges, such as the lack of continuity in primary care, as they may be in learning about whether, how and why particular interventions enhance continuity. Systematic reviews are increasingly addressing just such a diverse array of questions (Lavis et al. 2005a). Perhaps we are not moving from summative to interpretive synthesis (Lomas 2005); more likely we are moving from summative synthesis to a combination of several summative and interpretive syntheses (Pope et al. 2005).

Conclusion

While many interesting research questions remain to be asked about systematic reviews and a great many about deliberative processes, some questions can best be addressed by encouraging innovation and evaluating how well different approaches work in different contexts. The challenge for managers and policy makers in moving forward will be to avoid the confusion that comes from branding. For example, for most researchers the terms "systematic review" and "research synthesis" are synonymous (Cooper and Hedges 1994). But increasingly, we see particular approaches to systematic review being branded, and the combination of a systematic review and other types of evidence being branded. The same holds true for deliberative processes. Cut through the branding, however, and managers and policy makers may discover a treasure trove of information and processes to support their decision-making.

Correspondence may be addressed to: John N. Lavis, McMaster University, HSC-2D3, 1200 Main St. West, Hamilton, ON, Canada L8N 3Z5; tel.: +1-905-525-9140 (ext. 22907); fax: +1-905-529-5742; email: lavisj@mcmaster.ca; Web: www.researchtopolicy.ca.

REFERENCES

Cooper, H. and L.V. Hedges (eds.). 1994. The Handbook of Research Synthesis. New York: Russell Sage Foundation.

Lavis, J., H. Davies, R. Gruen, K. Walshe and C. Farquhar. 2005a. "Working Within and Beyond the Cochrane Collaboration to Make Systematic Reviews More Useful to Healthcare Managers and Policy Makers." *Healthcare Policy* 1(2): 21–33.

Lavis, J.N., H.T.O. Davies, A.D. Oxman, J.-L. Denis, K. Golden-Biddle and E. Ferlie. 2005b. "Towards Systematic Reviews That Inform Health Care Management and Policy-Making." *Journal of Health Services Research and Policy* 10 (Supplement 1): S1:35–S1:48.

Lavis, J.N., F.B. Posada, A. Haines and E. Osei. 2004. "Use of Research to Inform Public Policymaking." *Lancet* 364(9445): 1615–1621.

Lomas, J. 2005. "Using Research to Inform Healthcare Managers' and Policy Makers' Questions: From Summative to Interpretive Synthesis." *Healthcare Policy* 1(1): 55–71.

Lomas, J., T. Culyer, C. McCutcheon, L. McAuley and S. Law. 2005. Conceptualizing and Combining Evidence for Health System Guidance. Ottawa: Canadian Health Services Research Foundation.

Pope, C., N. Mays and J. Popay. 2005. "Informing Policy Making and Management in Healthcare: The Place for Synthesis." *Healthcare Policy* 1(2): 43–48.

Knowledge Exchange



These speakers will change your mind...

Dr. Sherry Cooper, Jan.31 Barry Monaghan, Feb. '06 Dr. Michael Guerriere, Feb. '06 Dr. Arthur Porter, Feb. 28 Richard Alvarez, March '06 Michael Decter Dieter Pagani Dr. Alan Bernstein Sheila Weatherill, Spring '06 Dr. Ross Baker John Tory

Breakfast with the Chiefs

Contact Lina Lopez at llopez@longwoods.com

Toronto • Vancouver

Bariatric Surgery in Canada

La chirurgie bariatrique au Canada

Obesity rates for Canadian adults are much higher today than in the past; however, rates of bariatric surgery, a treatment for high-risk severely obese individuals, have not risen in parallel.



by ALEKSANDRA JOKOVIC, BDS, MHSC, PHD Project Lead, Health Services Research, Canadian Institute for Health Information

JENNIFER FROOD, MSC Senior Analyst, Health Services Research, Canadian Institute for Health Information

KIRA LEEB, BA, HON BA, MA
Manager, Health Services Research,
Canadian Institute for Health Information

Abstract

Obesity rates for Canadian adults are much higher today than in the past, raising questions about how to achieve healthy weights and mitigate the associated health risks. While not a solution at the population level, bariatric surgery may be a treatment option for a relatively small proportion of obese individuals. In Canada, unlike in the United States, no consistent trend was evident in the use of this surgery

between 1996-97 and 2003-04 across the five provinces for which comparable data were available. In 2003-04, bariatric surgeries were performed predominantly for women (87%); the average length of stay in hospital was 5 days; and 1.4% of patients were readmitted to hospital within 7 days of their discharge after surgery.

Résumé

Les taux d'obésité chez les adultes canadiens sont beaucoup plus élevés aujourd'hui que par le passé, ce qui suscite des questions sur les façons d'atteindre un poids santé et de réduire les risques associés à l'obésité. Bien que ce ne soit pas une solution qui convient à l'ensemble de la population, pour un faible pourcentage de personnes obèses, la chirurgie bariatrique peut constituer un choix de traitement judicieux. Contrairement aux Etats-Unis, on n'a décelé, au Canada, aucune tendance soutenue quant au recours à cette intervention entre 1996–1997 et 2003–2004 dans les cinq provinces pour lesquelles des données comparables étaient disponibles. En 2003-2004, la majorité des chirurgies bariatriques ont été pratiquées sur des femmes (87 %); la durée moyenne du séjour à l'hôpital était de 5 jours et 1,4 % des patients ont dû être hospitalisés à nouveau dans les sept jours suivant l'obtention de leur congé de l'hôpital.

s in many countries, the prevalence of obesity among Canadian adults is much higher than it was 25 years ago (Colquitt et al. 2005). According to the most recent Canadian Community Health Survey, nearly one-quarter (23.1%) or 5.5 million Canadian adults were obese (defined by a body mass index [BMI] of 30 kg/m2 or more) in 2004 (Tjepkema 2005). Further, 2.7% of respondents were morbidly obese (BMI of 40 kg/m2 or more), with women twice as likely as men (3.8% versus 1.6%, respectively) to be morbidly obese (Tjepkema 2005).

Studies show that adults who are obese are more likely to have high blood pressure, coronary heart disease, strokes, diabetes, gallbladder disease, some cancers and musculo-skeletal disorders (Bellanger and Bray 2005). Emerging evidence also links obesity to some psychological and social disorders (White et al. 2004). Obesity also places a financial burden on the healthcare system, costing an estimated \$1.6 billion or 2.2% of total direct healthcare expenditures in Canada in 2001 (Katzmarzyk and Janssen 2004).

A wide variety of options from an individual to a societal level have been proposed to promote healthy weights (McGrail 2004). Potential therapeutic interventions are diverse. Examples include approaches to promote dietary change, alterations in physical activity and behaviour modification and drug therapy. For selected high-risk individuals, bariatric surgery may also be a treatment option (Colquitt et al. 2005).

Bariatric surgery is usually considered a last resort for morbidly obese individuals who have attempted non-surgical approaches but who have not lost weight permanently (Colquitt et al. 2005). Ontario guidelines, for example, indicate that surgery should

Obesity also places a financial burden on the healthcare system, costing an estimated \$1.6 billion or 2.2% of total direct healthcare expenditures in Canada ... be restricted to people with morbid obesity or with a BMI of at least 35 kg/m² and serious co-morbid conditions (Medical Advisory Secretariat, Ontario Ministry of Health and Long-Term Care 2005). Other considerations include a propensity for weight loss and absence of periop-

erative risk factors and eating disorders (Colquitt et al. 2005). According to a recent systematic review, bariatric surgery is generally effective for sustained weight loss and improvements in associated co-morbid conditions for individuals who are candidates for the surgery (Colquitt et al. 2005). Despite the narrow indications for bariatric surgery, rising obesity rates in the Canadian population have led to questions about whether a corresponding increase in the use of this procedure has occurred.

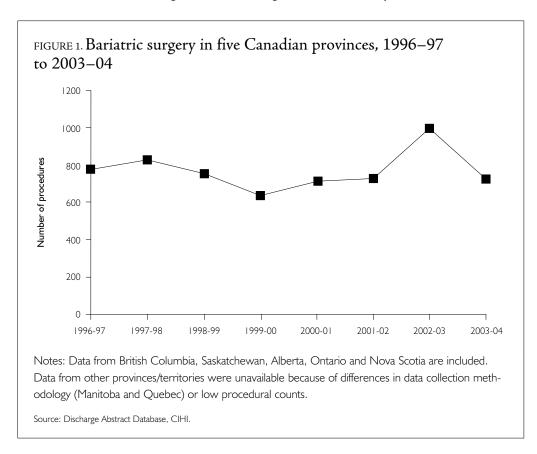
Methods

Data source and study population

We identified patients who had undergone bariatric surgery in hospitals in five provinces (British Columbia, Saskatchewan, Alberta, Ontario and Nova Scotia) between April 1, 1996 and March 31, 2004, using the Discharge Abstract Database of the Canadian Institute for Health Information. While bariatric surgery can be performed in conjunction with other diseases (e.g., cancer), here we focus on those surgeries performed for the purpose of weight reduction. In 1996–97, 57% of those who underwent bariatric surgical procedures (i.e., gastric bypass surgery) during this period had a concurrent diagnosis of obesity; in 2003–04, this percentage had increased to 64%. Bariatric surgery performed for weight reduction was identified using ICD-10-CA/CCI, ICD-9, ICD-9-CM procedure codes accompanied by diagnostic codes for obesity. The procedure codes were 1.NF.78^^ (CCI); 56.2, 56.93, 56.59 (ICD-9); and 44.31, 44.39, 44.69 (ICD-9-CM). The obesity codes were E66 (ICD-10); 278.0, 278.8 (ICD-9); and 278.00, 278.01, 278.88 (ICD-9-CM).

Data analysis

The annual frequencies of bariatric surgeries were calculated at both the provincial and combined level. Surgical procedure counts were based on where the procedures were performed, not on where the patients lived. Provincial/territorial results were excluded if fewer than five procedures were performed annually. For 2003-04, socio-



demographic characteristics, lengths of stay and readmission rates were also examined. Patients' residential postal codes were used to derive income quintiles based on an approach developed by Statistics Canada that assigns quintiles to neighbourhoods according to income data reported on the 2001 Census (Wilkins 2004). Only urban area postal codes were used in this analysis to minimize socio-economic misclassification (Wilkins 2004).

Results

Between 1996–97 and 2003–04, a total of 6,150 bariatric surgery procedures were performed on patients with a concurrent diagnosis of obesity in the five provinces.

Annual numbers of procedures varied across the years but no consistent trend was evident. The provision of these services varied across the country. In all provinces for which data are available, annual numbers fluctuated across the study years. For example, in Ontario there was a 57% increase from 2001–02 to 2002–03. This increase was not sustained the following year and is largely responsible for the overall peak in procedures performed in 2002–03 (Figure 1).

In 2003–04, 724 bariatric surgeries were performed on patients with a concurrent diagnosis of obesity in the five provinces. The vast majority of patients (86.9%) were women. The mean age of patients was 39 years, but surgery was conducted for patients younger than 19 and over 65 years of age. In urban areas, one in six patients (15%) came from the highest-income quintile neighbourhoods. The remaining patients were about equally likely to be from neighbourhoods in one of the other four quintiles of the income distribution (range, 20%–23%).

TABLE 1. Bariatric surgery in selected provinces in Canada*, 2003-04

	NUMBER OF PROCEDURES	MEAN AGE (YEARS)	% FEMALE	MEAN LOS (DAYS)
British Columbia	109	41	88	3.0
Alberta	224	37	91	5.5
Saskatchewan	41	39	83	10.3
Ontario	303	40	84	4.9
Nova Scotia	47	39	85	6.4
Total	724	39	87	5.2

^{*}Excludes Manitoba and Quebec because of differences in data collection methodology and provinces/ territories where fewer than five procedures were performed annually.

Source: Discharge Abstract Database, CIHI.

On average, the length of stay for these procedures was 5.2 days but differed within and across the provinces. Saskatchewan, for example, had the highest average lengths of stay (Table 1). These differences in lengths of stay may result from a variety of factors, including higher numbers of more invasive procedures being used in some jurisdictions as well as differences in patient populations. Across all provinces, lengths of stay in 2003–04 ranged from one to 61 days.

In the same year, over 99% of patients were discharged to their place of residence following recovery from the surgery. Readmission rates were 1.4% within the first seven

days after discharge; they rose to 6.4% when the first 30 days post-surgery were considered. Surgical complications were primarily responsible for readmissions to hospital.

Conclusion

Bariatric surgery has been performed for more than 50 years in the United States but has recently gained increased attention due to rising obesity rates (Hydock 2004). According to Santry at al. (2005), the number of bariatric surgeries performed in the United States with a confirmed diagnosis of obesity increased from 13,365 in 1998 to 72,177 in 2003. Analysis of hospitalizations for bariatric surgery with a diagnosis of obesity in five provinces in Canada between 1996–97 and 2003–04 did not reveal a similar trend. While the numbers of surgeries performed fluctuated annually both

... the number of bariatric surgeries performed in the United States with a confirmed diagnosis of obesity increased from 13,365 in 1998 to 72,177 in 2003.

across Canada and provincially, there was no consistent trend.

Use of bariatric surgery in Canada may differ from that in the United States. However, in some cases Canadians may be seeking care outside of the country. For example, the number of Ontario residents who had approved gastric bypass

surgery procedures (adjustable gastric banding procedures were not reported) in the United States increased from eight in 2002–03 to 346 at the time of reporting for 2004–05 (Medical Advisory Secretariat, Ontario Ministry of Health and Long-Term Care 2005). Including out-of-country procedures in future analyses using supplemental data may improve our understanding of how the use of bariatric surgery is changing in Canada.

Correspondence may be directed to Kira Leeb, Manager, Health Services Research, Canadian Institute for Health Information, 90 Eglinton Avenue East, Suite 300, Toronto, Ontario M4P 2Y3; email: KLeeb@cihi.ca.

REFERENCES

Bellanger, M. and G.A. Bray. 2005. "Obesity Related Morbidity and Mortality." Journal of the Louisiana State Medical Society 157(1): 42-49.

Colquitt, J., A. Clegg, E. Loveman, P. Royle and M.K. Sidhu. 2005. "Surgery for Morbid Obesity." The Cochrane Database of Systematic Reviews, Issue 4, Art. No. CD003641.pub2. DOI: 10.1002/14651858.CD003641.pub2.

Hydock, C.M. 2005. "A Brief Overview of Bariatric Surgical Procedures Currently Being Used to Treat the Obese Patients." *Critical Care Nursing Quarterly* 28(5): 217–226.

Katzmarzyk, P.T. and I. Janssen. 2004. "The Economic Costs Associated with Physical Inactivity and Obesity in Canada: An Update." *Canadian Journal of Applied Physiology* 29(2): 90–115.

McGrail, K., P. Schaub and C. Black. 2004. *The British Columbia Health Atlas* (2nd ed.). Vancouver: Centre for Health Services and Policy Research.

Medical Advisory Secretariat, Ontario Ministry of Health and Long-Term Care. 2005. "Bariatric Surgery. Health Technology Literature Review." Toronto: Author.

Santry, H.P., D.L. Gillen and D.S. Lauderale. 2005. "Trends in Bariatric Surgical Procedures." *Journal of the American Medical Association* 294(15): 1909–1917.

Tjepkema, M. 2005. "Adult Obesity in Canada: Measured Height and Weight." Ottawa: Statistics Canada. Catalogue no. 82-620-MWE.

White, M.A., P.M. O'Neil, R.L. Kolotkin and T.K. Byrne. 2004. "Gender, Race, and Obesity-Related Quality of Life at Extreme Levels of Obesity." *Obesity Research* 12(6): 949–955.

Wilkins, R. 2004. PCCF+ Version 4D User's Guide (geocodes/PCCF). Automated Geographic Coding on the Statistics Canada Postal Code Conversion Files, Including Postal Codes to December 2003. Catalogue no. 82F0086-XDB. Ottawa: Health Analysis and Measurement Group, Statistics Canada.

Call to Authors

Data Matters presents brief, focused papers that report analyses of health administrative or survey data that shed light on significant health services and policy issues. Submissions to Data Matters should be a maximum of 1,500 words, exclusive of tables, figures and references, and should include no more than three tables or figures.

Appel aux auteurs

« Questions de données » présente de brefs articles portant sur des analyses de données administratives sur la santé ou de données d'enquête et qui font la lumière sur d'importantes questions liées aux services et aux politiques de santé. Les articles soumis à « Questions de données » doivent être d'au plus 1 500 mots, excluant les tableaux, diagrammes et références et ne doivent pas comprendre plus de trois tableaux ou diagrammes.

For more information contact Rebecca Hart, Managing Editor at rhart@longwoods.com

Reflections on Conversations with Robert Bell and Michael Guerriere: What Is Relevant Research?

Réflexions sur des conversations avec Robert Bell et Michael Guerriere : La recherche pertinente : qu'est-ce que c'est au juste?

by ANTON HART
Publisher, Healthcare Policy

Abstract

Two decision-makers from the acute-care sector weigh in on the issue of relevant research. Between the two of them they look for patient-defined research, evidence to support the conclusions, information that can lead to interventions designed to improve quality and outcomes and defined control mechanisms to properly identify the practices that improved the system. Three examples are cited and discussed. The context is set by comments from one of Canada's leading researchers and the use of research from one of this decade's most lauded system turnarounds.

Résumé

Deux décideurs du secteur des soins actifs se prononcent sur la question de la recherche pertinente. À eux deux, ils cherchent des travaux de recherche axés sur le patient, des preuves pour étayer les conclusions, des renseignements pouvant mener à des interventions conçues pour améliorer la qualité et les effets, ainsi que des mécanismes de contrôle définis permettant de cerner les pratiques qui contribuent à améliorer

le système. Trois exemples sont présentés et discutés. Le contexte est établi par les commentaires d'un éminent chercheur canadien et les données sur l'utilisation de la recherche proviennent d'une des transformations de systèmes les plus louangées de cette décennie.

NE YEAR BEFORE THE RELEASE OF HEALTHCARE POLICY'S INAUGURAL issue, Morris Barer, Peter Coyte and I positioned the journal as one of "peerreviewed and relevant research." We wrote:

This journal will provide an important new outlet for peer-reviewed research of relevance to Canadian healthcare services. It will, more importantly, be designed to serve the evolving needs of health system decision-makers across the country looking for timely and relevant research, and new ideas, on the organization, financing, funding, management, regulation, delivery and use of health services for Canadians.

In short, it will provide a venue for peer-reviewed scholarly health services and policy research, debate and discussion that is accessible and useful to health system managers, policy makers and policy influencers. (Canadian Institutes of Health Research [CIHR] 2004)

"Policy makers have challenged the health system to develop more cost-effective, innovative and evidence-based ways of delivering care. Increasingly, Canada is moving towards an integrated and system-based approach to health service delivery. The health research community must also respond to similar challenges."

 Dr. Alan Bernstein, keynote address to the Canadian Academies of Health Sciences, September 21, 2005 A year later, introducing the first issue of this journal, Alan Bernstein, President and CEO of the Canadian Institutes of Health Research, reinforced the idea: "Changing values, technologies and other circumstances demand constant, critical, objective and evidence-based change" (Bernstein 2005a).

To support researchers serving the evolving needs of

health system decision-makers for timely and relevant research, the editorial advisory board of *Healthcare Policy* recommended a series of interviews and discussions with the journal's intended audience – decision-makers in healthcare. First to be interviewed was Dr. Brian Postl, President and CEO of Winnipeg Regional Health, who was

recently appointed the prime minister's federal adviser on wait times. "Research," he told us, "is key in the process of change." He suggested "evidence" as one of four themes that the journal should consider as it looks at knowledge and its impact on policy and practice. The other themes were defining the audience, using appropriate tools to transfer and translate research, and translating research so that it is meaningful.

The present article reflects discussions with two more health system decisionmakers: Dr. Michael Guerriere and Dr. Robert Bell. Anticipating that we would

"Rapid improvement is possible in healthcare, even in large, politically sensitive, financially stressed, publicly administered systems. Improved healthcare quality, better service and reduced cost can (and should be) achieved at the same time. The conceptual underpinnings of change are straightforward; execution is the challenge!"

- Dr. K.W. Kizer, "Making and Sustaining Change in Healthcare," presentation, November 29, 2005 explore "evidence," the topic was simply: "What is relevant research?"

Dr. Guerriere, a physician who has always focused on systems and informatics, is at the heart of change in his role as Managing Partner at Courtyard Group - a meticulously selected line-up of experts advising providers of both healthcare policy and healthcare services. Courtyard Group's

assignments are focused on the transformation of care and organizations for landmark clients in Canada, the United States and England. Dr. Guerriere is also Chair of the Ryerson University Board.

Dr. Bell, an orthopaedic surgeon specializing in cancer, is President and CEO of University Health Network (UHN) in Toronto, an organization with the explicit mission of providing exemplary patient care, research and education – a mission familiar to most academic health sciences centres. The scope of research and the complexity of cases in the network's care put Dr. Bell and his colleagues front and centre among patients and their families; researchers; providers of health policy, care and products; and the academic dons of both clinical and healthcare services.

Dr. Bell* reflected on evidence-based research, dissemination and implementation. As CEO of an academic health sciences centre, he looks for patient-defined research, something he believes nurses do well. As an administrator, he points to the importance of CIHR's Pillar Three (health systems and services) and Pillar Four (social, cultural and other factors that affect the health of populations): researchers should look at improved efficiency, utility and productivity of the system and process – but

^{*} based on a personal conversation with Dr. Bell.

all in the context of the patient. The results, he says, can best be measured if they are built on a basis of evidence – something he's prepared to get from both grey literature and peer-reviewed journals.

As we discussed UHN's mission, Bell underscored the importance of being able to measure the organization's success at the highest level. A focus on the mission at the highest level sets up a process that is then passed down to departments and individual units. Properly executed, it leads to a common mission throughout the organization.

In short, Dr. Bell wants (1) patient-defined research to improve efficiency and utility, (2) the evidence that backs it up and (3) the ability to measure its impact.

How did the Veterans Health Administration make research relevant? Consider the name of their research organization and its mission. Together they are very telling; you can see a whole strategy unfold. "The mission of a special team of researchers – the Veterans Evidence-based Research, Dissemination, and Implementation Center (VERDICT) – is to improve the health of veterans by researching methods of optimizing the performance of the clinical micro-systems which surround and support the health care system–patient interface."

 Website for Veterans Evidence-based Research Dissemination Implementation Center, 2005

Dr. Guerriere picks up this last point – the ability to measure results. Relevant research, he says, provides information that should lead to an intervention that will or can improve outcomes; only then does research add value to our hospitals and healthcare system. Measurement can determine whether the intervention has utility and how well it works. Relevant research, furthermore, sets up control mechanisms so that, eventually, management can properly identify the practices that improved the system.

The quality and utility of research data are critical. They must be enabling; otherwise, why do the research? Guerriere cites the work of former New York Mayor Rudolph Giuliani. New York's CompStat program, which won the 1996 Innovations in Government Award from the Kennedy School of Government at Harvard University, allows police to monitor statistics on criminal activity on specific street corners as well as citywide, holding precinct commanders accountable for crime in their neighbourhoods. Because these data are updated constantly, the police can become proactive in fighting crime, curtailing trends before they become crime waves. Dr. Guerriere recommends Giuliani's book *Leadership* (2002) as a key to understanding the use of information to manage complex organizations.

He then cites the work of Dr. Jack Tu and colleagues in the EFFECT Study (Canadian Cardiovascular Outcomes Research Team [CCORT] 2005), which focuses on a number of well-defined quality indicators that have demonstrably improved patient outcomes and provided direction and focus to quality improvement efforts for cardiac care. EFFECT is one of the largest and most comprehensive initiatives in

"The reality is that there is now an intimate, symbiotic and non-linear relationship between scientific understanding and its application into practice, products and policy. Initiatives like the Human Genome Project and the Grand Challenges in Global Health, initiated by the Gates Foundation, have gone a long way in blurring [the] post-World War II distinction between basic and applied research."

- Dr. Alan Bernstein, keynote address to the Canadian Academies of Health Sciences, September 21, 2005 the world to measure and improve the quality of cardiac care. Using a randomized trial of cardiac care report cards, the study's objective is to determine whether developing and publishing report cards based on clinical data collected from patient charts leads to greater use of evidence-based therapy at hospitals that receive them.

The fundamental purpose of the EFFECT Study is very specific: to assist in designing mechanisms to

reduce the delay between the acquisition of health research and evidence and their application in patient care. The intent is to raise awareness and provide information in a useful manner. By identifying both areas of high quality and areas for improvement, the study can support continued improvement in care as we strive for clinical excellence.

After phase I, the EFFECT researchers asked for feedback from participating hospitals and others in order to improve future reports. Phase II, involving a second round of chart abstraction, begins in late 2005; findings will be released in 2006-07. All quality indicators will be reviewed and revised as needed to ensure that they continue to reflect current evidence-based practice. Phase III – impact assessment – involves a comparison of the hospitals' performance between phases I and II. In their summary, Dr. Tu and colleagues write: "It is hoped that participating hospitals will view the EFFECT Study as a positive and constructive tool for change and that it will assist ongoing efforts to use the data for quality improvement initiatives" (CCORT 2005). That is relevant research, by Guerriere's standards.

He cites one more example of relevant research: the not-for-profit RAND Corporation, a major US think tank that, according to its own website, provides "objective analysis and effective solutions that address challenges facing the public and private sectors around the world." RAND conducts research in business, education, health,

law and science in "areas ... that reflect the changing nature of global society," with the objective of providing readily accessible research and analysis to improve public policy and decision-making. Some of RAND's research is carried out on behalf of public and private sponsors and clients; other studies are undertaken under its own aegis.

One of the RAND Corporation's ongoing projects is the Promising Practices Network (PPN), an organization "dedicated to providing quality evidence-based information about what works to improve the lives of children, families and communities" (PPN 2005). According to its website:

PPN's target audience includes policy makers, service providers and other decision-makers at all levels who care about improving outcomes for children and families. The site helps decision-makers understand what approaches and programs have been shown in the scientific literature to improve outcomes in various areas such as child health and education.

PPN promises objective, evidence-based information; comprehensiveness; accessibility; and impartiality. It offers program summaries of effective interventions, clearly defining outcome areas and indicators, levels of evidence, evaluation methods and key findings. Funding sources are identified, and program bibliographies list all materials used to make judgments (PPN 2005).

Publishers should welcome such resources as the Promising Practices Network and its rich website. These can only reinforce our own mission to explore ideas, share best practices and enable excellence in healthcare.

Researchers who join us at *Healthcare Policy* will only reach individual decision-makers like Dr. Bell and Dr. Guerriere if their research is relevant. Then, this journal will make a difference.

REFERENCES

Bernstein, A. 2005a. "The Commitment to Knowledge Transfer." Retrieved December 14, 2005. http://www3.longwoods.com/product.php?productid=17561&cat=392&page=1.

Bernstein, A. 2005b (September 21). "The Promise of the Health Sciences in the 21st Century." Keynote address to the Canadian Academies of Health Sciences. Retrieved December 14, 2005. http://www.cihr-irsc.gc.ca/e/29662.html.

Canadian Cardiovascular Outcomes Research Team (CCORT). 2005. "Enhanced Feedback for Effective Cardiac Treatment (EFFECT)." Retrieved December 14, 2005. ">http://www.ices.on.ca/webpage.cfm?site_id=1&org_id=2&morg_id=0&gsec_id=398&item_id=398&category_id=29>">http://www.ices.on.ca/webpage.cfm?site_id=1&org_id=2&morg_id=0&gsec_id=398&item_id=398&category_id=29>">http://www.ices.on.ca/webpage.cfm?site_id=1&org_id=2&morg_id=0&gsec_id=398&item_id=398&category_id=29>">http://www.ices.on.ca/webpage.cfm?site_id=1&org_id=2&morg_id=0&gsec_id=398&item_id=398&category_id=29>">http://www.ices.on.ca/webpage.cfm?site_id=1&org_id

Canadian Institutes of Health Research (CIHR). 2004 (September). "New Canadian Health Services and Policy Journal: Announcement, Call for Expressions of Interest for Editorial Team, and 'Name That Journal' Contest." Retrieved December 14, 2005. http://www.cihr-irsc.gc.ca/e/24637.html.

Giuliani, R.W. and K. Kurson. 2002. Leadership. New York: Hyperion.

Kizer, K.W. 2005 (November 29). "Making and Sustaining Change in Healthcare." Retrieved December 14, 2005. http://www3.longwoods.com/home.php?cat=105.

Promising Practices Network. 2005. Retrieved December 14, 2005. http://www.promising practices.net/about_network.asp>.

Rand Coporation. 2005. "About Rand." Retrieved December 14, 2005. http://www.rand.org/ about/>.

Veterans Evidence-based Research Dissemination Implementation Center (VERDICT). 2005. Mission statement and goals. Retrieved December 14, 2005. http://verdict.uthscsa.edu/verdict/ default.htm>.

The secret of knowing about it first.

The Longwoods eLetter – ideas, policies, best practices, careers, transitions and learning events. Sign up here: http://longwoods.com/skin1/eletter.html





Reflections on ...

Rudolf Klein's three types of evidence

- *Research evidence* is produced by scientists, in accordance with accepted research methodologies.
- Organizational evidence is information about an organization's capacity to complete the tasks being approached. It can also be characterized by the question "The last time we tried this, why did we fall flat on our faces?"
- Political evidence includes information about how the public, politicians, and other players will react to policies under consideration, helping or hindering the success of the policy decision.

Rudolf Klein (England)

Emeritus Professor of Social Policy, University of Bath; Visiting Professor, London School of Economics and London School of Hygiene and Tropical Medicine

For a full discussion on evidence in healthcare see: http://www.chsrf.ca/knowledge_transfer/pdf/2004_workshop_report_e.pdf

The Canadian Health Services Research Foundation: Evidence is ...

The foundation's mission is to support evidence-based decision-making in the health system. Defining what is meant by *evidence* in this mission requires a balance between researchers' and decision makers' understandings of the term.

As a follow-up to Conceptualizing and Combining Evidence for Health System Guidance, the foundation has adopted the following definition of evidence:

Evidence is information that comes closest to the facts of a matter. The form it takes depends on context. The findings of high-quality, methodologically appropriate research are the most accurate evidence. Because research is often incomplete and sometimes contradictory or unavailable, other kinds of information are necessary supplements to or stand-ins for research. The evidence base for a decision is the multiple forms of evidence combined to balance rigour with expedience—while privileging the former over the latter.

For more information on Conceptualizing and Combining Evidence see: http://www.chsrf.ca/other_documents/evidence_e.php

Linkage and Exchange

THE CASE STUDY PRESENTED HERE is drawn from a new publication from the Canadian Institutes of Health Research, Institute of Health Services and Policy Research. Evidence in Action, Acting on Evidence – A Casebook of Health Services and Knowledge Translation Stories highlights original submissions from across Canada that focus on lessons learned from both successful, and less than successful, knowledge translation activities. Designed as a means for both researchers and decision-makers to share and recognize their experiences, the casebook also demonstrates the impact that such research can have in shaping policy, program and practice changes.

Evidence in Action, Acting on Evidence will be published in early 2006. Please visit CIHR's website at www.cihr-irsc.gc.ca for more details.

LA CAS PRÉSENTÉ ICI SONT tirés d'une nouvelle revue publiée par l'Institut des services et des politiques de la santé des Instituts de recherche en santé du Canada. Evidence in Action, Acting on Evidence – A Casebook of Health Services and Knowledge Translation Stories présente des articles originaux provenant de partout au Canada et qui mettent l'accent sur les leçons apprises dans le cadre d'activités d'application des connaissances – dont certaines ont été fructueuses et d'autres, moins. Se voulant un outil pour permettre aux chercheurs et aux décideurs de partager et de reconnaître leurs expériences, le recueil démontre également l'incidence que ces travaux de recherche peuvent avoir sur l'élaboration des politiques, les changements apportés aux programmes et la pratique.

Les preuves comme moteurs d'initiatives sera publié en 2006. Visitez le site Web des IRSC à www.cihr-irsc.gc.ca pour plus de détails.

Knowledge Translation to Advance the Nurse Practitioner Role in British Columbia

Appliquer les connaissances en vue de faire avancer le rôle des infimières praticiennes en Colombie-Britannique

Researchers and decision-makers conduct policy-relevant research to guide legislative and regulatory development and the design of a nurse practitioner education program.

by MARJORIE MACDONALD, RN, PHD School of Nursing, University of Victoria, Victoria, BC

SANDRA REGAN, RN, MSN College of Registered Nurses of British Columbia

HEATHER DAVIDSON, PHD
British Columbia Services to Ministry of Health Services

RITA SCHREIBER, RN, DNS School of Nursing, University of Victoria, Victoria, BC

JANE CRICKMORE, RN, MPA
British Columbia Ministry of Health Services

LESLEY MOSS, MA Vancouver Island Health Authority, Victoria, BC

JANET PINELLI, RN, DNS McMaster University, Hamilton, ON

BERNADETTE PAULY, RN, MN School of Nursing, University of Victoria, Victoria, BC

Abstract

This project brought together a team of researchers and decision-makers to conduct policy-relevant research to support the introduction of advanced nursing practice roles in British Columbia. All team members, including decision-makers, were actively involved in the conceptualization, design, data collection, analysis and interpretation of the study. This level of engagement, coupled with ongoing knowledge translation (KT) activities, led to the implementation by stakeholders of a majority of the study's recommendations. The results have since been used to guide legislative and regulatory development and to design a nurse practitioner education program.

Résumé

Ce projet regroupait une équipe de chercheurs et de décideurs qui se sont réunis pour effectuer de la recherche liée aux politiques en vue d'appuyer l'introduction de rôles avancés dans la pratique des soins infirmiers en Colombie-Britannique. Tous les membres de l'équipe, y compris les décideurs, ont pris une part active à la conceptualisation, à la conception, à la collecte de données, à l'analyse et à l'interprétation de l'étude. Grâce à ce niveau d'engagement et à des activités continues d'application des connaissances (AC), la majorité des recommandations de l'étude ont été mises en œuvre par les intervenants. Les résultats ont depuis été utilisés pour orienter l'élaboration de mesures législatives et réglementaires et pour concevoir un programme d'enseignement à l'intention des infirmières praticiennes.

In 2001, the Canadian Health Services Research Foundation (CHSRF) funded us to study the opportunities and challenges for advanced nursing practice (ANP) in British Columbia. Nurses working in ANP roles have been shown to provide appropriate and cost-effective continuity of care (Horrocks et al. 2002; Safriet 1992). However, widespread adoption of advanced nursing practice has been hampered by considerable confusion and debate about definitions, roles and functions, as well as the required competencies, practice environments, educational qualifications, credentials, regulations and legislation (Bryant-Lukosius et al. 2004).

This project aimed to bring researchers and decision-makers together to conduct

policy-relevant research that would support the introduction of new ANP roles, including nurse practitioners, in British Columbia. Our research objectives were: to clarify the understanding of ANP and related roles within the healthcare system; to identify the current status of ANP in the province; to identify gaps in healthcare services that might be filled by the expansion or introduction of new nursing roles; to explore and describe models of ANP in other jurisdictions; to identify barriers to implementing new nursing service delivery models in British Columbia; and, on the basis of the above analysis, to identify and recommend future policy directions for new nursing roles and models in the province.

The project team, which was convened by the BC Ministry of Health, included researchers, educators, government and health authority decision-makers and nursing regulators. An advisory group, which provided advice and feedback on research methods and findings, included representatives of the public, other health professions (e.g., midwifery, medicine, pharmacy) and other constituencies (e.g., seniors, First Nations and Inuit Health Branch, British Columbia Nurses' Union).

The funding strategy of the CHSRF required co-funding arrangements involving both cash and in-kind contributions from a variety of national, provincial and local sources. Our co-funders included the Nursing Research Fund, the BC Health Research Foundation, the BC Ministry of Health, the Registered Nurses Association of BC, Capital Health Region in Victoria (now Vancouver Island Health Authority) and the University of Victoria. Some of the funders were also research partners and appointed representatives to the research team.

The KT Initiative

Our study was carried out in three phases, with knowledge translation (KT) goals incorporated directly into the research process. All team members, including decision-makers, were actively involved in the project throughout the study, from conceptualization and design through data collection, analysis and interpretation.

In Phase 1, data were gathered through telephone interviews and focus groups with nurses in a variety of roles and settings to determine how they understood ANP and how nurses in ANP roles were deployed in British Columbia. An email survey was conducted with employers to determine their understanding of ANP and to identify health service priorities, gaps in service and the potential for introducing new ANP roles in their organizations.

In Phase 2, we conducted five case studies of models of ANP in other jurisdictions to understand the nature and benefits of advanced practice, and to determine the feasibility of various service models for British Columbia.

Phase 3, which also comprised our major KT activity, was a provincial think tank attended by almost 100 key stakeholders to discuss preliminary research findings and

generate policy recommendations. Not only did the think tank inform the development of recommendations, but it also provided for dissemination of the preliminary findings to a broad stakeholder audience and acted as a mechanism to test the validity and relevance of our results for informing policy recommendations.

Decision-maker and researcher team members conducted interviews and observations and actively participated in analyzing and interpreting the data. We learned from other research teams funded in the same CHSRF competition that the full engagement of decision-makers at all phases of the research was unusual, and we believe that this level of involvement contributed to the successful use of the research findings.

Decision-maker partners also took a leadership role in developing the overall knowledge translation plan and strategies that were consistent with the information needs and preferred communication mechanisms of our audiences. Other KT activities included:

- regular status reports to senior administration in all partner organizations;
- sharing interim and final reports with multiple audiences, including the Federal/ Provincial/Territorial Advisory Committee on Health Human Resources and all partner organizations;
- creation of a website that included descriptions of the projects, regular updates, project reports, links to other resources and a mechanism for visitor feedback; and
- presentations by members of the research team to various partner organizations, including employers and the ministry.

The project's advisory group was also an important mechanism for knowledge translation, through our ongoing communication and members' ability to distribute information through their networks. The advisory group also participated in the think tank.

Results of the KT Initiative

Our KT strategies resulted in substantial buy-in from stakeholders and facilitated implementation of a majority of the study's recommendations in the following two years. The results were used directly in an instrumental fashion (Lavis et al. 2003) to inform the development of nurse practitioner competencies and practice standards, to guide legislative and regulatory development and to inform the development of at least one nurse practitioner education program. Five articles based on the study have been published to date (Schreiber & MacDonald 2003; Pauly et al. 2004; Schreiber et al. 2005a,b; MacDonald et al. 2005).

Instrumental use of research findings, which is defined as acting on research in specific and direct ways, is reported less frequently in the literature than conceptual or symbolic use (Lavis et al. 2003; Weiss 1980). Although we did not have a formal evaluation plan to assess the KT strategies, we recognized that indicators of success would include the actual implementation of study recommendations and, although we do not claim sole credit for implementation of the recommendations, there was a synergy between our research-based recommendations and the development of policy, as summarized in Table 1. In addition, the entire team engaged in a reflective exercise on the benefits and challenges of the partnership experience.

TABLE 1. ANP recommendations and action to date

RECOMMENDATIONS

- 1. In British Columbia (BC), there should be two recognized advanced nursing practice roles: the clinical nurse specialist and nurse practitioner (NP).
- 2. In developing legislation, the titles "Nurse Practitioner," "Clinical Nurse Specialist" and "Advanced Practice Nurse" should be protected.
- 3. Educational preparation for entering advanced nursing practice should be at the graduate level in nursing appropriate to the competencies required of the role.
- 4. Stakeholders in BC should continue to participate and take a leadership role in the development of a national framework for nurse practitioners that will allow for national standards and inter-provincial mobility.
- 5. A feasibility study should be conducted regarding the adoption of nurse anaesthesia as an advanced practice role in Canada.

ACTION TO DATE

The clinical nurse specialist is a well-established ANP role in BC. In 2005, the first graduates of BC NP programs began working in the province.

In August 2005, when nursing moved under the Health Professions Act, title protection was achieved for "Nurse Practitioner."

The expert advisory group, which included a research team member, developed NP competencies establishing that graduate preparation was required. In 2003, the Ministry of Advanced Education (MAVED) funded NP master's programs at UBC and the University of Victoria (UVIC).

The Canadian Nurse Practitioner Initiative (CNPI), led by the Canadian Nurses Association (CNA), has proposed a national standard for NP education, regulation, practice and planning. Many research team members participated on CNPI working groups. A recent CNA national symposium on ANP used published papers from our study as key preparatory readings.

Two of the team members published a paper on the nurse anaesthetist (NA) role and are launching a study to explore how NAs manage implementation of the role. The NA role was discussed at the recent CNA symposium in which one team member participated.

- 6. Further exploration is needed of the supports required by rural and remote-area nurses who are currently working in sites with the potential for development of advanced nursing practice.
- 7. The Ministry of Health and the Registered Nurses Association of British Columbia (now the College of Registered Nurses of British Columbia, or CRNBC) should establish an Implementation and Development Committee that includes relevant stakeholder groups and is charged with developing a plan for introducing the nurse practitioner role and for sustaining the clinical nurse specialist role in BC.
- 8. Legislation and regulation of nurse practitioners should be enabling within a professional practice model in which nurse practitioners have sole authority for their practice, clear standards of practice, accountability for decision-making and maintenance of competence.
- 9. A public education campaign should be developed and implemented by the government in conjunction with the professional associations in order to educate. market and sell advanced nursing practice roles to the public, policy makers and other providers.
- 10. The government should take a leadership role in providing regional seminars, guidelines and workshops to health authorities to support implementation and sustainability of advanced nursing practice roles.

The 2005 Health Professions Act sets out regulations of NPs and provides for certified practices for registered nurses in an expanded scope of practice for non-NPs working in these areas rather than regulates NPs. A specific government nursing strategy in 2005/06 is developing the role of rural nurses.

Various steering and advisory committees with broad stakeholder involvement were established to support the development and implementation of the nurse practitioner role in BC.

Under the Health Professions Act, the government, in consultation with the CRNBC, has developed regulations to govern NP practice that are consistent with this recommendation.

Various public relations initiatives have been undertaken by government, CRNBC and the universities. The health authorities have created print materials including pamphlets, fact sheets and Web-based resources, and have held faceto-face meetings with key members of the public. The CNPI has mounted a public education campaign.

Public relations initiatives undertaken by the Nursing Directorate of the BC Ministry of Health include development of a resource manual for NPs and ongoing meetings with health authorities.

Marjorie MacDonald, Sandra Regan, Heather Davidson, Rita Schreiber, Jane Crickmore, Lesley Moss, Janet Pinelli and Bernadette Pauly

- 11. Identification and development of nursesensitive outcome variables and measures, including outcomes from advanced nursing practice, should be undertaken.
- A reconfigured ANP research team is currently seeking funding to evaluate the implementation and integration of NPs into the healthcare systems of BC and New Brunswick and to develop NP-sensitive outcome variables/measures for a future study. The MOH is beginning to develop outcome measures to evaluate implementation of NPs in BC.

12. New funding should be allocated:

- · to Health Authorities for advanced nursing practice positions and to provide for infrastructure and organizational support of ANP
- · to support development of appropriate educational programs
- · to prepare faculty to teach in ANP programs
- to support continuing education opportunities
- 13. Exploration of existing sources of funding for possible reallocation to support salaried positions of advanced practice nurses is needed;
- 14. Further exploration of funding models to support development and sustainability of advanced nursing practice is needed; and
- 15. Legislation, regulation and deployment of nurse practitioners should not occur unless and until stable funding to support implementing and sustaining the role is in place.
- 16. Resources must be made available for evaluation of advanced nursing practice role implementation, impact and relevant outcomes.

The Ministry of Health has provided;

- · funding to each Health Authority for four NP positions per year for three years
- funding from MAVED was provided to UBC, UVIC and the University of New Brunswick for NP programs
- funding from MAVED was provided to UVIC to support existing faculty to obtain NP credentials
- funding is ongoing by Nursing Directorate and Health Authorities.

Ongoing under the leadership of the Nursing Directorate. Funding has been provided to the health authorities to create salaried NP positions, and NPs are excluded by legislation from the collective agreement.

The Nursing Directorate, CRNBC and health authorities are part of the reformulated research team seeking funding to evaluate the integration and implementation of the NP role. The Nursing Directorate and the health authorities are currently monitoring aspects of the role.

Lessons Learned

The research partnership was clearly a successful venture. Nonetheless, we had to deal with the challenge of negotiating and mediating our differing interests. Decisionmakers and researchers operate on very different time frames, with decision-makers often under pressure to produce swift results. In the time between writing the original research proposal and getting it funded, the political context changed dramatically, and we were under pressure to produce data much more quickly.

The tension between the researchers' needs to maintain scientific rigour and the decision-makers' needs for information actually created an opportunity for us to understand each other's approaches, as well as the demands and perspectives of our different work processes. At times, the researcher team members were somewhat frustrated by the demand to speed up study timelines, but through education, negotiation and prioritizing, we developed strategies (e.g., additional funding provided by government to focus on specific areas of data collection) that met the decision-makers' timesensitive information needs, while maintaining scientific rigour.

Although there were clear research goals, each team member had a somewhat different vision for the project and different reasons for engaging in the research process. These differences added depth to the research, but also needed to be negotiated as they emerged in subtle ways to create tensions and disagreements. Autonomy and academic freedom are core values in universities. The ability to speak openly and freely is both encouraged and expected. In the partner organizations, decision-makers operate within a policy context that explicitly and implicitly governs their work and that may, at times, preclude the public expression of personal opinion.

Within the research team, the same data also meant different things to different people, and we needed to negotiate how the data were interpreted, reported and disseminated. To complicate the situation, universities and organizations have differing reward systems. This fact influenced, more than we anticipated, the direction each of us wanted to take on particular issues, such as the focus and slant of a particular journal article.

Our ability to negotiate and mediate all these differences was made possible by several team characteristics, including:

- the steadfast commitment of all partners to the research enterprise and the goals of the project;
- the willingness of team members to compromise;
- trust and respect for one another based on established prior relationships;
- researchers who had been policy makers and policy makers who had been researchers, with understanding of the values and constraints faced by each partner; and

 decision-maker team members with the authority and accountability to make important decisions, and to make and honour commitments.

Conclusions and Implications

Our research experience and our findings have been used extensively by our own organizations to inform policy and program development. The results have also been used outside the original partnership. As noted in Table 1, the Canadian Nurses Association (CNA) held an invitational forum in the fall of 2005 on advanced nursing practice, and some of our published research was used to inform the discussion and debate about the direction of ANP in Canada. In addition to the recommendations from the study that were implemented, other examples of knowledge translation include the fact that our final report has been used and cited by other nursing education institutions in the development of graduate programs in advanced nursing practice. On a national level, the findings of this research have informed discussions of a national Primary Healthcare Nurse Practitioner Education task force. Finally, this research provides the starting point of a longer-term program of research that will include many of the original research team.

Correspondence may be directed to: Marjorie MacDonald, Associate Professor and Interim Director, School of Nursing, University of Victoria, Victoria, BC V8W 2Y2; tel: (250) 721-7953; email: marjorie@uvic.ca.

REFERENCES

Bryant-Lukosius, D., A. DiCenso, G. Browne and J. Pinelli. 2004. "Advanced Practice Nursing Roles: Development, Implementation and Evaluation." *Journal of Advanced Nursing* 48(5): 519–529.

Horrocks, S., E. Anderson and C. Salisbury. 2002. "Systematic Review of Whether Nurse Practitioners Working in Primary Care Can Provide Equivalent Care to Doctors." *British Medical Journal* 324: 819–823.

Lavis, J.N., D. Robertson, J.M. Woodside, C.B. MacLeod, J. Abelson and the Knowledge Transfer Study Group. 2003. "How Can Research Organizations More Effectively Transfer Research Knowledge to Decision-Makers?" *Milbank Quarterly* 81(2): 221–248.

MacDonald, M., R. Schreiber, H. Davidson, B. Pauly, L. Moss, J. Pinelli, S. Regan, J. Crickmore and C. Hammond. 2005 (June). "Moving towards Harmony: Exemplars of Advanced Nursing Practice for British Columbia." *Canadian Journal of Nursing Leadership*. Online exclusive. Retrieved December 1, 2005. http://www.longwoods.com/website/NL/onlineExclusive/NL0605MacDonald.pdf.

Pauly, B., R. Schreiber, M. MacDonald, H. Davidson, J. Crickmore, L. Moss, J. Pinelli, S. Regan and C. Hammond. 2004. "Dancing to Our Own Tune: Understandings of Advanced Nursing Practice in British Columbia." *Canadian Journal of Nursing Leadership* 17(2): 47–57.

Safriet, B.J. 1992. "Health Care Dollars and Regulatory Sense: The Role of Advanced Practice Nursing." Yale Journal of Regulation 9: 417-488.

Schreiber, R. and M. MacDonald. 2003. "Nurse Anesthesia: The Time Has Come." Canadian Nurse 99(6): 20-23.

Schreiber, R., M. MacDonald, B. Pauly, H. Davidson, J. Crickmore, L. Moss, J. Pinelli, S. Regan and C. Hammond. 2005a (June). "Singing from the Same Songbook: The Future of Advanced Nursing Practice in British Columbia." Canadian Journal of Nursing Leadership. Online exclusive. Retrieved December 1, 2005. http://www.longwoods.com/website/NL/onlineExclusive/ NL0605bSchreber.pdf>.

Schreiber, R., M. MacDonald, B. Pauly, H. Davidson, J. Crickmore, L. Moss, J. Pinelli, S. Regan and C. Hammond. 2005b (June). "Singing in Different Keys: Enactment of Advanced Nursing Practice in British Columbia." Canadian Journal of Nursing Leadership. Online exclusive. Retrieved December 1, 2005. http://www.longwoods.com/website/NL/onlineExclusive/ NL0605aSchreber.pdf>.

Weiss, C.H. 1980. "Knowledge Creep and Decision Accretion." Knowledge: Creation, Diffusion, Utilization 1(3): 381-404.

Call to Authors

Linkage and Exchange provides a forum for knowledge translation (KT) case studies. Submissions should include an abstract of no more than 100 words, a brief statement of background and context, a description of the KT initiative, a presentation of results (including challenges that arose and how they were addressed) and a discussion of lessons learned, highlighting those that are potentially transferable to other topics and settings. Manuscripts should be a maximum of 2,000 words, excluding the abstract and references.

Appel aux auteurs

« Liens et échanges » fournit un forum pour des études de cas en application des connaissances (AC). Les articles soumis doivent comporter un résumé d'au plus 100 mots, une brève mise en contexte, une description de l'initiative d'AC, une présentation des résultats (y compris les défis qui se sont présentés et comment ils ont été relevés), ainsi qu'une discussion des leçons apprises, surtout celles qui sont potentiellement transférables à d'autres sujets et à d'autres cadres. Les manuscrits doivent être d'au plus 2 000 mots, excluant le résumé et les références.

For more information contact Rebecca Hart, Managing Editor at rhart@longwoods.com

Interactions: Trade Policy and Healthcare Reform After Chaoulli v. Quebec

Interactions : les politiques commerciales et la réforme des soins de santé après Chaoulli c. Québec

Is it time for Canada to acknowledge the fragile boundary between health and trade policies and strengthen the separation between private and public health insurance?



by MARK CRAWFORD, LLB, DPHIL Lecturer, Department of Political Science University of Northern British Columbia Prince George, BC

Abstract

The insulation of Canada's healthcare system from trade treaty obligations is crucial to the legitimacy of Canada's trade policy. Legal analysis has suggested, however, that competitive and for-profit delivery of the kind contemplated by the Kirby Report and some provinces may make healthcare more vulnerable to challenges under NAFTA and GATS. The Government of Canada has tried to counter this interpretation by stressing the importance of public financing as the principal criterion for exemption of healthcare from trade treaties, but now the potential for private financing of essential medical services indicated by the Supreme Court's decision in *Chaoulli v. Quebec* has made that line of argument look risky as well. It is apparent that Canada failed to anticipate the possible interactions of domestic, international and constitutional

law when it made commitments in the area of private health insurance at the WTO in 1997. Accordingly, the time has come to acknowledge the fragility of the boundary between health and trade policies, to take the risks and costs associated with trade treaty obligations fully into account when undertaking healthcare reform and to strengthen the separation between private and public health insurance.

Résumé

L'isolation du système de soins de santé canadien par rapport aux accords commerciaux est essentielle à la légitimité des politiques commerciales du Canada. Les analyses juridiques ont suggéré, cependant, que la prestation concurrentielle et à but lucratif envisagée dans le rapport Kirby et par certaines provinces peut rendre les soins de santé plus vulnérables à des défis sous l'ALÉNA et l'AGCS. Le gouvernement canadien a essayé de contredire cette interprétation en insistant sur l'importance du financement public comme principal critère pour soustraire les soins de santé aux accords commerciaux; mais maintenant la possibilité de financer les services médicaux essentiels avec des fonds privés, tel qu'indiqué par la décision de la Cour suprême dans l'affaire Chaoulli c. Québec, fait paraître cet argument un peu risqué également. Il appert que le Canada a mal anticipé les interactions possibles entre le droit national, international et constitutionnel lorsqu'il a pris des engagements envers l'OMC en matière d'assurance-santé privée en 1997. Le temps est donc venu de reconnaître la fragilité de la frontière entre les politiques de santé et les politiques commerciales, de tenir pleinement compte des risques et des coûts associés aux engagements pris dans le cadre des accords commerciaux lorsqu'on entreprend une réforme des soins de santé, et de renforcer la séparation entre l'assurance-santé publique et privée.

NAFTA and GATS obligations might apply to Canada's health sector. Many observers have agreed that, generally speaking, it appears unlikely that most medically necessary services provided through public health insurance in Canada fall within the scope of either NAFTA or GATS, in large part because the "public" nature of Canada's healthcare financing is a more important factor in determining the scope of exemptions from trade treaty obligations than the primarily "private" nature of Canada's healthcare delivery (i.e., the use of private for-profit and not-for-profit actors and institutions to organize, manage and provide health services) (Epps and Flood 2002; Van Duzer 2004b; Crawford 2005).

The recent trend towards market-based reform proposals, most of which experiment with competitive models of delivery as a way to improve efficiency and sustainability of the system, has raised new questions about the risk that Canada will incur trade treaty obligations that could constrain future policy options. The Government of Canada and other defenders of Canada's participation in NAFTA and GATS have argued that this risk is acceptably small, relying once again on the crucial distinction between financing and delivery (Deber 2002): how healthcare is paid for (i.e., whether hospital and physician services under medicare are paid for through public or private insurance) is the point that matters most in developing legal tests for NAFTA and GATS obligations (DFAIT 2005).

The Supreme Court decision in *Chaoulli v. Attorney-General (Quebec)* – a case that struck down a Quebec law prohibiting private health insurance for publicly insured hospital and physician services – is about financing. As Quebec and other provinces consider their options in terms of introducing private health insurance to cover physician and hospital services, we must carefully re-examine the relationships between trade treaties, proposals for healthcare reform and the insurance market. This paper contributes to that discussion by investigating two questions in the light of the *Chaoulli* decision: first, whether the present degree of insulation of public healthcare from trade treaty obligations can be maintained in the face of growing pressures for liberalization, both inside and outside the healthcare system; and second, what policy options can best restore and secure the balance between trade and health policy in the future.

The Scope of Chaoulli and Its Significance for the Interface Between Trade Policy and Healthcare Reform

In Chaoulli, the Supreme Court of Canada decided in a narrow 4–3 judgment to invalidate Quebec's prohibition against the sale of private insurance for core medical services provided through medicare on the grounds that it violated the guarantee of rights "to life and to personal inviolability" in Quebec's Charter of Human Rights and Freedoms (s. 1). Although Deschamps J. noted in the majority judgment that section 1 of the Quebec Charter is broader in scope than the equivalent section of the Canadian Charter of Rights and Freedoms, three of the concurring justices (Chief Justice McLachlin, Justice Major and Justice Bastarache) also found Quebec's ban to be in contravention of the guarantee of "life, liberty and security of the person" contained in section 7 of the Canadian Charter of Rights and Freedoms. While the McLachlin/ Major judgment allows that the prohibition on obtaining private health insurance "might be constitutional in circumstances where healthcare services are reasonable as to both quality and timeliness," it leaves open the possibility for challenges to even less restrictive legislation aimed at promoting the single-payer principle (such as the

measures in Ontario, Nova Scotia and Manitoba that prevent physicians from charging more privately than they would receive in the public plan) if such laws are found to have prevented certain individuals from gaining timely access to medical treatment (Flood and Lewis 2005).

In contrast, the dissenting minority judgment of Justices Binne, LeBel and Fish found that the "debate [about whether government ought to discourage a second private tier of healthcare] cannot be resolved as a matter of constitutional law by judges." Noting that the Quebec health plan shared the health policy objectives of the Canada Health Act, i.e., that Quebec wanted a health system where access is governed by need rather than by wealth or status, the dissenting justices were unprepared to pre-empt an ongoing public debate over fundamental social policy in the absence of a clear violation of an established principle of fundamental justice. In their view, even the broader wording of the Quebec Charter could not justify striking down the law, in the light of that Charter's requirement that rights be exercised with "proper regard" to "democratic values, public order and the general well-being of the citizens of Québec."

While couched in the language of constitutional interpretation, the dissent expressed the more general standpoint of critics of judicial activism in matters of complex social policy: "Designing, financing and operating the public health system of a modern democratic society remains a challenging task and calls for difficult choices. ... Shifting the design of the health system to the courts is not a wise outcome" (Chaoulli 2005: para. 276). Some critics of the Chaoulli decision who believe in the appropriateness of political solutions to the problem of waiting lists in the healthcare system may advocate that Canadian governments be prepared to use the Canadian Charter's section 33 (the "notwithstanding" clause) in response to the Chaoulli ruling (Evans 2005). This would permit Parliament to override the effect of the ruling for five years before it would be reviewed again.

Although it is seldom remarked upon, the ban on private health insurance has also been a fundamental assumption of Canada's trade policy ever since NAFTA and GATS took effect over a decade ago. That is because, in order to assure Canadians that the expansion of trade liberalization to include services would not adversely affect our healthcare system, while at the same time assuring the Canadian life and health insurance industry that it could gain more secure access to foreign markets through trade agreements, public insurance and private insurance were sharply distinguished. Public insurance was delineated as financing medically necessary physician and hospital services through provincial health plans. Private insurance was strictly reserved for services that, whatever their status in other countries, are "supplemental" to the core of medicare in Canada and are not publicly funded. This complete separation between public and private insurance appears to have been taken for granted by Canadian governments, which negotiated specific commitments for financial services under GATS and made no attempt to exclude private health insurance from the terms of NAFTA.

Is Healthcare Really "Off the Table" in International Trade Negotiations?

The two major principles that have been developed as essential to the long-term achievement of trade liberalization are the most-favoured-nation principle (MFN), or external non-discrimination by a member country among its foreign trading partners, and the national treatment principle, or non-discrimination between foreign and domestic interests inside a member country. If MFN were applied to a service in the healthcare sector, the degree of access to the Canadian market afforded to that service imported from one "most-favoured" trading partner would have to be extended to all other trading partners who are parties to the same trade agreement. (Conversely, Canadian healthcare exporters of that service would be entitled to the same degree of access to the market of any other signatory country as that country's most-favoured partner.)

This obligation would not necessarily be onerous or highly disruptive of our healthcare system because it does not require that we open our markets to foreign suppliers, only that we not discriminate among those suppliers when we do. However, if governments experiment with private insurance, subsequently change their mind and wish to return to the present status quo, this policy switch may be thwarted by the prospect of having to compensate foreign suppliers who lose business access as a result.

The effects of the national treatment could be potentially even more intrusive and less consistent with the principles governing our existing healthcare system. The principle requires that foreign suppliers of a particular health service be given the same commercial opportunities as domestic suppliers. For example, applying national treatment to hospital services could force Canadian hospitals to compete with foreign corporate for-profit hospital chains, a possibility that could have far-reaching consequences for the nature of the service.

If by "medicare" we mean the two major publicly funded programs of hospital services and physician services (Evans 2003), then we may state that it has not yet been subjected to either MFN or national treatment obligations. Nevertheless, when the complex and changing nature of healthcare services funding and delivery is combined with the broad and largely untested scope of GATS and NAFTA rules, there is also bound to be a large penumbra of uncertainty surrounding the application of those rules. Estimating healthcare's insulation from trade treaties is therefore a probabilistic, not a categorical, exercise (Crawford 2005).

The task is further complicated by the very different architectures of NAFTA and the WTO/GATS. Under NAFTA, which is principally a "top-down" agreement that imposes its obligations except where expressly exempted, reservation clauses are the most important instrument for shielding public healthcare. The most serious concern raised by NAFTA for healthcare policy is whether changes in the domestic policy

environment – such as the expansion of private health insurance, changes in the scope of the public system or even the expansion of for-profit delivery – might cause important, medically necessary services to be no longer shielded from national treatment, MFN or other NAFTA obligations. This exposure could in turn lead to NAFTA claims for financial compensation by US or Mexican private investors if governments tried to establish or re-establish a public monopoly. Under GATS, which is primarily a "bottom-up" agreement, national treatment and associated market access obligations apply only when countries choose to list them in their schedules of specific commitments. (A special exemption clause for services "supplied in the exercise of governmental authority" also exists to protect certain public services from being covered by the more generally applicable GATS MFN and transparency obligations.) Failure to meet these obligations could lead to a claim by governments of affected service suppliers and an award by a WTO dispute panel of compensation in the form of trade concessions to those countries.

It might seem a simple matter to avoid making any such commitments that could affect medicare, but in practice it is proving to be more difficult. In particular, the supply of private health insurance was classified for GATS purposes as a "financial service," an area in which Canada has a comparative advantage and has been aggressive in seeking reciprocal commitments. Insurance exports rose from \$1.957 billion annually to \$3.067 billion between 1990 and 2001, and imports from \$2.238 billion to \$4.462 billion. Like other knowledge-intensive commercial services, this industry is an important source of Canadian competitiveness and high-paying jobs. It is thus not surprising that Canada has continued to make offers in this sector in the WTO's Doha round of negotiations since 2001, including an offer in 2003 of commitments to open foreign bank entry, to ease foreign ownership restrictions and to improve transparency of financial regulations. It now appears in the wake of Chaoulli, however, that the Canadian government failed to anticipate the possible repercussions of making commitments with respect to market access and national treatment in the area of private health insurance when it concluded the Financial Services Agreement along with 103 other WTO members in 1997.

NAFTA Reservations and Healthcare

NAFTA is a large document, running over a thousand pages, which, in addition to liberalizing trade in goods between Canada, the United States and Mexico (virtually all trade in the NAFTA region has flowed tariff-free since 2003), has helped break new ground in such areas as government procurement, investment, services trade, intellectual property and dispute settlement. Investment was a key item on the US agenda in its negotiations with both Canada (in the earlier Canada—US Free Trade Agreement) and Mexico. Chapter 11 (investment) extends national treatment and

MFN rules to the establishment of new businesses, raises the threshold for the review of foreign direct investment by the Canadian government and states that the expropriation of businesses can occur only for a "public purpose," on a non-discriminatory basis and for financial compensation at "fair market value." Chapter 12 (services) contains similar provisions imposing national treatment and MFN obligations on each country's policies towards service providers, although it does contain (in Article 1201) a provision that nothing in the agreement shall be construed to prevent a party from providing such services as social welfare, public education, health and child care. Both of these chapters are also explicitly subject to reservations and exceptions set out in each country's schedule to Annex I.

The view that the scope of NAFTA reservations in relation to health services is sufficient to protect publicly funded healthcare in Canada from any NAFTA challenge is a reasonable interpretation from a static perspective, based upon the accepted definitions of public and private health services at the time of NAFTA's inception (Epps and Flood 2002; Van Duzer 2004a). Canada's Annex I Reservation states that all provincial government measures that were in force as of January 1, 1994 are outside NAFTA rules relating to national treatment, MFN and some other disciplines relating to local-presence requirements for cross-border services and nationality requirements for senior managers. Laws, measures or amendments thereto subsequent to January 1, 1994 that exclude or otherwise discriminate against US and Mexican providers of services are contrary to NAFTA, unless they are saved by the Annex II Social Service Reservation.

Under Annex II of NAFTA, each party reserved the right to adopt or maintain any measure relating to health services that may be characterized a "social service established or maintained for a public purpose." The precise scope of this Social Service Reservation is the subject of much debate and speculation. The US Trade Representative in 1995 suggested that the reservation is intended to cover only services that "are similar to those provided by government, such as childcare or drug treatment programs"; if those services are supplied by a private firm on a profit or nonprofit basis, chapters 11 (investment) and 12 (services) would apply. The Canadian government has claimed that, to the contrary, NAFTA panels should look at the government's intent in determining whether a service is "established or maintained for a public purpose." Legal academics generally agree that an objective test based on general criteria for what constitutes a public service is necessary. Where full state funding is combined with extensive government control over delivery, then there is a very strong case for the application of the reservation. It is probable (though by no means certain) that full state funding alone is sufficient, even where governments permit competition and for-profit delivery in the interests of efficiency (Epps and Flood 2002).

Accordingly, the fact that insured services are designated by a provincial government as "medically necessary" and are paid for by a public authority is a good indica-

tion that such services fall within Annex II and thus outside NAFTA.

If governments choose to respond to the *Chaoulli* decision by allowing the growth of private insurance to cover services that are presently publicly insured (medically necessary hospital and physician services), then the condition of government-funded monopoly will disappear. It is already apparent that the Social Service Reservation does not protect measures related to for-profit, privately funded services of physicians and other healthcare professionals, or privately funded home care or nursing home services (Van Duzer 2004a). It is very likely that allowing private insurance for services designated as "medically necessary" would further reduce the scope of this NAFTA reservation (Epps and Schneiderman 2005).

GATS "Governmental Authority" Exclusion

Canada's GATS obligations present a similar picture of current insulation of healthcare coupled with increasing future vulnerability to coverage (Van Duzer 2004b; Crawford 2005). GATS contains an exemption from the most basic MFN and transparency obligations for services "supplied in the exercise of governmental authority," which are defined in Article I:3 as any service that is "supplied neither on a commercial basis, nor in competition with one or more service suppliers." The legal meaning of "competition" probably involves consumers' ability to choose between "like" services offered by different suppliers, but it is unclear, even if services are fully publicly funded and competition is tightly regulated, whether the system would still meet the GATS criterion. There seems to be little doubt, however, that the introduction of private competition on the financing side would guarantee that the service being supplied would fall outside the Article I:3 exclusion. Similarly, any finding of supply to be on a commercial basis" would need to consider a range of criteria: whether a service is supplied on a for-profit basis; whether user fees are charged; whether any revenues earned in excess of cost are devoted to fulfillment of a not-for-profit purpose; and the degree of government involvement and control over conditions of service delivery. Most of these criteria, when applied to core medical services as they are currently supplied in Canada, would not indicate their classification as being supplied "on a commercial basis" (Krajewski 2003; Van Duzer 2004b; Crawford 2005).

In its response to J. Anthony Van Duzer's (2004b) report, *Health, Education and Social Services in Canada: The Impact of the GATS*, the government agreed with most of these conclusions, except that it questioned whether "degree of government involvement is a determinant of whether or not a service is provided on a commercial basis" and argued that a wider range of services, such as physician services operating outside of hospitals, would fall within the scope of "governmental authority" (DFAIT 2005). It is not surprising that the Government of Canada would put forward a slightly broader interpretation of the GATS exclusion clause than that of GATS critics or

most of the leading legal academic opinions. The crucial point is that the federal government's emphasis on public funding as the criterion for what is excluded from GATS coverage helps to downplay the risk that expansion of publicly funded and privately delivered healthcare or Kirby-style reforms (i.e., experiments with competitive, private for-profit or not-for-profit delivery) (Standing Committee on Social Affairs, Science and Technology 2002) will incur those obligations. But the government's reliance and emphasis on protections being sourced in the extent of public funding clearly exposes the dangers that arise from allowing inroads from private insurance and other forms of financing.

Specific GATS Commitments: The Scope of National Treatment and Market Access Obligations

The most onerous WTO/GATS obligations are those that are incurred through commitments to accept national treatment and market access obligations in specific sectors. A look at Canada's Schedule of Specific Commitments shows that Canada has avoided undertaking obligations in respect of "health and public education," consistent with its pronouncements. There is one notable and worrisome exception: private insurance, such as Blue Cross, is categorized as a "financial service" for WTO/GATS purposes, just as it is for NAFTA purposes. Canada in 1997 made a commitment in "life, accident and health insurance services," subject only to the limitation on market access that these services "must be supplied through a commercial presence" (i.e., through direct investment and establishment within Canada).

Some critics and health policy advocates have worried that public health insurance is possibly already covered under Canada's GATS commitments on financial services (Sanger 2001). In response, the Government of Canada has maintained that Canada's commitments with respect to "health insurance services" are clearly restricted to supplemental health insurance services provided by private insurers, since GATS excludes governmental services that are not "in competition with one or more service suppliers." Technically, the government has probably been right, at least to date – the distinction between public and private health insurance is likely to be recognized by WTO dispute panels because medicare is not insurance in the same sense as private life insurance or other financial services. The main threat of a trade challenge stems from compensation claims created by the expansion of medicare into territory previously occupied by private insurers, not from a failure to enter specific limitations that would shield existing provincial public health insurance plans from GATS commitments or a misplaced faith in a narrow Article I:3 exclusion clause (Van Duzer 2004b: n. 5, 417–425).

But now there is Chaoulli, and all the old conclusions and safe harbours must be

revisited. The assumption that medically necessary services are "public" and that supplemental insurance is "private" - that the two areas of insurance are mutually exclusive - clearly underpinned the government's decision to make commitments in private health insurance in the first place. If Canada's public health insurance plans are forced by judicial decisions into competition with private suppliers, then that fundamental assumption no longer obtains and the worries of GATS critics over medicare's vulnerability to GATS obligations will be warranted. In response to the question, "Will GATS commitments for private insurance prevent Canada from expanding medicare?" the Government of Canada has stated on its website that "foreign firms represent a minority of the private health insurance market," that "private insurers could lose some customers without affecting their overall profitability, making compensation unnecessary" and that "it would be premature to speculate on any potential implications that may arise from any proposed policy changes affecting private health insurance" (DFAIT 2005). Again, these comforting conclusions were all reached prior to the Chaoulli decision. The principal issue now is not how much the development of a private insurance market could prevent expansion of medicare, but whether medicare's current monopoly on single-payer insurance can continue to be protected. It is no longer premature, but indeed necessary, to consider how much foreign penetration of the Canadian market, when combined with lifting the ban on private insurance, could result in a combination of potential NAFTA financial compensation to private investors and GATS compensation in the form of trade concessions to WTO member governments that would make reversing market-based changes difficult.

Conclusion

If, as a result of the Chaoulli decision, the stage is set for the introduction of parallel private coverage for services currently covered by the public system, there will be an interesting debate in Canada about whether Parliament and provincial legislatures should use the "notwithstanding" clause. But as long as Chaoulli does not lead to the creation of a full-blown, two-tier health system in Quebec and across Canada, it should serve as a salutary "shot across the bow" that not only galvanizes governments to shorten waiting lists, but also to "trade-proof" their health policies.

First, in order to increase the chances that NAFTA reservations and the GATS exemption clause will apply to any given policy, a checklist of objective criteria likely to be used by NAFTA and WTO dispute panels should be kept in mind and assigned values in the cost-benefit analyses of policy options. These include: the extent of government regulation and control over delivery of the service; the degree to which the service is provided by not-for-profit organizations; the presence of competitive and commercial markets; and, perhaps most importantly, the degree of public versus private financing.

Second, healthcare reforms can be structured to minimize the opportunities for US and Mexican investors to claim compensation under the expropriation provisions of chapters 11 and 12 of NAFTA. In order to accomplish this, however, the agnostic attitude of the Kirby Committee towards public versus private delivery of healthcare may need to be modified, and the benefits of expanded private financing promoted by the Mazankowski Commission will need to be reassessed. It is ironic that the two most influential advocates of greater competition and market-based reform of Canadian healthcare have not invested a commensurate amount of effort into investigating the trade treaty implications of their proposals (Grieshaber-Otto and Sinclair 2004).

On the policy front, it is noteworthy that in Canada's initial requests for GATS market access commitments in 2002, its initial conditional GATS offer in 2003 and its more recent revised offer, Canada has consistently maintained that it has preserved full policy flexibility with respect to health, public education and social services, while at the same time continuing to push for a more liberalized global market for financial services. A similar position is being taken with respect to the negotiations towards the Free Trade Area of the Americas (FTAA).

Canada has also been vigorously promoting its healthcare exports (which are currently worth about \$5 billion annually), especially in the areas of bio-health, medical devices, pharmaceuticals and telehealth, while avoiding them as subjects for trade negotiations, out of sensitivity to domestic concerns. None of these positions are necessarily inconsistent or wrong; indeed, they may well be wise. They should be accompanied by three caveats, however:

- Binding commitments to open markets to greater penetration by foreign service providers should always take into account the potential compensation costs that may be incurred should policy priorities or policy environments unexpectedly change.
- The classification of services for one purpose may have unintended and unforeseen consequences for other purposes.
- The separation between public and private financing of healthcare should never be assumed to be either clear or immutable.

In this regard, one measure could help to repair the firewall between private and public insurance that was damaged by *Chaoulli*, and thereby serve to restore and secure our domestic health policy space. Article XXI of GATS sets out the procedures for the withdrawal or modification of members' specific commitments. The member concerned must give at least three months' notice, and then negotiate compensatory adjustments with other countries whose trade interests have been affected, with the compensation applied on an MFN basis. (If an affected member is not satis-

fied with the compensation offered, it can refer the matter to arbitration.) The ability of WTO members to withdraw their commitments has long been touted by the WTO Secretariat and member governments as a flexible feature of GATS. Canada should now put this claim to the test by withdrawing, or at least modifying, its 1997 commitment covering private health insurance. Whatever the cost or difficulty of such a procedure, we can be reasonably certain that it will never be purchased at a lower price.

Correspondence may be directed to: Mark Crawford, Department of Political Science, University of Northern British Columbia; email: mchammer@technologist.com.

REFERENCES

Chaoulli v. Québec (Attorney General), 2005 SCC 35.

Crawford, M. 2005. "Truth or Consequences? The Law and Politics of the GATS Health Care Debate." Canadian Foreign Policy 12(2): 97-133.

Deber, R. 2002. Delivering Health Care Services: Public, Not-for-Profit, or Private? Discussion Paper No. 17. Ottawa: Commission on the Future of Health Care in Canada.

Department of Foreign Affairs and International Trade (DFAIT). 2005. Frequently Asked Questions about the Report. Retrieved December 1, 2005. http://www.dfait-maeci.gc.ca/tna-nac/ TS/faq-report-en.asp>.

Epps, T. and C. Flood. 2002. "Have We Traded Away the Opportunity for Innovative Health Care Reform? The Implications of the NAFTA for Medicare." McGill Law Journal 47: 747.

Epps, T. and D. Schneiderman. 2005. "Opening Medicare to Our Neighbours or Closing the Door on a Public System? International Trade Law Implications of Chaoulli v. Quebec." In C.M. Flood, K. Roach and L. Sossin, eds., Access to Care, Access to Justice: The Legal Debate Over Private Health Insurance. Toronto: University of Toronto Press.

Evans, R. 2003. Political Wolves and Economic Sheep: The Sustainability of Public Health Insurance in Canada. Vancouver: Centre for Health Services and Policy Research. Retrieved December 1, 2005. http://www.chspr.ubc.ca/chspr/pdf/chspr03-16W.pdf.

Evans, R. 2005. "Preserving Privilege, Promoting Profit." In C.M. Flood, K. Roach and L. Sossin, eds., Access to Care, Access to Justice: The Legal Debate Over Private Health Insurance. Toronto: University of Toronto Press.

Flood, C. and S. Lewis. 2005. "Courting Trouble: The Supreme Court's Embrace of Private Health Insurance." *Healthcare Policy* 1(1): 26–35.

Grieshaber-Otto, J. and S. Sinclair. 2004. Bad Medicine: Trade Treaties, Privatization and Health Care Reform in Canada. Ottawa: Canadian Centre for Policy Alternatives.

Krajewski, M. 2003. "Legal Services and Trade Liberalization: Mapping the Legal Framework." *Journal of International Economic Law* 6(2): 341–367.

Sanger, M. 2001. Reckless Abandon: Canada, the GATS and the Future of Health Care. Ottawa: Canadian Centre for Policy Alternatives.

Standing Committee on Social Affairs, Science and Technology ("Kirby Committee"). 2002. *The Health of Canadians – The Federal Role. Final Report.* Retrieved December 1, 2005. http://www.parl.gc.ca/37/2/parlbus/commbus/senate/com-e/soci-e/rep-e/repoct02vol6-e.htm.

Van Duzer, J.A. 2004a. "The Canadian Preoccupation with NAFTA's Impact on Health Services: A Serious Issue, a Non-Issue or Something in Between?" In K.C. Kennedy, ed., *The First Decade of NAFTA: The Future of Free Trade in North America*. New York: Transnational Publishers.

Van Duzer, J.A. 2004b. Health, Education and Social Services in Canada: The Impact of the GATS. Trade Policy Research 2004. Retrieved December 1, 2005. http://www.dfait-maeci.gc.ca/eet/research/TPR-2004/TPR-2004-10-en.asp#*d.

Research. Evidence. Dissemination.



www.healthcarepolicy.net

Experiencing Difficulties Accessing First-Contact Health Services in Canada

Difficultés d'accès aux soins de santé de première ligne au Canada

Canadians without regular doctors and recent immigrants have difficulties accessing first-contact healthcare services. Reports of difficulties in accessing care vary by age, sex and region.



by CLAUDIA SANMARTIN, PHD
Senior Analyst, Health Analysis and Measurement Group
Statistics Canada, Ottawa, ON
Adjunct Research Assistant Professor, Dept. of Community Health Sciences,
University of Calgary

NANCY ROSS, PHD

Assistant Professor, Department of Geography, McGill University, Montreal, QC Associate, Health Analysis and Measurement Group, Statistics Canada

Abstract

In this study, we identify the significant factors associated with having difficulties accessing first-contact healthcare services. Population-based data from two national health surveys, the Health Services Access Survey and the Canadian Community

Health Survey, were used to identify respondents who required first-contact services for themselves or for a family member during 2003. Fifteen percent of Canadians reported difficulty accessing routine care, and 23% reported difficulties with immediate care. Physician/service availability was the chief reason cited for difficulties accessing routine care, while for urgent care, it was long wait times. Women, younger respondents and residents of eastern Canada and Quebec were consistently more likely to report difficulties accessing both types of these first-contact services, whereas less educated Canadians were less likely to report problems. Canadians without a regular family doctor were more than twice as likely to report difficulties accessing routine care compared to those who had a regular doctor. New immigrants were almost two and a half times more likely to report difficulties accessing immediate care than were Canadian-born respondents. Household income was not associated with difficulties accessing either type of care. The relatively low level of reporting of difficulties by older and less educated Canadians may be related, in part, to more modest expectations about the healthcare system.

Résumé

Dans cette étude, nous répertorions les principaux facteurs liés aux obstacles à l'accès à des soins de santé de première ligne. Nous avons utilisé des données sur la population provenant de deux enquêtes nationales sur la santé – l'Enquête sur l'accès aux services de santé et l'Enquête sur la santé dans les collectivités canadiennes – pour repérer les répondants qui avaient besoin d'avoir accès à des services de santé de première ligne pour eux-mêmes ou pour un membre de leur famille en 2003. Quinze pour cent des Canadiens ont dit avoir éprouvé des difficultés à avoir accès à des soins de base, et 23 % ont dit avoir eu de la peine à trouver des soins immédiats. Les femmes, les répondants plus jeunes et les résidents de l'Est du Canada et du Québec étaient les plus susceptibles de signaler des difficultés d'accès aux deux types de soins de santé de première ligne, tandis que les Canadiens peu instruits étaient moins susceptibles d'en faire mention. Les Canadiens qui n'vaient pas de médecin de famille étaient plus que deux fois plus susceptibles de signaler des difficultés que ceux qui en avaient un. Les nouveaux immigrants étaient presque deux fois plus susceptibles de signaler des difficultés d'accès à des soins immédiats que les répondants nés au Canada. Il existe un profil sociodémographique indéniable associé au signalement des difficultés d'accès aux soins de première ligne au Canada. Le niveau relativement faible de signalement des difficultés d'accès par les Canadiens plus âgés et moins instruits peut être lié, en partie, à des attentes plus modestes à l'égard du système de soins de santé.

the health policy debate in Canada. In a recent national consultation, timely access to healthcare services was identified as a key area for health research (Dault et al. 2004). Access to healthcare services can be conceptualized as having two key components: potential access, defined as the process of accessing care, and realized access, defined as the actual use of healthcare services (Aday and Andersen 1974, 1981). Increasingly, health services data and national health surveys have been used to monitor realized access indicators, such as rates of physician visits, surgery and use of diagnostic tests (Statistics Canada and CIHI 2005; CIHI 2004). Researchers are also using health services data in conjunction with health status and socio-demographic information to clarify who is accessing services and what clinical and non-clinical factors may affect service use (Roos and Mustard 1997; Dunlop et al. 2000; Finkelstein 2001; Glazier et al. 2000; Black et al. 1995; Roos et al. 2003).

Although health services use can tell us about realized access, it cannot inform us about potential access – the experiences of patients in the process of accessing care, including whether or not they face difficulties obtaining the care they need when they need it. Recent concerns about lengthy waits and timely access to care in Canada have shifted the focus towards the need for more information regarding patients' experiences in accessing healthcare services (Sanmartin et al. 2002). Measures of access difficulties have been included as part of a suite of indicators agreed upon by ministries of health across the country to report on the performance of the healthcare system (Performance Reporting Technical Working Group 2004). These performance indicators revealed that up to one in four Canadians requiring healthcare services, such as routine primary care and immediate care for a minor health problem, encountered difficulties. Barriers such as contacting a healthcare provider and long waits were identified as key problems (Sanmartin, Gendron et al. 2004).

There are strong arguments for concern about patients' experiences in the process of accessing care. Those who experience difficulty may delay seeking and obtaining treatment, underuse preventive healthcare services and be at greater risk for the complications of delayed diagnoses. These potential consequences, in turn, may put increased financial pressure on the healthcare system if individuals arrive in the system sicker and stay in it longer. Therefore, it is important to extend the work on access to care beyond the use of services towards a more comprehensive understanding of the process of accessing care.

In this study, we used data from two national health surveys to explore the determinants of potential access to first-contact healthcare services. We examined a range of demographic, socio-economic and health status variables, all hypothesized to be associated with access to care (Andersen 1995) to better understand the characteristics of Canadians reporting difficulties accessing first-contact healthcare services.

Methods

Data

The study is based on cross-sectional analysis of data from the 2003 Health Services Access Survey (HSAS). The HSAS was designed specifically to collect additional information regarding patients' experiences accessing healthcare services and was conducted by Statistics Canada as a supplement to the Canadian Community Health Survey (CCHS). The CCHS is a large, cross-sectional survey containing information on the health status and healthcare use of Canadians, with a sample size of 135,575 (Beland 2002). The survey represents approximately 98% of the population aged 15 and older living in private dwellings in the 10 provinces. 36,731 CCHS respondents were selected by stratified random sampling to participate in the HSAS. The response rate was 87%, resulting in a final sample size of 32,005. Data were collected by personal and telephone interviews between January and December 2003.

The study sample includes all those who required the following types of first-contact services for themselves or for a family member in the 12 months before the survey: routine care provided by a family or general practitioner, such as annual examinations or ongoing care for an illness (n = 18,339), or immediate care for a minor, non-life-threatening health problem, such as a fever or minor cuts and burns (n = 10,113). Immediate care for these minor health problems could have been sought from a variety of providers, including family physicians, walk-in clinics and urgent-care facilities such as hospital emergency rooms. Respondents could be represented in both samples if they required both types of services. Respondents were asked whether they experienced difficulties getting the care they needed for themselves or for a family member (yes/no). All respondents to the HSAS were also asked whether they had a regular family physician (yes/no).

The HSAS data were linked to the CCHS data to obtain respondents' demographic, socio-economic and health status information. Information derived from the CCHS included gender, age, province of residence, rural or urban residence, immigration status, number of children 12 years of age or under in the household, lone-parent status, education, income level and employment status. Lone-parent status was determined using information identifying family relationships within households. Lone parents were defined as either female or male parents living with children under 25 years of age. Education information represented the highest level of education attained by the respondent: less than secondary school graduation; secondary school graduation, no post-secondary education; some post-secondary education; and post-secondary degree or diploma.

Respondents were classified into one of the following four groups based on total household income adjusted for household size: lowest income (<\$15,000 if 1 or 2 people in household; <\$20,000 if 3 or 4 people; <\$30,000 if 5+ people); lower-middle income (\$15,000 to \$29,999 if 1 or 2; \$20,000 to \$39,999 if 3 or 4; \$30,000

to \$59,999 if 5+); upper-middle income (\$30,000 to \$59,999 if 1 or 2; \$40,000 to \$79,999 if 3 or 4; \$60,000 to \$79,999 if 5+); or highest income (>\$60,000 if 1 or 2; >\$80,000 if 3+). Individuals between the ages of 15 and 75 who had worked in the previous year were classified as working either full time (\geq 30 hours per week) or part time (<30 hours per week). Those over 75 years of age and those who had not worked in the previous year were classified as not working.

CCHS respondents were asked to describe their overall general health status as either excellent, very good, good, fair or poor. Responses were collapsed into three categories: fair/poor, good and very good/excellent health. As a more precise mobility measure, we included the concept of activity limitation. Individuals were asked whether or not they required assistance with a range of activities, such as preparing meals or shopping for groceries or other necessities, owing to health reasons.

Analysis

We used univariate analyses and logistic regression (weighted) to examine the relation between the two principal outcome measures (difficulties accessing routine healthcare and difficulties accessing immediate care) and various demographic, socio-economic and health status factors. We used the bootstrap technique to determine the significance of the odds ratios (ORs) and to estimate 95% confidence intervals. This technique fully accounts for the design effects of the survey (Davison and Hinkley 1997).

Results

According to the HSAS results, 15% of Canadians needing first-contact health services reported difficulty accessing routine care, and 23% reported difficulties obtaining immediate care (Table 1). When compared with the general CCHS sample, the linked HSAS subsample had a higher proportion of female respondents and tended to be more highly educated. Individuals requiring routine care tended to be less represented in the youngest age group (<35 years) and reported poorer health status than did the general CCHS population. Individuals requiring immediate care for themselves or for a family member were more likely to have children under age 12 in the household and to have full-time employment compared with the general CCHS population.

The unadjusted rates for difficulties accessing routine care ranged from a low of 8% for respondents aged 65 years and over to a high of 28% for those without a regular family doctor. For difficulties obtaining immediate care, the rates ranged from 14% among those aged 65 and older to 43% among new immigrants (immigrated <5 years) (Table 2).

TABLE 1. Characteristics of persons who required first-contact health services (HSAS subsample) and of the general population, Canadian Community Health Survey (CCHS)

	PERCENTAGE OF THE POPULATION					
	ROUTINE CARE SUBSAMPLE (N=18,339)	IMMEDIATE CARE SUBSAMPLE (N=10,113)	GENERAL POPULATION (N=135,575)			
Difficulties accessing care						
Yes	14.8	22.7	n/a			
No	85.2	77.3				
Gender						
Female	55.9	54.1	49.3			
Male	44.1	45.9	50.7			
Age group						
<35	24.0	36.7	36.3			
35–64	58.3	55.6	49.5			
65+	17.6	7.7	14.2			
Residence						
Rural	18.5	17.9	18.8			
Urban	81.5	82.1	81.2			
Region						
East	8.3	8.3	7.6			
Quebec	26.7	22.9	24.0			
Ontario	38.7	40.3	38.7			
West	26.3	28.5	29.7			
Immigration status						
Immigrant (<5 yrs ago)	2.2	3.0	3.6			
Immigrant (≥5 yrs ago)	18.3	16.3	18.1			
Not an immigrant	79.5	80.7	79.3			
Number of children ≤ 12 yrs of age						
> I child	12.0	19.3	11.8			
l child	12.8	18.1	13.5			
None	75.2	62.7	74.7			
Lone-parent status						
Yes	4.6	5.4	5.5			
No	95.5	94.6	94.5			
Education						
Less than high school	20.3	16.8	26.7			
High school/Some post-secondary	25.9	26.3	25.9			
Post-secondary degree/diploma	53.7	56.9	47.4			
Income						
Lowest quartile	6.7	6.5	7.6			
Lower-middle quartile	17.8	16.2	16.5			

continued

Experiencing Difficulties Accessing First-Contact Health Services in Canada

Upper-middle quartile	30.5	27.9	28.6
Highest quartile	32.1	36.3	30.6
Missing	12.9	13.1	16.8
Job status			
Full time	55.9	65.0	55.7
Part time	13.5	15.6	12.8
Not working	30.6	19.4	31.5
Health status			
Fair/poor	14.1	10.1	11.3
Good	32.3	30.4	30.2
Excellent/very good	53.6	59.5	58.4
Some restriction			
Yes	17.7	12.7	13.6
No	82.3	87.3	86.4
Regular family doctor			
Yes	7.9	11.2	n/a
No	92.1	88.8	

HSAS = Health Services Access Survey

n/a = data not available

TABLE 2. Unadjusted rates (%) of reporting difficulties accessing routine and immediate healthcare

	PERCENTAGE OF THE POPULATION					
	ROUTINE CARE (N=18,339)	IMMEDIATE CARE (N=10,113)				
Gender						
Female	17.0	26.2				
Male	14.3	21.9				
Age group						
<35	18.0	26.4				
35–64	17.4	24.2				
65+	7.6	13.5				
Residence						
Rural	16.7	23.7				
Urban	15.6	26.5				
Region						
East	16.3	24.9				
Quebec	18.7	26.1				
Ontario	15.4	25.0				
West	13.3	21.4				

continued

Immigration status		
Immigrant (<5 yrs ago)	15.8	42.9
Immigrant (≥5 yrs ago)	11.5	23.2
Not an immigrant	16.8	23.6
Number of children ≤ I 2 yrs of age		
> I child	15.1	22.8
I child	17.9	26.8
None	18.2	26.5
Lone-parent status		
Yes	19.2	27.3
No	15.7	24.0
Education		
Less than high school	11.3	18.1
High school/Some post-secondary	14.2	24.5
Post-secondary degree/diploma	18.1	25.7
Income		
Lowest	14.4	29.0
Lower-middle	13.8	23.4
Upper-middle	17.4	22.5
Highest	16.8	25.3
Missing	13.2	23.5
Job status		
Full time	18.3	25.4
Part time	18.1	22.6
Not working	10.4	21.9
Health status		
Fair/poor	16.5	22.2
Good	16.7	25.2
Excellent/very good	15.1	24.0
Some restriction		
Yes	17.8	24.8
No	15.4	24.1
Regular family doctor		
Yes	14.7	23.9
No	28.4	26.5

Over half (54%) of the respondents who experienced problems accessing routine care cited physician and/or service availability as the primary barrier, and 43% cited long waits (Table 3). Conversely, waiting time was the main barrier reported by 61% of those who experienced difficulties accessing immediate care, and 41% cited physician/service availability. Personal reasons, including difficulties with transportation, language or cost, were identified by fewer than 5% of the respondents who had difficulties getting routine or immediate healthcare.

TABLE 3. Reasons for difficulties accessing routine and immediate healthcare

	PERCENTAGE OF THOSE ROUTINE CARE (N=2,850)	E REPORTING DIFFICULTIES IMMEDIATE CARE (N=2,693)
Physician/service availability ¹	54.0	40.7
Waiting too long ²	43.3	60.8
Personal reasons ³	3.2	4.8
Other	12.9	14.3

Notes:

- I. Includes difficulty contacting a physician or getting an appointment, or services not available in the area or at the time required
- 2. Includes waiting too long to get an appointment or to see a physician
- 3. Includes difficulties due to transportation, language, cost or lack of information

Determinants of difficulties accessing healthcare

ROUTINE CARE

The logistic regression analysis showed that, among respondents who had trouble accessing routine care, women had significantly higher odds of reporting difficulties than did men (OR 1.33; p < 0.05), as did those younger than 65 when compared with those aged 65 and over (OR 1.95 for those <35, p < 0.05; OR 1.90 for those 35 – 64, p < 0.05) (Table 4). Residents of eastern Canadian provinces (OR 1.23, p < 0.05) and Quebec (OR 1.38, p < 0.05) were also more likely to report difficulties accessing routine care than were residents of western provinces. Immigrants who have been in Canada for more than five years were less likely to report difficulties accessing care (OR 0.71, p < 0.05) compared with Canadian-born residents. Individuals with less than high school education (OR 0.68, p < 0.05) and those with high school and/or some post-secondary education (OR 0.76, p < 0.05) were less likely to report difficulties accessing routine care compared to those with post-secondary level education.

As expected, working status was associated with higher odds of reporting difficulties accessing routine care, with persons working full time (OR 1.57, p < 0.05) or part time (OR 1.53, p < 0.05) being more likely to report difficulties than those who were not working.

We also found poor health status to be significantly associated with having problems accessing routine care. Individuals reporting fair or poor health (OR 1.42, p < 0.05) or good health (OR 1.26, p < 0.05), or some restriction of activities (OR 1.52, p < 0.05) were more likely to report difficulties than were those reporting excellent or very good health, or no activity limitation, respectively. Those without a regular family

doctor were more than twice as likely (OR 2.17, p < 0.05) to report difficulties accessing routine care than those with a regular doctor.

We observed no differences in reporting difficulties accessing routine care between rural and urban residents, by number of children under 12 years of age, by lone-parent status or across income groups.

		JTINE C N=17,670		IMMEDIATE CARE (N=9,786)		
	ODDS RATIO	95%	CI	ODDS RATIO	95%	CI
Gender						
Female	1.33*	1.13	1.57	1.26*	1.04	1.55
Male				1		
Age group						
<35	1.95*	1.41	2.72	2.10*	1.40	3.19
35–64	1.90*	1.43	2.56	1.74*	1.18	2.59
65+	1			1		
Residence						
Rural	1.04	0.87	1.24	1.30*	1.03	1.60
Urban	1			1		
Region						
East	1.23*	1.02	1.47	1.24*	1.01	1.51
Quebec	1.38*	1.12	1.68	1.30*	1.02	1.64
Ontario	1.20	0.98	1.45	1.21	0.97	1.49
West	1			1		
mmigration status						
Immigrant (<5 yrs ago)	0.81	0.41	1.65	2.40*	1.26	4.45
Immigrant (≥5 yrs ago)	0.71*	0.55	0.93	1.06	0.79	1.38
Not an immigrant	1			1		
Number of children ≤I2 yrs						
> I child	0.90	0.69	1.11	0.92	0.74	1.16
l child	1.00	0.71	1.30	1.05	0.80	1.38
None	1			I		
one-parent status						
Yes	0.99	0.66	1.50	1.18	0.82	1.68
No	1			1		
Education						
Less than high school	0.68*	0.55	0.86	0.69*	0.52	0.90
High school/Some post-secondary	0.76*	0.63	0.92	1.00	0.80	1.21
Post-secondary degree/diploma	1			1		

continued

ncome						
Lowest	1.02	0.73	1.41	1.11	0.74	1.64
Lower-middle	0.92	0.70	1.19	0.85	0.65	1.13
Upper-middle	1.12	0.93	1.35	0.81	0.66	1.00
Highest	1					
ob status						
Full time	1.57*	1.24	2.01	1.02	0.80	1.37
Part time	1.53*	1.14	2.07	0.91	0.67	1.27
Not working	1					
Health status						
Fair/poor	1.42*	1.09	1.81	0.99	0.70	1.39
Good	1.26*	1.05	1.49	1.12	0.89	1.39
Excellent/very good	I			1		
Some restriction						
Yes	1.52*	1.20	1.90	1.26	0.93	1.71
No	I			1		
Regular family doctor						
No	2.17*	1.69	2.73	1.07	0.79	1.44
Yes	1			1		
* p < 0.05						

IMMEDIATE CARE

Among respondents who had problems accessing immediate care, the influences of age, gender and region were similar to the findings for routine care. Women (OR 1.26, p < 0.05) and persons under age 65 (OR 2.10 for those <35, p < 0.05; OR 1.74 for those 35–64, p < 0.05) had significantly higher odds of reporting difficulties in accessing immediate care for a minor health problem. Similarly, residents of eastern Canadian provinces (OR 1.24, p < 0.05) and Quebec (OR 1.30, p < 0.05) were also more likely to report difficulties than were those living in western provinces.

However, unlike the findings for routine care, we found that rural residents were significantly more likely than their urban counterparts to report difficulties accessing immediate care (OR 1.30, p < 0.05). In addition, new immigrants (<5 years in Canada) were nearly two and a half times more likely to report difficulties with immediate care compared with the Canadian-born population. Individuals with less than high-school education were significantly less likely than were those with a post-secondary degree to report problems obtaining immediate care (OR 0.69, p < 0.05).

The reports of difficulties accessing immediate healthcare were not influenced by income level, job status, the presence of young children, lone-parent status, health status or access to a regular family doctor.

Interpretation

This study is the first national-level analysis of Canadians experiencing difficulties accessing first-contact health services. Overall, we found that 15% of Canadians who sought routine care and 23% of those who sought immediate care reported difficulties in accessing care for themselves or for family members. Physician and/or service availability and long waiting times were cited as the top two reasons for difficulties accessing both types of services. Compared with other international jurisdictions, Canada ranks among the highest regarding difficulties accessing general and family physicians. In a 2001 multi-country survey conducted by the Commonwealth Fund, 24% of Canadian respondents indicated long waits as a "big problem" when accessing general and family physicians compared with less than 15% in New Zealand and the United States (Blendon et al. 2003). Similarly in 2003, 25% of Canadian respondents indicated that it took six or more days to get an appointment to see a doctor compared with 2% in New Zealand, 7% in Australia, 13% in the United Kingdom and 19% in the United States (Schoen et al. 2004).

... 15% of Canadians who sought routine care and 23% of those who sought immediate care reported difficulties in accessing care for themselves or for family members. Physician and/or service availability and long waiting times were cited as the top two reasons for difficulties accessing both types of services.

The results of this study identified various demographic, socio-economic and health status factors that were associated with having difficulties accessing care. For both routine and immediate care, women (as compared with men), younger Canadians (as compared with those 65 and over) and those with post-secondary education were consistently more likely to report diffi-

culties. As well, residents of eastern Canadian provinces and Quebec were more likely to report problems than those living in Ontario. The regional findings do not seem to be closely related to the supply of general and family physicians given that Quebec, Newfoundland and Nova Scotia have some of the highest levels of physician-percapita rates. Prince Edward Island and New Brunswick, however, do have lower physician-per-capita rates than the national average (CIHI and Statistics Canada 2003). Income level, on the other hand, was not associated with difficulties accessing first-contact health services. This result supports the notion that universal health insurance is effective at eliminating cost-related barriers to care, unlike in the United States, for example, where income plays a greater role in determining access to care (Blendon et al. 2002; Sanmartin, Ng et al. 2004).

The differences we observed across various subgroups may reflect true differences in experiences accessing first-contact services between women and men, between older and younger Canadians, between those reporting fair or poor and good or better health, between those with more or less education and across different regions. For example, the higher rates of difficulties reported by women and those reporting poorer health may result from their different experiences in accessing the healthcare system (Kazanjian et al. 2004). Women, for example, have more contacts with the healthcare system in Canada than do men and are more likely than men to be the primary care-seekers for dependent children and elderly family members (Advisory Committee on Women's Health Surveillance 1999; Mustard et al. 1998). Similarly, individuals with poorer health status are more likely to require healthcare services compared with those reporting very good health. Consequently, these individuals have more opportunities to experience difficulties accessing care and, therefore, are at higher risk compared with those less likely to need and use healthcare services.

Alternatively, differences in reporting difficulties accessing the healthcare system may be the result of differential expectations across groups. In general, patients evaluate their encounters with the healthcare system against a set of expectations about when and how services ought to be provided (Newsome and Wright 1999; Linder-Pelz 1982). Expectations, therefore, likely play a key role in an individual's determination of whether or not difficulties were experienced. Expectations are shaped by various factors, including social context, demographics and socio-economic status (Thompson and Sunol 1995). Evidence suggests that older and less educated patients tend to have more modest expectations and are less likely to be dissatisfied with their care (Sitzia and Wood 1997). The differences we noted between younger and older Canadians and between more educated and less educated Canadians may be partially explained by higher service expectations among younger and more educated patients.

Our study also identified factors associated with difficulties accessing care that are specific to each type of first-contact service. In particular, we found rural residents and new immigrants to be at higher risk for experiencing difficulties accessing immediate care, whereas persons without a regular family doctor were more likely to report problems obtaining routine care. Urban/rural differences in access to healthcare services have been a longstanding concern in Canada, given the vastness of our country and the high concentration of services in more urban areas. Although access to primary care services in general has been identified as needing improvement (Romanow 2002), our results demonstrate the need to focus more specifically on access to immediate care for persons living in rural areas.

We also identified immigrants as an at-risk group for access to first-contact services. New immigrants were almost two and a half times more likely to experience difficulties accessing immediate care compared with those born in Canada. We saw no differences between new immigrants and Canadian-born respondents regarding access

to routine care. This could be due to the fact that immigrants tend to use these services less frequently and therefore have less opportunity to experience difficulties (Ali et al. 2004). Concerns about access to care among new immigrants have been raised before (Newbold 2005), and the evidence to date suggests that this difficulty might be caused by knowledge barriers such as not always knowing where to go to access services when needed (Neufeld et al. 2002; Steele et al. 2002; Wu et al. 2005). This hypothesis was confirmed through further analysis of the study data, which indicated that new immigrants were 10 times more likely than Canadian-born respondents to identify barriers related to personal circumstances, such as transportation, language, cost or lack of information about where to go for care.

... new immigrants were 10 times more likely than Canadian-born respondents to identify barriers related to personal circumstances, such as transportation, language, cost or lack of information about where to go for care.

Our results clearly indicated that having a regular family physician had a protective effect against having problems accessing routine care but was not associated with difficulties obtaining immediate care. Respondents without a family physician were more than twice as likely to report that they had difficulties accessing routine care compared with those who had

a regular family doctor. Previous evidence demonstrates that having a regular doctor or regular source of care results in improved access to primary care services such as preventive care (Lambrew et al. 1996; Grumbach et al. 1993; DeVoe et al. 2003; McIssac et al. 2001) and reduces the inappropriate use of services such as emergency rooms (Dunlop et al. 2000; Sarver et al. 2002). In our study, respondents with a regular family doctor, however, were just as likely to face difficulties accessing immediate care as were those without a regular family doctor. This finding is supported by other research showing that even patients with a regular family doctor experience difficulties accessing urgent care when they need it (Love and Mainous 1999; Pereira and Pearson 2003; Mathews and Barnsley 2003). While it is important to have a regular family doctor, having one does not always guarantee that patients will have access to care for all types of services at all times. The study findings support the notion of changes to primary care that seek to expand patient access to a broader range of providers who are available outside routine office hours.

The data used in this study are based on self-assessments of need for first-contact services and of difficulties accessing routine and immediate care in the 12 months

leading up to the survey. This information, therefore, may be subject to recall bias and, in the case of medical needs, has not been clinically validated. Also, compared with the general CCHS population, the HSAS subsample was more educated and affluent. These differences may have influenced the reporting of need for first-contact services and, in turn, limited the generalizability of the findings to the Canadian population at large.

In conclusion, information regarding patients' experiences accessing healthcare services is needed to provide a more complete picture regarding access to care in Canada. The results of this study provide valuable insight regarding potential access to first-contact services. In addition to identifying factors associated with difficulties accessing care, the study also identifies population groups who may be more vulnerable to experiencing difficulties accessing specific types of first-contact services. This information can be used to guide future policy initiatives to improve patients' experiences in obtaining first-contact services in Canada.

ACKNOWLEDGMENTS

This survey was funded by Statistics Canada.

Correspondence may be directed to: Claudia Sanmartin, Senior Analyst, Health Analysis and Measurement Group, Statistics Canada, R.H. Coates Bldg., 24th Floor Section R, Ottawa, ON K1A 0T6; tel. 613-951-6059; fax: 613-951-3959; email: claudia.sanmartin@statcan.ca.

REFERENCES

Aday, L.A. and R. Andersen. 1974. "A Framework for the Study of Access to Medical Care." *Health Services Research* 9(3): 208–220.

Aday, L.A. and R. Andersen. 1981. "Equity of Access to Medical Care: A Conceptual and Empirical Overview." *Medical Care* 19(12): 4–27.

Advisory Committee on Women's Health Surveillance. 1999. Women's Health Surveillance: A Plan of Action for Health Canada. Ottawa: Minister of Public Works and Government Services Canada.

Ali, J.S., S. McDermott and R.G. Gravel. 2004. "Recent Research on Immigrant Health from Statistics Canada's Population Surveys." Canadian Journal of Public Health 95(3): I9–I13.

Andersen, R.M. 1995. "Revisiting the Behavioral Model and Access to Medical Care: Does It Matter?" Journal of Health and Social Behavior 36: 1–10.

Beland, Y. 2002. "Canadian Community Health Survey – Methodological Overview." *Health Reports* 13(3): 9–14.

Black, C.D., N.P. Roos and C.A. Burchill. 1995. "Utilization of Hospital Resources." *Medical Care* 33: DS55–DS72.

Blendon, R.J., C. Schoen, C.M. DesRoches et al. 2002. "Inequities in Health Care: A Five-Country Survey." *Health Affairs* 21: 182–191.

Claudia Sanmartin and Nancy Ross

Blendon, R.J., C. Schoen, C.M. DesRosches et al. 2003. "Common Concerns among Diverse Systems: Healthcare Experiences in Five Countries." *Health Affairs* 22: 106–121.

Canadian Institute for Health Information (CIHI). 2004. Healthcare in Canada 2003. Ottawa: Author.

Canadian Institute for Health Information and Statistics Canada. *Health Indicators* 2003. Ottawa: The Institute, 2003.

Dault, M., J. Lomas and M. Barer. 2004. *Listening for Direction II: A National Consultation on Health Services and Policy Issues for 2004–2007*. Ottawa: Canadian Health Services Research Foundation.

Davison, A.C. and D.V. Hinkley. 1997. *Bootstrap Methods and Their Application*. Cambridge Series in Statistical and Probabilistic Mathematics. Cambridge: Cambridge University Press.

DeVoe, J.E., G.E. Fryer, R. Phillips and L. Green. 2003. "Receipt of Preventive Care among Adults: Insurance Status and Usual Source of Care." *American Journal of Public Health* 92: 786–791.

Dunlop, S., P.C. Coyte and W. McIsaac. 2000. "Socioeconomic Status and the Utilization of Physicians' Services: Results from the Canadian National Population Health Survey." Social Science and Medicine 51: 123–133.

Finkelstein, M.M. 2001. "Do Factors Other Than Need Determine Utilization of Physicians' Services in Ontario?" Canadian Medical Association Journal 165: 565–570.

Glazier, R.H., E.M. Badley, J.E. Gilbert and L. Rothman. 2000. "The Nature of Increased Hospital Use in Poor Neighbourhoods: Findings from a Canadian Inner City." *Canadian Journal of Public Health* 91: 268–273.

Grumbach, K., D. Keane and A. Bindman. 1993. "Primary Care and Public Emergency Department Overcrowding." *American Journal of Public Health* 83(3): 372–378.

Kazanjian, A., D. Morettin and R. Cho. 2004. "Health Care Utilization by Canadian Women." BMC Women's Health 4 (Supplement 1): S33.

Lambrew, J.M., G.H. DeFriese, T.S. Carey, T.C. Ricketts and A.K. Biddle. 1996. "The Effects of Having a Regular Doctor on Access to Primary Care." *Medical Care* 34(2): 138–151.

Linder-Pelz, S. 1982. "Toward a Theory of Patient Satisfaction." Social Science and Medicine 16: 577–582.

Love, M.M. and A.G. Mainous 3rd. 1999. "Commitment to a Regular Physician: How Long Will Patients Wait to See Their Own Physician for Acute Illness?" *Journal of Family Practice* 48: 202–207.

Mathews, M. and J. Barnsley. 2003. "Patients Seeking Care During Acute Illness: Why Do They Not See Their Regular Physicians?" Canadian Family Physician 49: 1498–1503.

McIssac, W.J., E. Fuller-Thomson and Y. Talbot. 2001. "Does Having Regular Care by a Family Physician Improve Preventive Care?" Canadian Family Physician 47: 70–76.

Mustard, C.A., P. Kaufert, A. Kozyrskyj and T. Mayer. 1998. "Sex Differences in the Use of Health Care Services." New England Journal of Medicine 338: 1678–1683.

Neufeld, A., M.J. Harrison, M.J. Stewart, K.D. Hughes and D. Spitzer. 2002. "Immigrant Women: Making Connections to Community Resources for Support in Family Caregiving." *Qualitative Health Research* 12: 751–768.

Experiencing Difficulties Accessing First-Contact Health Services in Canada

Newbold, B. 2005. "Health Status and Health Care of Immigrants in Canada: A Longitudinal Analysis." Journal of Health Services Research and Policy 10(2): 77-83.

Newsome, P.R. and G.H. Wright. 1999. "A Review of Patient Satisfaction: 1. Concepts of Satisfaction." British Dental Journal 186: 161–165.

Pereira, A.G. and S.D. Pearson. 2003. "Patient Attitudes toward Continuity of Care." Archives of Internal Medicine 163: 909–912.

Performance Reporting Technical Working Group. 2004. "Considerations for Data Production for Reporting Comparable Health Indicators in November 2004." Working Paper.

Romanow, R.J. 2002. Building on Values: The Future of Health Care in Canada – Final Report. Ottawa: Commission on the Future of Health Care in Canada.

Roos, N., C. Burchill and K. Carriere. 2003. "Who Are the High Hospital Users? A Canadian Case Study." Journal of Health Services Research and Policy 8(1): 5–10.

Roos, N.P. and C.A. Mustard. 1997. "Variation in Health and Healthcare Use by Socioeconomic Status in Winnipeg, Canada: Does the System Work Well? Yes and No." Milbank Quarterly 75(1): 89-111.

Sanmartin, C., C. Houle, S. Tremblay and J.J. Berthelot. 2002. "Changes in Unmet Health Care Needs." *Health Reports* 13(3): 15–21.

Sanmartin, C., F. Gendron, J.M. Berthelot and K. Murphy. 2004. Access to Health Care Services in Canada, 2003. Ottawa: Statistics Canada Cat. no. 82-575-XIE.

Sanmartin, C., E. Ng, D. Blackwell, J.F. Gentleman, M. Martinez and C. Simile. 2004. Joint Canada/United States Survey of Health, 2002-03. Analytic report released jointly by Statistics Canada and the National Center for Health Statistics. Ottawa: Statistics Canada Cat. no. 82M0022-XIE. Retrieved December 10, 2005. http://www.statcan.ca:8096/bsolc/english/ bsolc?catno=82M0022X>.

Sarver, J.H., R.K. Cydulka and D.W. Baker. 2002. "Usual Source of Care and Nonurgent Emergency Department Use." Academy of Emergency Medicine 9: 916–923.

Schoen, C., R. Osborn, P.T. Huynh, M. Doty et al. 2004. "Primary Care and Health System Performance: Adults' Experiences in Five Countries." Health Affairs W4: 487–503.

Sitzia, J. and N. Wood. 1997. "Patient Satisfaction: A Review of Issues and Concepts." Social Science and Medicine 45: 1829–1843.

Statistics Canada and Canadian Institute for Health Information. 2005. Health Indicators 2004. Ottawa: Authors.

Steele, L.S., L. Lemieux-Charles, J.P. Clark and R.H. Glazier. 2002. "The Impact of Policy Changes on the Health of Recent Immigrants and Refugees in the Inner City. A Qualitative Study of Service Providers' Perspectives." Canadian Journal of Public Health 92: 118-122.

Thompson, A.G. and R. Sunol. 1995. "Expectations as Determinants of Patient Satisfaction: Concepts, Theory and Evidence." International Journal of Qualitative Health Care 7: 127–141.

Wu, Z., M.J. Penning and C.M. Schimmele. 2005. "Immigrant Status and Unmet Health Care Needs." Canadian Journal of Public Health 96(5): 369–373.

Inclusivity and Dementia: Health Services Planning with Individuals with Dementia

Inclusivité et démence : planification des services de santé pour les personnes atteintes de démence

Effective inclusion requires action at multiple levels by individuals with dementia, care partners, service providers and funding organizations.



by KYLE WHITFIELD, MSC, PHD
Assistant Professor, Department of Extension
University of Alberta, Edmonton, AB

SUSAN WISMER, MED, PHD
Chair, Associate Professor, Department of Environment and Resource Studies
University of Waterloo, Waterloo, ON

Abstract

Historically, Alzheimer societies have identified the care partners of persons with dementia as their central clients. This focus is broadening to include the person with the disease, as well. This paper presents the results of a Canadian research study addressing organizational considerations related to effective inclusion of persons with dementia in planning and decision-making about health services and programs. Our findings suggest that effective inclusion requires action at multiple levels by individuals with dementia, care partners and friends; service organizations and providers; and funding organizations. Additional research is needed to explore the applicability of these findings to other organizations in different localities and to examine emergent

themes further. Of these, one that has received little attention to date concerns the potential risks associated with effective inclusion.

Résumé

Les sociétés Alzheimer ont toujours considéré les partenaires participant aux soins des personnes atteintes de démence comme étant leurs principaux clients. Cette définition est en train de s'élargir pour englober les personnes atteintes de la maladie elles-mêmes. Cet article traite des résultats d'une étude canadienne qui visait à cerner les considérations d'ordre organisationnel liées à l'inclusion efficace des personnes souffrant de démence dans la planification et la prise de décisions relatives aux programmes et aux services de santé. Les conclusions suggèrent que l'inclusion efficace exige la prise de mesures, à des paliers multiples, par les personnes atteintes de démence, les partenaires en matière de soins et les amis, les organismes et les fournisseurs de services, ainsi que les bailleurs de fonds. Des travaux de recherche plus poussés sont nécessaires afin d'explorer la pertinence de ces résultats pour d'autres organismes situés à différents endroits et d'examiner plus en profondeur les thèmes émergents. Le risque, par exemple, est un des éléments auxquels on n'a accordé que peu d'attention jusqu'ici.

EALTH PLANNING PRACTICES ARE SHIFTING AS THE CANADIAN POPULation ages. Those aged 65 and older will constitute 22% of the Canadian population by the year 2031 (Health Canada 2002). At present, 8% of all Canadians 65 or older are identified as suffering from dementia, 5.1% as having Alzheimer disease. If prevalence estimates are accurate, the number of Canadians with dementia will rise to 592,000 by 2021 (Canadian Study of Health and Aging Working Group 1994).

Alzheimer societies are community-based organizations supporting people with dementia and their care partners (Robson and Locke 2002; Eayrs 2002). In Ontario, there are 39 local Alzheimer societies providing information, education, individual and group support, advocacy and referral (Alzheimer Society of Canada 2005). Historically, Alzheimer societies have identified the care partners of persons with dementia as their central client. These organizations now want stronger direct working relationships with individuals with dementia.

This paper reports on a study examining organizational issues relevant to effective direct inclusion of persons with dementia. The study's purpose has been to identify key considerations for the inclusion in decision-making of community members living with dementia.

Literature Review

Literature suggests that one crucial component of good governance systems is that they effectively represent the interests of their stakeholders (Light 2002; Institute on Governance 2005). Good governance is also described as drawing on democracy, social responsibility and the public good as guiding principles for the development of policies and for setting goals regarding citizen participation in organizational decision-making (Carver 1997). In this same vein, good governance in the field of healthcare requires organizations to ask how they have helped improve the situation for those who are least well off and how they may avoid excluding others who are typically marginalized with respect to resources and supports (Labonte 2004). Wheatley (2005) and Carver (1997) suggest that participatory leadership approaches are characteristic of good governing systems.

Our review of the literature on inclusion and good governance identified three key areas specifically relevant to organizations serving clients with Alzheimer disease: communication, collaborative management strategies and consumer participation in organizational decision-making.

Communication with people with dementia

Individuals with dementia are rarely consulted regarding their opinions and preferences (Nolan et al. 2002). Wilkinson (2002) refers to persons with dementia as one of the most excluded groups in society.

Some strong feelings about exclusion were expressed. People talked about "meeting walls," feeling unwelcome and being told that opportunities for involvement and services such as support groups could not be made available.

One recent focus in the dementia care literature is on better understanding the perspective of persons with the condition. Recent studies have explored the everyday life experience of people with dementia (Gwyther 1997; Phinney 1998; Snyder 2001; Werezak and Stewart 2002) and questions of

personhood and identity (Goldsmith 1996; Kitwood 1997; Killick and Allan 2001). In addition, numerous effective communication techniques have been identified for people with dementia at various stages of the disease process (Carnaby 1997; Stalker et al. 1999; Allan 2001; Smith 2002; Moyes 2002). Results of this research suggest that, at most stages of the illness and to varying degrees, people with dementia can express issues and concerns. Appropriate strategies and flexibility regarding time frames and approaches are important (Allan 2000).

Much of the research focuses on individuals. (See, for example, Bartlett and Martin 2002; Downs 2000.) Our literature review found little examination of the role that organizations can play as facilitators for including people with dementia in making decisions, planning and evaluating health services in the community. One exception is the Alzheimer's Association of Australia, which has reported on the involvement of people with dementia in Alzheimer organizations and how that involvement might be strengthened through capacity building and resource re-allocation (Eayrs 2002).

Collaborative management strategies

Community-based, non-profit organizations generally endorse inclusion (Dreessen 2001; Shookner 2002; Ochocka et al. 2002). Prior et al. (1995) describe key organizational characteristics: accountable service providers and decision-makers; involved consumers; accessible information; accessible services; client-directed needs assessments; and identified systems for responding to consumer complaints. Similarly, Chaskin et al. (2001: 91) discuss the need for organizations to engage in ongoing monitoring, consumer feedback and consumer involvement in services, planning and evaluation:

... the more an organization can develop relationships that are authentic rather than token, mutual rather than one-sided, and flexible rather than rigid, the more an organization is likely to be able to connect effectively to its constituency and through this connection, contribute to community capacity.

Kretzmann and McKnight (1993) advocate networking with other similar-minded organizations. Petit (2000) proposes that organizations engaging individuals in decision-making share responsibility with other organizations. Light (2002) identifies one characteristic of high-performing, inclusive, non-profit organizations as capacity to collaborate with other organizations.

Heller et al. (1998) assert that participation is an organization-wide effort, undertaken by stakeholders, staff, management and boards, and that it must be supported with resources and policies. Light (2002) highlights the need for leadership to foster open communication.

Effective inclusion of people with dementia requires that organizations value openness, trust and support; draw out the capabilities of individuals with dementia; and have highly developed sensitivity, listening and counselling skills (Barnett 2000). A "genuine appreciation of their awareness and experience by each and every person in the organization involved with that service" is required (Barnett 2000: 204). Kitwood (1997) states that inclusive organizations are caring, that they work at building trust and fostering cooperation and that they seek to minimize the power differences between staff and clients.

Consumer participation in organizational decision-making

Barnes (1997) suggests that service users become more knowledgeable and experience greater confidence when they are involved in planning processes. Expectations of consumers have increased – they want more direct decision-making power (Locke et al. 2003). Public frustration with historically low levels of transparency and public accountability in the healthcare system have also fuelled consumer demand for involvement (Abelson et al. 2004).

Frankish et al. (2002) raise questions about whether there is a positive relationship between participation and organizational effectiveness. In contrast, Jewkes and Murcott (1998) report that community participation results in more cost-effective decisions, contributes to a sense of community control and provides an opportunity to release untapped resources. Citizen participation in decision-making processes can enable citizens to be "freed" from professionals and may allow needs to be assessed more accurately (Rifkin 1996).

Methods

The methodological approach for this research has been qualitative, using interview techniques derived from appreciative inquiry (Watkins 2001), additional interview techniques, analysis of documents and participant observation techniques from ethnographic research (Emerson et al. 1995), and analytical approaches based in grounded theory (Strauss and Corbin 1998). Such a mixed methods approach is recommended particularly for exploratory research as one means of addressing the need for data richness and for purposes of triangulation (Neuman 2003; Palys 2003).

We conducted 37 in-depth, semi-structured individual interviews, with three groups of informants: paid and volunteer staff, people with dementia and identified "experts." The literature review, which we carried out prior to the interviews, provided us with a framework for our selection of groups of interviewees and for the development of questions. Our decision to carry out a relatively small number of in-depth exploratory interviews with a mixed group of key informants was based on our desire to generate a rich base of foundation findings that could provide the basis for future investigation. We also carried out document reviews and engaged in participant observation, focusing on the experiences of the two Ontario Alzheimer organizations that served as case studies for our research. Case study organizations were purposively selected; both directors requested involvement in our research because their organizations were interested in moving towards greater consumer inclusion.

Twelve interviewees were selected purposively, in consultation with executive directors from the two case study organizations, to include key actors in each organization: staff members, volunteers and board members. Interviews explored current and potential involvement of persons with dementia and identified barriers to participation.

Eleven individuals with a diagnosis of Alzheimer disease, who are in the early to middle stages of the disease process, were contacted through references from the two Alzheimer Society case study organizations, through an online request to the chat room associated with the Dementia Advocacy Support Network International (DASNI) and through references from dementia care service providers. These interviews examined present and desired levels of involvement with local Alzheimer organizations.

Identified experts in the field of dementia care (n=14) included clinicians, researchers, support group facilitators and individuals identified as leading advocates. These experts were identified through Alzheimer networks and from the literature. Questions for experts were developed in response to key themes and issues emerging from first-stage analysis of interviews with organizational representatives and people with dementia.

The first author carried out all interviews individually. They were tape-recorded and transcribed. Interviews with organizational representatives and people with dementia were carried out concurrently, followed by interviews with experts. Data analysis was carried out sequentially. Transcribed results of each interview were compared cumulatively within each subgroup and then across subgroups in order to identify general patterns and themes. Key words and phrases were coded and grouped into categories representing major concepts derived from the data. Coded results from the interviews were then analyzed in relation to relevant literature in order to develop a proposed set of key considerations for organizational practice. Next, these considerations were evaluated and further refined in partnership with the two case study organizations and with interviewees with dementia, who were sent a two-page summary. Finally, based on feedback received, analysis of themes and subthemes was further refined.

Summary of Findings

Our interviews with people with dementia indicated that inclusion is important to them. They want more opportunities to be involved in decision-making. One individual, wishing to be involved in creating community awareness about dementia, said, "I have done less of this awareness work because that has not been made available to me. ... I need the Society to open the door" (PWiD01-P1). People with dementia said in our interviews that they want meaningful involvement: "I want to feel like I am adding something to the meeting" (PWiD08-P1).

People with dementia also told us that an organization that includes them as decision-making partners facilitates leadership roles for them; it "makes inclusion happen" and enables people with dementia to connect with one another:

We [volunteers with dementia] are supposed to go and give nice feelings to

people who have got the problem. Here I am, I have the problem ... but at my stage I am OK. So I can go and talk to people. ... They may feel comfortable with me because I have Alzheimer's disease. (PWiD06-P1)

Direct connections to Alzheimer Society chapters are relatively recent and are evolving:

I have seen some real growth in my Alzheimer Society. ... My initial experience was really bad. ... Now I am on a Steering Committee, have been on a panel talk ... , sent to a conference and written an article for their newsletter. (PWiD02-P1)

People with dementia who are involved in decision-making with Alzheimer societies reported feeling better because of their involvement, feeling nurtured and feeling an improvement in their health:

Maybe I feel better just taking action and taking control and I feel good about it and it enhances my overall performance. Or is it actually having an effect on my brain? Whichever way, I can't lose. ... You have to work your brain. (PWiD01-P1)

Some strong feelings about exclusion were expressed. People talked about "meeting walls," feeling unwelcome and being told that opportunities for involvement and services such as support groups could not be made available. Several individuals with dementia told us that they had to be persistent because "they [their local Alzheimer Society] were not accommodating" (PWiD02-P1). While these sentiments indicate that there is still considerable work to be done, they also affirm the importance and relevance of initiatives dedicated to inclusion.

Alzheimer societies involved in our study clearly believe that inclusion matters. However, only since 2001, as part of a major policy initiative by provincial and national organizations, have these societies begun to think about new roles for the person with dementia. The case study organizations currently include people with dementia as support group members, as co-facilitators of support groups, as advisory committee members, as friendly visitors, as speakers at Annual General Meetings, as representatives on speakers' panels and as writers of book reviews or other articles in local Alzheimer Society newsletters. At the time of our study, neither organization had people with dementia serving on their board of directors.

Those representing Alzheimer organizations told us that an inclusive organization creates structures that intentionally foster inclusion. Some interviewees saw inclusion as possible because the culture of Alzheimer organizations is friendly, learning orient-

ed and sincere, and promotes possibility. Key informants suggested that an inclusive organization should have an identified staff person whose role is to ensure successful inclusion.

The societies reported several challenges. A funder focus on care partners makes it difficult to concentrate on developing a strong working partnership with people with dementia. Case study organizations said the progressive nature of the disease also challenges inclusion: "The farther people move along the disease, they have less insight" (HN-05-P1). Resources generally are limited: "We are so focused on our existence and sustainability; it's hard to be innovative when you are just sustaining yourself financially" (S06-P1).

"You can't always take the experience of the person with dementia as fact, ... [therefore] we need to be well educated about the disease process in order to balance what they say (which may not be fact) with the process of the disease"

Interviews with experts corroborated findings from other interviews and additionally indicated that involving people with dementia in selected issues that are most relevant and of greatest interest to them is the most effective approach. One interviewee suggested, for example, asking people with dementia to act as resource persons to be consulted on relevant issues

by the board of directors, as an alternative to board representation. Other recommendations included evaluating organizational constitutions for inclusivity; updating language, membership and objectives of the organization and its programs; creating new roles that are meaningful for people with dementia; providing skill-building opportunities for staff and for people with dementia; and fostering an organizational culture and a board that is open to change and willing to take risks.

Experts identified risks of participation for people with dementia. Some said that people with dementia who are involved in health service planning processes risk feeling belittled or demeaned if they are misunderstood or if they are frustrated in attempts at communication. Two experts suggested that people with dementia might also be at risk because their lives are already stressful. If organizational involvement creates additional stress, stress levels could become overwhelming.

Experts talked also about organizational risks. Not being able to respond to all the requests of a person with dementia exposes organizations to criticism from those whom they mean to serve. Consumer involvement may shift power from staff, volunteers, board members and caregivers to people with dementia with the result that

"there is danger that some people may feel their interests are not being as strongly represented as before" (EXPRT15-P1). Another identified risk was that comments made by people with dementia might not always be accurate: "You can't always take the experience of the person with dementia as fact, ... [therefore] we need to be well educated about the disease process in order to balance what they say (which may not be fact) with the process of the disease" (EXPRT09-P1). (It is important to note here that people without Alzheimer disease may also hold inaccurate views.)

Experts we interviewed differed about the degree of caution needed regarding inclusion of persons with dementia in organizational initiatives. More cautious experts talked about people with dementia being at risk of exploitation and in need of protection (EXPRT07-P1) and "containment" (EXPRT11-P1). Others, representing a middle ground, talked about weighing the risks and the benefits: "We don't want to swing the pendulum too far because there are unique elements to the disease." Less cautious experts said: "We live with risk every day, and people with dementia cannot be denied the opportunity to speak about their own experience. This is paternalistic" (EXPRT06-P1); "It's a risk to not hear their voice" (EXPRT-11-P1); "Get over it, we have to take a risk, we can't live in a state of fear – life is a risk" (EXPRT09-P1). Experts differed in their views about the degree of consideration needed when involving persons with dementia in health services planning and decision-making. There was consensus, however, that organizational initiatives directed towards inclusion are not risk-free for the person with dementia or for organizations.

Discussion: Towards Inclusive Health Services Delivery for Persons with Dementia

Our results indicate that major shifts will be required for most organizations if they are to move from a focus on providing "support" or services to a broader focus on including people with dementia as partners in planning and decision-making with regard to programs and services. There is good opportunity for this: our case studies indicated that people with dementia are typically embedded within a broader community context, one that moves beyond relationships with family members, friends and neighbours to include agencies and organizations in supporting communities, offering a variety of opportunities for enhancing inclusion at multiple levels (Figure 1).

We have concluded that organizations that include people with dementia in decision-making must be adaptive and flexible enough to accommodate changing needs. Issues of scale may be critical in increasing adaptive capacities for inclusive organizations serving people with dementia. Although improved communication strategies at the level of the individual are important in maximizing the benefits of service provi-

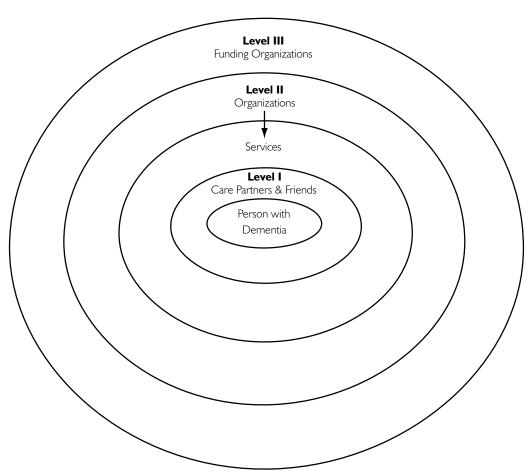


FIGURE 1. Connections between individuals with dementia and their broader community

sion for people with dementia, they will not necessarily create organizations that are effectively inclusive. Specific strategies for change at the level of the organization are required and include a vision, structure and board that accommodate people with dementia; leadership opportunities for people with dementia; acknowledgment that inclusion requires resources; and development of an organizational culture that is ready and willing to move towards inclusion. At the meta-level (Level III in Figure 1) of funders and government-based funding agencies, the critical role of resources in supporting organizational change means that changes at the policy and program levels are also necessary. While our study focuses on addressing a research gap with respect to organizations and organizational change (Level II in Figure 1), our findings also suggest that effective inclusive organizations will be nested in comprehensive and ongoing initiatives at all three levels. For example, a funder focus on caregiver support was identified as a major challenge by our organizational interviewees.

Findings from this study suggest three important areas for further research and analysis: governance, resource requirements and risk.

Organizational governance issues

Our interviews with individuals with dementia confirmed their interest in participating in decision-making roles as board or committee members in Alzheimer organizations. Organizational representatives also were strongly committed to inclusion. There are, however, limits that need to be considered.

Dementia, and Alzheimer disease in particular, is a changing disease. The ability of any individual to be involved as a board or committee member is likely to be time limited and may vary considerably within that period depending on individual factors (e.g., fatigue, stress, wellness) and environmental considerations (e.g., level and type of organizational supports, communication protocols, etc.). While these people have the ability to attend meetings, grasp the process and reflect on and communicate about relevant board or committee issues, this is likely to be possible mainly in the earlier stages of the disease. The changeable nature of dementia creates challenges for affected individuals and also for other board or committee members. Sensitivity, developed listening skills and a partnership approach to inclusion are necessary. Honest communication about anticipated fluctuations and long-term changes in cognitive capacity is likely to be important at the outset among all involved.

Frankish et al. (2002) suggest that there are mixed indications in the literature about citizens' representation. In their exploration of the role of citizens on regional health boards, the authors found no evidence of better decisions being made or resources being used more efficiently because of citizen representation. Barnes (1997) also points out that citizens involved in a long-term planning process are not a reliably representative sample of the user population simply by virtue of their experience. This broader research on citizen representation indicates that people with dementia, like other identified groups, are not homogeneous, making representation a challenge. Effective inclusion must take into account the need to support people in representing the full range of their constituencies (Pitkin 1967).

Resource-related issues

Eayrs (2002) reports lack of resources as one of the biggest barriers to inclusion in the Alzheimer's Association of Australia. In Ontario, the 39 Alzheimer societies receive varying proportions of their funding from the provincial government (Société Alzheimer Society Ontario 2005). In general, there is significant reliance upon the Ontario Ministry of Health and Long-Term Care. This is not unusual for not-for-profit organizations. Phillips (1995: 12) argues that "it is simply a myth to think that

... the voluntary sector ... does - or could - operate entirely independently of government."

Government cutbacks mean that voluntary sector organizations, such as local Alzheimer societies, are experiencing reduced funding just as they are being asked to take on a larger share of responsibility for delivering services. At the same time, the demand for services is increasing. There is, typically, a financial risk associated with change: "Funding cuts hamper the capacity of the voluntary sector to carry out its other roles with respect to innovation and moral leadership" (Torjman 1999: 4).

The non-profit organizational management literature suggests that understanding of the current and potential role of the not-for-profit sector is lacking (Prince and Chappell 1994; Phillips 1995; Dreessen 2001). Several authors suggest that governments need to appreciate that voluntary organizations "weave the fabric of society by engaging citizens, and cultivating trust and collaboration among sectors. ... [They] act as the social glue that helps bind together the diverse elements of society into a cohesive whole" (Torjman 1999: 7).

Risk

A third theme emerging from our findings relates to risk. We found agreement that inclusion entails risk, both for individuals and for organizations. We also found considerable disagreement about what constitutes acceptable risk and how to respond to it. Risk perception and risk assessment have emerged as a potentially important area for further investigation regarding organizational inclusion of people with dementia.

Conclusion

People with dementia in our study would like to play a stronger role in healthcare decision-making. Our findings suggest that there is an important role for Alzheimer societies in "opening the door" for them to do so. Direct relationships between individuals with dementia and Alzheimer organizations are still relatively recent. Currently, much of the research focuses on improvements in methods of communication with individuals with dementia. While communication is critically important, our findings suggest that improved communication is not sufficient to achieve inclusivity. Inclusive organizations need to place priority on good governance; involvement of consumers in service-related decision-making; leadership that fosters open communication and draws out people's capacities and potential for creative problem-solving; and supportive policies and resources. As Figure 1 suggests, effective inclusion requires action at multiple levels by individuals with dementia, care partners and friends; organizations and service providers; and funding organizations.

Because our study is based on only two case studies and our sample size is not

large, we cannot claim that our results are broadly generalizable. Additional research is needed to explore the relevance of these findings to other organizations in different localities and to examine further the themes that emerged in our study. Of these, one that has received little attention to date is risk.

ACKNOWLEDGMENTS

The authors would like to thank reviewers for their comments on earlier versions of this paper. This study was supported in part by the Canadian Institutes of Health Research – Institute on Aging and the Scottish Rites Charitable Foundation of Canada.

Correspondence may be directed to: Kyle Whitfield, Faculty of Extension, University of Alberta, Edmonton, Alberta, T6G 2T4, tel: 780-492-2681, fax: 780-492-6735, email: kw16@ualberta.ca

REFERENCES

Abelson, J., P.G. Forest, J. Eyles, A. Casebeer and G. Mackean. 2004. "Will It Make a Difference If I Show Up and Share? A Citizen's Perspective on Improving Public Involvement Processes for Health System Decision-Making." *Journal of Health Services Research Policy* 9: 205–212.

Allan, K. 2000. "Drawing Out Views on Services: A New Staff-Based Approach." *Journal of Dementia Care* 8: 16–19.

Allan, K. 2001. Communication and Consultation: Exploring Ways for Staff to Consult People with Dementia about Services. Bristol, UK: The Policy Press.

Alzheimer Society of Canada. 2005. Retrieved December 9, 2005. http://www.alzheimer.ca/english/index.php.

Barnes, M. 1997. Care, Communities and Citizens. London, UK: Addison Wesley Longman.

Barnett, E. 2000. Including the Person with Dementia in Designing and Delivering Care: "I Need to be Me." London, UK: Jessica Kingsley Publishers.

Bartlett, H. and W. Martin. 2002. "Ethical Issues in Dementia Care Research." In H. Wilkinson, ed., *The Perspectives of People with Dementia: Research Methods and Motivations* (pp. 47–61). London, UK: Jessica Kingsley Publishers.

Canadian Study of Health and Aging Working Group. 1994. "Canadian Study of Health and Aging: Study Methods and Prevalence of Dementia." Canadian Medical Association Journal 150: 899–913.

Carnaby, S. 1997. "What Do You Think?': A Qualitative Approach to Evaluating Individual Planning Services." *Journal of Intellectual Disability Research* 41: 225–231.

Carver, J. 1997. Boards That Make a Difference: A New Design for Leadership in Nonprofit and Public Organizations. San Francisco: Jossey-Bass.

Chaskin, R., P. Brown, S. Venkatesh and A. Vidal. 2001. *Building Community Capacity*. New York: Aldine de Gruyter.

Downs, M. 2000. "Dementia in a Socio-Cultural Context: An Idea Whose Time Has Come." *Ageing and Society* 20: 369–375.

Dreessen, E. 2001. "What We Should Know about the Voluntary Sector But Don't Know." *Isuma: Canadian Journal of Policy Research* 2: 1–15.

Eayrs, A. 2002. Consumer Focus Project. Higgins, Australia: Alzheimer's Association Australia.

Emerson, R., R. Fretz and L. Shaw. 1995. Writing Ethnographic Fieldnotes. Chicago: University of Chicago Press.

Frankish, J., B. Kwan, C. Larsen, P. Ratner and J. Wharf Higgins. 2002. "Challenges of Community Participation in Health-System Decision-Making." Social Science and Medicine 54(10): 1471–1480.

Goldsmith, M. 1996. Hearing the Voice of People with Dementia: Opportunities and Obstacles. London, UK: Jessica Kingsley Publishers.

Gwyther, L. 1997. "The Perspective of the Person with Alzheimer Disease: Which Outcomes Matter in Early to Middle Stages of Dementia?" *Alzheimer's Disease and Associated Disorders* 11: 18–24.

Health Canada. 2002. Canada's Aging Population. Ottawa: Minister of Public Works and Government Services Canada.

Heller, F., E. Pusic, G. Strauss and B. Wilpert. 1998. Organizational Participation: Myth and Reality. New York: Oxford University Press.

Institute on Governance. 2004. "Board Governance. Fact Sheet." Retrieved December 9, 2005. http://www.iog.ca.

Jewkes, R. and A. Murcott. 1998. "Community Representatives: Representing the 'Community'?" Social Science Medicine 46: 843–858.

Killick, J. and K. Allan. 2001. Communication and the Care of People with Dementia. Buckingham, UK: Open University Press.

Kitwood, T. 1997. "The Experience of Dementia." Aging and Mental Health 1: 13-22.

Kretzman, J. and J. McKnight. 1993. Building Communities from the Inside Out. Evanston, IL: Center for Urban Affairs and Policy Research, Northwestern University.

Labonte, R. 2004. "Social Inclusion/Exclusion: Dancing the Dialect." *Health Promotion International* 19: 115–121.

Light, P. 2002. Pathways to Nonprofit Excellence. Washington, DC: Brookings Institution Press.

Locke, M., N. Begum and P. Robson. 2003. "Service Users and Charity Governance." In C. Cornforth, ed., *The Governance of Public and Non-Profit Organizations* (pp. 57–73). London, UK: Routledge.

Moyes, M. 2002. "The Voice of the User Group." Signposts Review 6: 42–44.

Neuman, W.L. 2003. Social Research Methods (5th ed.). Boston: Pearson Education.

Nolan, M., T. Ryan, P. Enderby and D. Reid. 2002. "Towards a More Inclusive Vision of Dementia Care Practice and Research." *Dementia* 1: 193–211.

Ochocka, J., R. Janzen and G. Nelson. 2002. "Sharing Power and Knowledge: Professional and Mental Health Consumer/Survivor Researchers Working Together in a Participatory Action

Research Project." Psychiatric Rehabilitation Journal 25: 379-387.

Palys, T.S. 2003. Research Decisions (3rd ed.). Toronto: Thomas Nelson.

Petit, J. 2000. "Strengthening Local Organizations – 'Where the Rubber Hits the Road." IDS Bulletin 31: 57–67.

Phillips, S.D. 1995. "Redefining Government Relationships with the Voluntary Sector: On Great Expectations and Sense and Sensibility." Voluntary Sector Roundtable Publications. Retrieved December 9, 2005. http://www.vsr-trsb.net/publications/phillips-e.html.

Phinney, A. 1998. "Living with Dementia: From the Patient's Perspective." *Journal of Gerontological Nursing* 24. 8–15.

Pitkin, H. 1967. The Concept of Representation. Berkeley: University of California Press.

Prince, M. and N. Chappell. 1994. Voluntary Action by Seniors in Canada. Victoria, BC: University of Victoria Centre on Aging.

Prior, D., J. Stewart and K. Walsh. 1995. Citizenship: Rights, Community and Participation. London, UK: Pitman.

Rifkin, S. 1996. "Paradigms Lost: Toward a New Understanding of Community Participation in Health Programmes." *Acta Tropica* 61: 79–92.

Robson, P. and M. Locke. 2002. Changing Voices: Involving People with Dementia in the Alzheimer's Society. Final Evaluation Report. London, UK: Centre for Institutional Studies.

Shookner, M. 2002. An Inclusion Lens: Workbook for Looking at Social and Economic Exclusion and Inclusion. Halifax: Health Canada.

Smith, J. 2002. "From Rhetoric to Reality." Nursing Older People 14: 10-13.

Snyder, L. 2001. "The Lived Experience of Alzheimer's – Understanding the Feelings and Subjective Accounts of Persons with the Disease." *Alzheimer's Care Quarterly* 2: 8–22.

Société Alzheimer Society Ontario. 2005. Retrieved December 9, 2005. http://alzheimer ontario.org.

Stalker, K., J. Gilliard and M. Downs. 1999. "Eliciting User Perspectives on What Works." *International Journal of Geriatric Psychiatry* 14: 120–134.

Strauss, A. and J. Corbin. 1998. Basics of Qualitative Research. London, UK: Sage Publications.

Torjman, S. 1999. Unravelling the Threads of Democracy. Toronto: Caledon Institute of Social Policy.

Watkins, J.M. 2001. Appreciative Inquiry: Change and the Speed of Imaginations. San Francisco: Jossey-Bass.

Werezak, L. and N. Stewart. 2002. "Learning to Live with Early Dementia." Canadian Journal of Nursing Research 34: 67–85.

Wheatley, M. 2005. Finding Our Way: Leadership for an Uncertain Time. San Francisco: Berrett–Koehler Publishers.

Wilkinson, H. 2002. The Perspectives of People with Dementia. London, UK: Jessica Kingsley Publishers.

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

Rentabilité de l'étendue des services d'intervention comportementale intensive à tous les enfants autistes de l'Ontario

In the past year, several court cases have been brought against provincial governments to increase funding for Intensive Behavioural Intervention (IBI). This economic evaluation examines the costs and consequences of expanding an IBI program.



by SANOBER S. MOTIWALA, MSC

Department of Health Policy, Management and Evaluation

University of Toronto, ON

SHAMALI GUPTA, MSC
Department of Health Policy, Management and Evaluation
University of Toronto, ON

MEREDITH B. LILLY, HON BA
Department of Health Policy, Management and Evaluation
Fellow, CIHR Program in Healthcare, Technology and Place
University of Toronto, ON

WENDY J. UNGAR, PHD

Scientist, Population Health Sciences, Hospital for Sick Children Adjunct Scientist, Institute for Clinical Evaluative Sciences Assistant Professor, Department of Health Policy, Management and Evaluation University of Toronto, ON

> PETER C. COYTE, PHD Health Services Chair

Canadian Health Services Research Foundation and Canadian Institutes of Health Research Professor, Health Economics, Department of Health Policy, Management and Evaluation University of Toronto, ON

Abstract

Intensive Behavioural Intervention (IBI) describes behavioural therapies provided to autistic children to overcome intellectual and functional disabilities. The high cost of IBI has caused concern regarding access, and recently, several court cases have been brought against provincial governments to increase funding for this intervention. This economic evaluation assessed the costs and consequences of expanding an IBI program from current coverage for one-third of children to all autistic children aged two to five in Ontario, Canada. Data on the hours and costs of IBI, and costs of educational and respite services, were obtained from the government. Data on program efficacy were obtained from the literature. These data were modelled to determine the incremental cost savings and gains in dependency-free life years. Total savings from expansion of the current program were \$45,133,011 in 2003 Canadian dollars. Under our model parameters, expansion of IBI to all eligible children represents a cost-saving policy whereby total costs of care for autistic individuals are lower and gains in dependency-free life years are higher. Sensitivity analyses carried out to address uncertainty and lack of good evidence for IBI efficacy and appropriate discount rates yielded mixed results: expansion was not cost saving with discount rates of 5% or higher and with lower IBI efficacy beyond a certain threshold. Further research on the efficacy of IBI is recommended.

Résumé

L'intervention comportementale intensive (ICI) décrit les thérapies comportementales fournies aux enfants autistes pour les aider à surmonter leurs déficiences intellectuelles et fonctionnelles. Les coûts élevés de cette intervention ont soulevé des préoccupations quant à l'accès et, récemment, plusieurs poursuites judiciaires ont été intentées contre les gouvernements provinciaux en vue d'amener ces derniers à augmenter le finance-

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

ment accordé à l'ICI. Cette analyse économique visait à évaluer les coûts et les conséquences de l'élargissement de la portée d'un programme d'ICI pour le rendre accessible à tous les enfants autistes âgés de deux à cinq ans en Ontario, au Canada – au lieu du tiers des enfants comme c'est le cas actuellement. Les données sur les heures et les coûts liés à l'ICI, ainsi que sur les coûts des services éducatifs et de relève, ont été obtenues auprès du gouvernement. Les données sur l'efficacité du programme ont été tirées de la littérature. Ces données ont été modelées afin de déterminer les économies supplémentaires et les années de vie autonome gagnées. L'élargissement de la portée du programme actuel a permis de réaliser des économies de 45 133 011 \$ CAN en 2003. Selon les paramètres de notre modèle, étendre l'ICI à tous les enfants admissibles constitue une mesure de réduction des dépenses en vertu de laquelle les coûts totaux des soins fournis aux enfants autistes sont moins élevés et les gains d'autonomie sont plus élevés. Les analyses de sensibilité effectuées pour aborder l'incertitude et le manque de données solides corroborant l'efficacité de l'ICI et les rabais appropriés pour cette dernière ont donné des résultats mixtes : l'élargissement de la portée de l'ICI ne permet pas de réaliser des économies avec des rabais de 5 p. cent ou plus ou avec un seuil d'efficacité en deçà d'un certain niveau. Nous recommandons d'effectuer des travaux de recherche plus poussés sur l'ICI.

TISM IS AN EARLY-ONSET DEVELOPMENTAL DISABILITY CHARACTERized by impairments in social interaction, abnormal verbal and non-verbal communication, repetitive, stereotyped behaviour and resistance to change (Howlin 1998; American Psychiatric Association 1994). Most cases are diagnosed by three years of age, with a male–female ratio of 3:1 (Ontario Ministry of Community, Family and Children's Services [MCFCS] 2000). The reported prevalence of autism in Ontario almost doubled between 1996 and 1998, with the 1998 prevalence being 2.09 per 1,000 children aged five and younger (Ontario Health Insurance Program [OHIP] 2000). The etiological cause of autism is believed to be dysfunction of the right hemisphere of the brain, which is responsible for appropriate visual–spatial and emotional interactions (Gillberg and Coleman 2000).

Intensive Behavioural Intervention (IBI) is the general term for behavioural therapies provided to autistic children to overcome their intellectual and functional disabilities. Several variants of IBI and non-IBI therapies have been reported, but strong evidence is lacking regarding the effectiveness of many of these approaches. No single form of behavioural intervention is appropriate for all individuals with autism (Dawson and Osterling 1997). IBI typically involves one-on-one training provided by a therapist, in which children are trained to respond to environmental changes, understand and use language and interact appropriately with others in social settings

(Dawson and Osterling 1997). Positive reinforcement is used to internalize appropriate behaviours. Success of IBI is believed to correspond to the intensity and duration of the treatment – between 20 and 40 hours per week of one-on-one therapy, for a minimum of two years, is generally believed to yield optimal results (MCFCS 2000; Lovaas 1987). Beyond a minimum threshold of 20 hours per week, there is little agreement in the peer-reviewed literature as to the exact number of hours required to achieve the most favourable results (MCFCS 2000; Dawson and Osterling 1997; Bassett et al. 2000; Sheinkopf and Sigel 1998; Smith 1999; Ludwig and Harstall 2001). Annual IBI costs range from \$40,000 to \$75,000 per child in 2003 Canadian dollars, depending on the number of treatment hours provided and other factors, including administrative costs and training (Ontario Ministry of Children's Services [MCS] and Ontario Ministry of Community and Social Services [MCSS] 2003; Jacobson and Mulick 2000; Jacobson et al. 1998; Hildebrand 1999; Freeman 1997).

IBI outcomes are generally categorized by level of functioning, assessed at the end of the intervention period. "Normal-functioning" individuals integrate into the community, receive schooling in mainstream classrooms and live independently as adults. "Semi-dependent" and "very dependent" individuals make partial and minimal gains, respectively, and continue to rely on social assistance throughout their lifetime (Lovaas 1987; Freeman 1997; Rutter 1996; Howlin 1997; Howlin et al. 2004). The most optimistic estimates available in the literature suggest that without receiving any form of intervention, as many as 25% of autistic individuals live normal lives, 25% are moderately disabled and 50% are severely compromised (Freeman 1997). However, other studies have reported lower rates of normalization without intervention (Rutter 1996; Howlin 1997). Success rates of IBI and similar interventions vary.

A highly publicized and controversial study, conducted by Lovaas (1987), reported a large proportion of children (up to 47%) achieving normal intellectual and educational functioning at the end of the intervention. However, Lovaas's primary study and its follow-up (McEachin et al. 1993) have been criticized for their methodological limitations, particularly, exclusion of the poorest-functioning 15% of referred subjects, the non-random assignment of children to treatment groups and the statistically significant difference in sex ratios between the treatment and control groups. These limitations have led to concerns regarding the validity of Lovaas's findings (Bassett et al. 2000).

In Canada, funding for IBI varies across provinces, but most provincial governments offer some support for IBI to children diagnosed with autism up to a certain age. As a result of high costs of treatment, several lawsuits have been launched by families of autistic children, rallying for increased government funding for IBI. In most cases, rulings have been favourable for the families, requiring governments to increase funding for IBI. In contrast, the Supreme Court of Canada recently ruled favourably in an appeal from the British Columbia government, denying increased funding for

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

IBI on the grounds that the therapy did not constitute "medically necessary" care as defined by the *Canada Health Act*.

In Ontario, the government currently funds up to three years of IBI for approximately a third of autistic children younger than six years of age (OHIP 2000; MCSS 2002). The Ontario government does not promote any particular form of IBI. It has contracted with a private organization (Behaviour Institute, Hamilton) that delivers training to regional service providers, who in turn are contracted through a competitive tendering process. In its provincial program guidelines for IBI, the government lists principles and teaching methods that regional providers are expected to follow, which include, where appropriate, one-on-one training, task analysis, positive reinforcement and small-group instruction (MCFCS 2000). Eligibility for IBI, duration and intensity of treatment are determined through formal assessment, with allocation of services geared towards children with more severe forms of autism (MCFCS 2000). Earlier this year, the Superior Court of Ontario ruled in favour of the plaintiffs in a class-action lawsuit against the Ontario government, challenging the termination of public funding for IBI at the age of six. The decision is currently being appealed.

The purpose of this study was to conduct a cost-effectiveness analysis to evaluate the expansion of the IBI program to all autistic children in Ontario from two to five years of age, commencing in 2003. We included costs incurred only by the government and excluded all other costs, for example, those incurred by autistic individuals, their families and employers. The government's perspective was employed for the analysis because it is highly relevant to ongoing legal and policy debates across the country. The provision of IBI in this model was limited to children aged two to five because (1) IBI is believed by many to be most effective when provided at an early age (MCFCS 2000); (2) currently, the Ontario government funds IBI only for children under the age of six (MCS and MCSS 2003); and (3) previous economic analyses carried out in other jurisdictions have limited IBI provision to children of similar ages (Jacobson et al. 1998; Hildebrand 1999). Thus, the present model would facilitate comparisons.

Methods

Including costs incurred only by the government, we developed a model that reflects the current public provision of autism services in Ontario. The prevalence of autism in Ontario, or the cohort size for this study (n=1,309), was calculated as the sum of the number of children receiving IBI (n=485), the number of children eligible but waitlisted for IBI (n=91) and the number of children waiting for an assessment, multiplied by the proportion of assessed children who have historically been deemed eligible for IBI ($n=952\times0.77$). The three comparison groups were (1) Status Quo provision, (2) Expansion of IBI services and (3) No Intervention. Status Quo was based on the current provision of autism services by the provincial government, whereby 37% of

children with autism aged two to five (n = 485) receive up to three years of IBI for 23 hours per week on average, while the remainder (n = 824) do not receive IBI. While the majority of children currently eligible for IBI in Ontario receive it for less than three years because of diagnostic delays and waiting lists, our study was based on the assumption that all children eligible for these services would receive them for a fixed three-year duration. Under *Expansion*, IBI was provided to all autistic children (n = 1,309) for three years at 23 hours per week. Under the third scenario, *No Intervention*, IBI was not provided to any of the 1,309 children in the cohort. Although this scenario represents an unlikely regression from the current situation in Ontario, it makes our findings relevant for jurisdictions where IBI may not be currently publicly funded.

Efficacy rates

Under all three scenarios, children were categorized according to their levels of functioning – normal, semi-dependent and very dependent – upon completion of IBI until the age of 65 (Table 1) (Jacobson et al. 1998; Hildebrand 1999). Efficacy rates for *No Intervention*, the cohort that received no IBI, were based on published literature (Freeman 1997; Howlin et al. 2004; Green et al. 2002). It was assumed that 25% attain normal functioning, 25% are semi-dependent and 50% are very dependent without receiving IBI (Freeman 1997). The figures from Freeman (1997) are the most optimistic reported in the literature; they match closely more recent estimates of adult functioning by Howlin et al. (2004), which are slightly lower. Although many studies report even lower rates of normalization (Rutter 1996; Howlin 1997), we selected the highest published rates to investigate the cost-effectiveness of IBI from a best-case scenario, thereby increasing the robustness of our model.

Because of ongoing controversy regarding the reported efficacy of Lovaas's treatment and other forms of behavioural intervention (Dawson and Osterling 1997; Bassett et al. 2000; Sheinkopf and Sigel 1998; Smith 1999; Ludwig and Harstall 2001; Green et al. 2002), we assigned IBI efficacy rates that were more conservative than those reported for Lovaas's intervention (1987) and its replications (McEachin 1993; Sallows and Graupner 2001). The efficacy rates for *Expansion* were assumed to be 30% normal, 50% semi-dependent and 20% very dependent. *Status Quo* efficacy was based on a weighted average of 824 children receiving no IBI (efficacy equivalent to *No Intervention*) and 485 children receiving IBI (efficacy equivalent to *Expansion*) for three years. The resultant efficacy rates for *Status Quo* were 26.9% normal, 34.3% semi-dependent and 38.9% very dependent.

Cost Data Sources

All costs in the model were converted to 2003 Canadian dollars using growth in the

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

consumer price index from the period when the underlying data were available, and were estimated for individuals from age two to 65.

The Ontario Ministry of Children's Services and Ontario Ministry of Community and Social Services (2003) reported the annual cost of IBI as \$75,670 per child aged two to five, based on 23 hours per week of therapy. This figure represents the aggregate cost of the IBI program incurred by the Ontario government and includes the training costs of IBI therapists, contractual payments to service providers, and salaries, benefits and overhead costs incurred by provincial civil servants. Average wage rates from Statistics Canada's Ontario Wage Survey (1999) were used to estimate costs for government-funded respite services and speech and language therapy (BBB Autism Support Network 2002). In all cases, costs were converted to 2003 dollars.

No autism-related costs were assumed for normal-functioning individuals after the age of five; families of semi-dependent and very dependent individuals in both the *Status Quo* and *Expansion* groups continued to receive respite services until 18 years of age. All education costs were derived from Ontario Ministry of Education documents (2000; 2001a,b,c). This ministry incurs two levels of special-education costs, Intensive Support Amount 2 (ISA 2) and Intensive Support Amount 3 (ISA 3) for semi- and very dependent individuals from five to 18 years of age.

Adult care costs for semi- and very dependent individuals were based on reports prepared by the Auditor of Ontario (MCSS 2001). Costs for adult day programs were obtained from Ontario Agencies Supporting Individuals with Special Needs (OASIS 2000). Due to limited availability of data on housing and care of autistic adults, 50% of semi-dependent individuals were assumed to live independently and 50% in public residential facilities, while all very dependent individuals were assumed to live in public residential facilities. Autistic adults are eligible for compensation through the Ontario Disability Support Program (ODSP) (Canadian Legal Information Institute 2004). ODSP benefits represent transfer payments rather than costs related directly to autism; therefore, these monthly ODSP entitlements were excluded from the model. The cost to government and other employers of administering assisted-employment programs for developmentally disabled adults was based on current programs of Human Resources Development Canada (HRDC 1999, 2001).

While healthcare utilization might be related to the level of functioning (Jarbrink and Knapp 2001), we did not have access to such data; hence, the cost-effectiveness analysis does not capture these healthcare costs. However, since utilization may increase with the level of dependence, the potential cost savings identified in this study would increase if healthcare utilization were included.

In projecting costs over the productive lifetime, a discount rate of 3.0% per annum was applied to calculate present values (Drummond et al. 1997). In sensitivity analyses, discount rates from 1.0% to 5.0% were used.

TABLE 1. Levels of functioning, efficacy rates, and dependency-free years gained for No Intervention, Status Quo and Expansion

DESCRIPTION	EFFICACY RATES			
	No Intervention	Status Quo*	Expansion	
Mainstream classroom education; independent functioning; earn aver- age Canadian high school graduate income as adults	25%	26.9%	30%	
Special education; respite services; 50% live independently as adults; 50% live in residential facilities; participate in day programs; earn assisted employment income as adults	25%	34.3%	50%	
Intensive special education; respite services; 100% live in residential facilities as adults; participate in day programs; earn assisted employment income as adults	50%	38.9%	20%	
ency-free years gained until 65	9.6 years	II.2 years	14.0 years	
	Mainstream classroom education; independent functioning; earn average Canadian high school graduate income as adults Special education; respite services; 50% live independently as adults; 50% live in residential facilities; participate in day programs; earn assisted employment income as adults Intensive special education; respite services; 100% live in residential facilities as adults; participate in day programs; earn assisted employment income as adults	Mainstream classroom education; independent functioning; earn average Canadian high school graduate income as adults Special education; respite services; 50% live independently as adults; 50% live in residential facilities; participate in day programs; earn assisted employment income as adults Intensive special education; respite services; 100% live in residential facilities as adults; participate in day programs; earn assisted employment income as adults	Mainstream classroom education; independent functioning; earn average Canadian high school graduate income as adults Special education; respite services; 50% live independently as adults; 50% live in residential facilities; participate in day programs; earn assisted employment income as adults Intensive special education; respite services; 100% live in residential facilities as adults; participate in day programs; earn assisted employment income as adults	

Outcomes

IBI outcomes were measured by the number of dependency-free years gained to age 65, where dependency was defined as the need for special education and other special services comprising adult day programs, disability supports and assisted employment. Normal-functioning individuals were not dependent after age five and, as a result, gained 60 dependency-free years. Very dependent individuals made minimal gains

†Calculated as a weighted average based on efficacy rates for each scenario, discounted at 3% per annum

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

from IBI, remained dependent throughout life and gained zero dependency-free years. Semi-dependent individuals continued to be partially dependent. Their outcome was assumed to be the midpoint between normal and very dependent functioning outcomes; they gained 30 dependency-free years. Estimated dependency-free years for the study time horizon were discounted at 3.0% per annum. The discounted number of dependency-free years gained under *No Intervention, Status Quo* and *Expansion* were calculated as the weighted average of dependency-free years for normal, semi- and very dependent individuals under each scenario (Table 1). The number of discounted dependency-free years per person to age 65 was 9.6 years for *No Intervention*, 11.2 years for *Status Quo* and 14.0 years for *Expansion*.

Results of the analysis were expressed in terms of incremental cost savings in present values (PVs) and gains in dependency-free years (also measured in PVs). The incremental cost analyses compared *Status Quo* to *No Intervention*, *Expansion* to *No Intervention* and *Expansion* to *Status Quo*.

Productivity costs incurred by semi- and very dependent individuals were included in a sensitivity analysis to examine costs and benefits from a partial societal perspective. Lost wages to age 65 were derived from sex-adjusted income estimates from the 1996 and 2001 Canadian censuses (Statistics Canada 1996; 2001a,b,c) and federal assisted-employment initiatives data (HRDC 1999, 2001). Potential earnings for the normal-functioning group were assumed to be equivalent to the sex-adjusted annual income of high school graduates. Semi-dependent incomes are derived from the average earnings of workers in a supported employment initiative in Newfoundland, adjusted for Ontario (HRDC 2001). Owing to lack of data, income for very dependent individuals was assumed to be 60% of the semi-dependent income. All earnings were converted to 2003 dollars. Sensitivity analyses performed also varied IBI efficacy rates and discount rates to compensate for potential estimation uncertainties and methodological controversies (Drummond et al. 1997). Additional sensitivity analyses varied the cost of IBI, adult care costs and number of dependency-years, but did not significantly affect the results presented.

Results

The annual cost during the intervention period (age two to five) for each autistic child was \$5,378 for *No Intervention*, \$33,414 for *Status Quo* and \$81,048 for *Expansion* (Table 2). The annual cost during schooling (age five to 18) was \$6,616 for normal, \$21,422 for semi-dependent and \$38,672 for very dependent individuals. No costs were incurred during adulthood for normal-functioning individuals. The annual cost during adulthood (age 18 to 65) was \$37,380 for semi-dependent adults and \$75,648 for very dependent adults. The average total discounted cost per individual, based on a weighted average of normal, semi-dependent and very dependent costs

over the study time horizon, was \$1,014,315 for No Intervention, \$995,074 for Status Quo and \$960,595 for Expansion. The cost of Status Quo was lower than the cost of No Intervention, indicating that the present provision of IBI was preferable to providing no IBI at all. While significant costs were incurred under all scenarios, the cost of Expansion was lowest, resulting in savings of \$34,479 per individual over his or her lifetime compared to Status Quo. Expansion of the current program to fund IBI for all autistic children (n = 1,309) in Ontario younger than six years of age results in net cost savings of \$45,133,011 for the government. The greatest number of dependency-free life years was gained under Expansion: 4.5 years per person compared to No Intervention and 2.8 years per person compared to Status Quo. Expansion is the dominant strategy, as it yields both a decrease in cost as well as gains in dependency-free years.

TABLE 2. Average costs per person of No Intervention, Status Quo and Expansion and cost savings from pair-wise comparisons								
		NOI	RMAL	SEMI-DE	PENDENT	VERY D	EPENDENT	
AGE RANGE	COST ITEM	ANNUAL COST (\$)	PV OF TOTAL COST (2003 \$)	ANNUAL COST (\$)	PV OF TOTAL COST (2003 \$)	ANNUAL COST (\$)	PV OF TOTAL COST (2003 \$)	
	IBI and other costs: No Intervention	5,378	15,211	5,378	15,211	5,378	15,211	
Intervention Age (2-5)	IBI and other costs: Status quo* OR	33,414	94,516	33,414	94,516	33,414	94,516	
	IBI and other costs: Expansion	81,048	229,252	81,048	229,252	81,048	229,252	
Schooling Age (5-18)	Education and Respite Services	6,616	64,393	21,422	208,490	38,672	376,372	

continued

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

Adulthood (18-65)	Day programs, residential costs, and assisted employ- ment pro- gram costs	0	0	37,380	588,568	75,648	1,191,110
	No Intervention		\$ 79,604		\$ 812,269		\$ 1,582,693
Total cost	Status quo Expansion		\$ 158,909 \$ 293,645		\$ 891,574 \$ 1,026,310		\$ 1,661,998 \$ 1,796,734
Average cost per			\$1,014,315				
No Intervention † Average cost per Status quo ‡			\$ 995,074				
Average cost per Expansion **	individual (PV):		\$ 960,595				
Incremental cost : No Intervention -	savings per individual:		\$ 19,241				
	savings per individual:		\$ 53,720				
Incremental cost : Status quo → Ex	savings per individual: pansion		\$ 34,479				
Cost savings for c No Intervention -	ohort (n=1,309): → Status quo		\$ 25,186,469				
Cost savings for c No Intervention -	ohort (n=1,309): → Expansion		\$ 70,319,480				
Cost savings for c Status quo → Ex	ohort (n=1,309):		\$ 45,133,011				

Sensitivity analyses

The cost-effectiveness model was run with productivity costs to examine the economic impact of IBI from a partial societal perspective. Inclusion of productivity costs incurred by semi- and very dependent adults resulted in increased cost savings from Expansion of \$54,757 per person and \$71,676,776 for the entire cohort compared to Status Quo.

[#] Based on a weighted average: 25% normal, 25% semi-dependent, 30% very dependent # Based on a weighted average: 26.9% normal, 34.3% semi-dependent, 38.9% very dependent

^{**} Based on a weighted average: 30% normal, 50% semi-dependent, 20% very dependent

TABLE 3. I	TABLE 3. Results of sensitivity analysis varying the efficacy of IBI								
			DECREASED EFFICACY	BASELINE CASE	INCREASED EFFICACY				
		Normal	25.0%	30.0%	40.0%				
	Expansion	Semi-dependent	50.0%	50.0%	50.0%				
		Very dependent	25.0%	20.0%	10.0%				
Efficacy									
rates		Normal	25.0%	26.9%	30.6%				
	Status quo	Semi-dependent	34.3%	34.3%	34.3%				
		Very dependent	40.7%	38.9%	35.2%				
Results	Incremental sa Status quo →	vings (cost) per individual: Expansion	\$ (13,493)	\$ 84,031	\$ 128,433				
Results	Discounted de Status quo →	ependency-free years gained: Expansion	2.0 years	2.8 years	4.4 years				

IBI efficacy was modified to accommodate controversy in the research literature (Table 3). When the efficacy of IBI was increased to 40% of subjects who achieve normal functioning, 50% achieving semi-dependent functioning and 10% achieving very dependent functioning, the cost savings from *Expansion* compared with *Status Quo* increased to \$128,433 per person. In contrast, under the assumption that IBI yielded efficacy rates of 25% for normal functioning, 50% for semi-dependent functioning and 25% for very dependent functioning, *Expansion* cost \$13,493 more per person compared to *Status Quo* and yielded gains of 2.0 dependency-free years per person. Results of the sensitivity analyses suggest that a significant drop in treatment efficacy from the base case scenario would be required in order to yield a net cost for achieving dependency-free years in this population.

Varying the discount rate modified the present value of the cost savings. With a discount rate of 1%, cost savings from *Expansion* were even greater than those realized in the base case. Cost savings were not realized with a discount rate of 5%: it cost \$29,912 more per person to expand from *Status Quo* to *Expansion*, but gains of 1.8 dependency-free years per person were still realized under *Expansion*.

Discussion

The results demonstrate that expansion of the IBI program, which currently serves 485 children (*Status Quo*), to all 1,309 autistic children in Ontario (*Expansion*) would

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

yield savings of \$45,133,011 over the entire cohort's lifetime (from two to 65 years of age). Significant costs are incurred under both *Status Quo* and *Expansion*; however, under *Expansion*, the government would spend \$45 million less on autistic individuals when compared with *Status Quo*.

The cost of expanding IBI to all autistic individuals is small (less than 10% of total costs) compared to the significant cost of educating and supporting semi-and very dependent individuals over their lifetime. The present value of total costs incurred during intervention (ages two to five), including respite services and speech and language therapy, is higher for *Expansion* (\$229,252 per person) compared with *Status Quo* (\$94,516 per person). However, the larger intervention cost under *Expansion* yields lower support costs during schooling and adulthood (ages five to 65) compared to *Status Quo*. The primary reason for cost savings from expansion of IBI, from *No Intervention* to *Status Quo* and from *Status Quo* to *Expansion*, is the change in the distribution of functional dependence. Increased provision of IBI results in a shift of individuals from the very dependent to semi-dependent category and, to a lesser extent, from the semi-dependent to the normal-functioning group.

To guard against criticisms of previous economic evaluations (Marcus et al. 2000), IBI efficacy rates in this study were deliberately conservative. The proportion of children who attain normal functioning from IBI was set lower, and the proportion of children who function normally without IBI was set higher, than the proportions cited in the literature (Jacobson et al. 1998; Hildebrand 1999). As a result, cost savings realized under this model (\$34,479 per individual for *Expansion* vs. *Status Quo* and \$53,720 per individual for *Expansion* vs. *No Intervention*) are lower than those reported by previous studies (Jacobson et al. 1998; Hildebrand 1999). Lower normalization rates under *No Intervention* and higher normalization rates from IBI would yield more favourable results for expansion of the current IBI program in Ontario.

Although the costing data utilized in this study are specific to Ontario, our findings may be generalized to inform health policy decisions in other jurisdictions. The increased awareness of intensive behavioural intervention and its high program cost have made the financing of IBI and its cost-effectiveness relevant concerns for governments and other payer organizations. The grounding of our model parameters in peer-reviewed research evidence and the scope of the sensitivity analyses make our findings relevant for policy decision-makers.

Limitations

Several study limitations should be noted. First, only costs borne by the Ontario government were included in this economic evaluation; hence, costs borne by other payers, including autistic individuals, their families and employers, were not considered. Inclusion of such cost items as opportunity costs, quality of life of families and unpaid

caregiver expenses could potentially increase the savings realized under Expansion (Curran et al. 2001; Jarbrink and Knapp 2001; Jarbrink et al. 2003). Second, expansion of the IBI program may result in higher average costs per child in the short term due to shortage of qualified IBI therapists in the province and the resulting increase in their earnings. Third, this model assumed that all children initiated IBI at the age of two. However, children may be diagnosed with autism at later ages. Because of age restrictions currently enforced by the Ontario government, these children may not receive IBI for the full three-year period. This contingency may affect the efficacy of the treatment and the associated IBI costs incurred. Fourth, the 485 children currently receiving government-funded IBI in Ontario were assumed to be representative of the entire cohort of autistic children. Fifth, while healthcare utilization might be related to the level of functioning, we did not have access to such data and, hence, the cost-effectiveness analysis does not include these costs. However, since utilization may increase with the level of dependence, the cost savings identified in this study would increase if healthcare utilization were included. Sixth, the provincial government provided only aggregate costs for its entire IBI program, resulting in the very high annual IBI therapy cost of \$75,670 per child. This figure includes the operating costs associated with the launch of the IBI program in Ontario, including a large training component for new IBI therapists. As a result, costs per child are expected to decrease in coming years as start-up costs diminish. Finally, every attempt was made to obtain accurate costing information. However, in the absence of reliable estimates, costs from other jurisdictions within Canada, and costs for developmentally disabled people in general, were used to represent costs incurred for autistic individuals in Ontario.

Conclusion

This economic evaluation demonstrates positive outcomes from expansion of the current IBI program offered by the Ontario government. In the absence of high-quality evidence on the efficacy of IBI, but under reasonable assumptions, estimated cost savings in present-value terms associated with this expansion were \$45 million for the government, with potential improvement in the quality of life of autistic individuals and their families because of increased dependency-free years gained under *Expansion*. These cost savings and improvements in outcomes were largely maintained in the sensitivity analyses. However, savings to government disappeared when the annual discount rate of 5% was used or when IBI was assumed to be less effective than in the base case scenario, with *Expansion* resulting in 25%, 50% and 25% of individuals in normal, semi-dependent and very dependent categories (compared to 30%, 50% and 20% in the base case), respectively. Owing to uncertainty surrounding the efficacy of IBI, further study in the area is recommended, perhaps in the form of a randomized, controlled trial, to allow more definitive economic evaluations in the future.

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

ACKNOWLEDGMENTS

S.S. Motiwala and S. Gupta were partially funded by Canadian Institutes of Health Research (CIHR)/Canadian Health Services Research Foundation (CHSRF) Research Training Awards. M.B. Lilly is supported by the CIHR Strategic Research Training Program in Healthcare, Technology and Place, and a CHSRF/CIHR Chair in Health Services Research Trainee Award; Dr. Ungar is supported by a New Investigator Career Award from CIHR; Dr. Coyte is supported by funds from CHSRF/CIHR and the Ontario Ministry of Health and Long-Term Care for his Chair in Healthcare Settings and Canadians.

The opinions expressed in this paper are those of the authors and do not necessarily reflect the opinion of any funding agency or institution. The authors would like to thank Marianna Ofner for her useful comments on an earlier draft of this paper.

Correspondence may be directed to: Dr. Peter C. Coyte, Department of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto, 155 College Street, Suite 425, Toronto, ON M5T 3M6; tel.: 416-978-8369; fax 416-978-7350; email: peter. coyte@utoronto.ca.

REFERENCES

American Psychiatric Association. 1994. Diagnostic and Statistical Manual of Mental Disorders (4th ed.). Washington, DC: Author.

Bassett, K., C. Green and A. Kazanjian. 2000. Autism and Lovaas Treatment: A Systematic Review of Effectiveness Evidence. Vancouver: BC Office of Health Technology Assessment, University of British Columbia.

BBB Autism Support Network. 1999. "Sample Requests for Services. Special Services at Home Program." Retrieved December 7, 2005. http://www.bbbautism.com/ssah_acsd_guidelines. htm>.

Canadian Legal Information Institute. 1997. Ontario Disability Support Program Act, 1997. Retrieved December 7, 2005. http://www.canlii.org/on/laws/sta/1997c.25sch.b/index.html.

Curran, A.L., P.M. Sharples, C. White and M. Knapp. 2001. "Time Costs of Caring for Children with Severe Disabilities Compared with Caring for Children without Disabilities." Developmental Medicine and Child Neurology 43: 529–533.

Dawson, G. and J. Osterling. 1997. "Early Intervention in Autism." In M.J. Guralnick (ed.), The Effectiveness of Early Intervention (pp. 307–326). Baltimore: Paul H. Brooks.

Drummond, M.F., B. O'Brien, G.L. Stoddart and G.W. Torrance. 1997. Methods for the Economic Evaluation of Health Care Programmes (2nd ed.). Oxford: Oxford University Press.

Freeman, B.J. 1997. "Guidelines for Evaluating Intervention Programs for Children with Autism." Journal of Autism and Developmental Disorders 27: 644–645.

Gillberg, C. and M. Coleman. 2000. The Biology of the Autistic Syndromes (3rd ed.). London: MacKeith Press.

Green, C., K. Bassett and A. Kazanjian. 2002. Critical Appraisal of Submitted Cost-Benefit Models for Lovaas's Early Intensive Behavioural Intervention for Autism. Victoria: BC Office of Health Technology Assessment, Centre for Health Services and Policy Research.

Hildebrand, D. 1999. Cost–Benefit Analysis of "Lovaas" Treatment for Autism and Autism Spectrum Disorder (ASD). Preliminary report prepared for Harper Grey Easton, Barristers and Solicitors. Vancouver: Columbia Pacific Consulting.

Howlin, P. 1997. "Prognosis in Autism: Do Specialist Treatments Affect Long-Term Outcomes?" European Children and Adolescents Psychiatry 6: 56.

Howlin, P. 1998. Children with Autism and Asperger Syndrome – A Guide for Practitioners and Carers. Chichester, UK: John Wiley & Sons.

Howlin, P., S. Goode, J. Hutton and M. Rutter. 2004. "Adult Outcomes for Children with Autism." *Journal of Child Psychology and Psychiatry* 45: 212–229.

Human Resources Development Canada (HRDC). 1999. Lessons Learned from Evaluations of Disability Policy and Programs. Retrieved December 7, 2005. http://www11.hrdc-drhc.gc.ca/pls/edd/DPPTR_81000.htm.

Human Resources Development Canada (HRDC). 2001. Supported Employment Initiative – Summative Evaluation Final Report. Retrieved December 7, 2005. http://www.releases.gov.nl.ca/releases/2002/hre/0509n15Report.pdf.

Jacobson, W.J. and A.J. Mulick. 2000. "System and Cost Research Issues in Treatments for People with Autistic Disorders." Journal of Autism and Developmental Disorders 30: 585–593.

Jacobson, W.J., A.J. Mulick and G. Green. 1998. "Cost–Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case." *Behavioral Interventions* 13: 201–226.

Jarbrink, K., E. Fombonne and M. Knapp. 2003. "Measuring the Parental, Service and Cost Impacts of Children with Autistic Spectrum Disorder: A Pilot Study." *Journal of Autism and Developmental Disorders* 33(4): 395–402.

Jarbrink, K. and M. Knapp. 2001. "The Economic Impact of Autism in Britain." *Autism* 5(1): 7–22.

Lovaas, O.I. 1987. "Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children." *Journal of Consulting Clinical Psychology* 55: 3–9.

Ludwig, S. and C. Harstall. 2001. Intensive Intervention Programs for Children with Autism. Health Technology Assessment Report. Edmonton: Alberta Heritage Foundation for Medical Research.

Marcus, L.M., J.S. Rubin and M.A. Rubin. 2000. "Benefit-Cost Analysis and Autism Services: A Response to Jacobson and Mulick." *Journal of Autism and Developmental Disorders* 30(6): 595–598.

McEachin, J.J., T. Smith and O.I. Lovaas. 1993. "Long-Term Outcome for Children with Autism Who Received Early Intensive Behavioural Treatment." *American Journal of Mental Retardation* 97: 359–372.

Ontario Agencies Supporting Individuals with Special Needs (OASIS). 2000. "How Agencies Use Their Resources for Administration and Direct Support." Retrieved December 7, 2005. http://www.oasisonline.ca/pages/pdf/admincoststudy.pdf.

Ontario Health Insurance Program (OHIP). 2000. Review of OHIP Databases with Respect to Autism: Ministry of Health Report, Assessment of Autistic Children. Toronto: Ontario Ministry of Health.

Ontario Ministry of Children's Services (MCS) and Ontario Ministry of Community and Social Services (MCSS). 2003 (December). *Intensive Early Intervention Program (IEIP) Source Document*. Presented by the Ontario Government in the case of *Wynberg v. Ontario*.

The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario

Ontario Ministry of Community, Family and Children's Services (MCFCS). 2000. Integrated Services for Children Division. Program Guidelines for Regional Intensive Early Intervention Programs for Children with Autism. Toronto: Author.

Ontario Ministry of Community and Social Services (MCSS). 2001. Community Accommodation Program. Provincial Auditor's Report, Follow-up to VFM Section 3.04, 1999 Annual Report. Retrieved December 7, 2005. http://www.auditor.on.ca:81/isysquery/irl1088/3/doc>.

Ontario Ministry of Community and Social Services (MCSS). 2002. "Intensive Early Intervention Services for Children with Autism - Questions and Answers." Letter dated January 25, 2002.

Ontario Ministry of Education. 2000 (March). "Fact Sheet: Special Education Grant." Retrieved December 7, 2005. http://www.edu.gov.on.ca/eng/document/nr/00.03/fs2.html.

Ontario Ministry of Education. 2001a. "Student-Focused Funding: School Board Funding Projections for the 2001–2002 School Year." Retrieved December 7, 2005. http://www.edu.gov. on.ca/eng/funding/fund0102.html>.

Ontario Ministry of Education. 2001b. "Intensive Support Amount (ISA) Guidelines for School Boards." Ministry of Education, Student-Focused Funding. Retrieved December 7, 2005. http:// www.edu.gov.on.ca/eng/funding/t4.html>.

Ontario Ministry of Education. 2001c. "Parents Guide 2001–2002 – Student-Focused Funding." Retrieved November 18, 2002. http://www.edu.gov.on.ca/eng/funding/guide02.pdf>.

Rutter, M. 1996. "Autism Research: Prospects and Priorities." Journal of Autism and Developmental Disorders 26: 257–275.

Sallows, G. and G. Graupner. 2001 (May). "Replicating Lovaas: Results After Three Years." Proceedings of the 27th Annual Convention of the Association for Behavior Analysis, New Orleans, LA.

Sheinkopf, S. and B. Sigel. 1998. "Home-Based Behavioral Treatment of Young Children with Autism." Journal of Autism and Developmental Disorders 28: 15–23.

Smith, T. 1999. "Outcome of Early Intervention for Children with Autism." Clinical Psychology and Scientific Practice 6: 33-49.

Statistics Canada. 1996. "Average Earnings of the Population 15 Years and Over in 1995 by Highest Level of Schooling: Census 1996, Ontario and Newfoundland and Labrador Data." Ottawa. http://www.statscan.ca.

Statistics Canada. 1999. "Occupational Summary Table (Ontario): Ontario Wage Survey." Retrieved December 7, 2005. http://www.statscan.ca.

Statistics Canada. 2001a. "2000 Canadian Average Earnings by Sex and Work." Ottawa. http:// www.statscan.ca>.

Statistics Canada. 2001b. "2000 Population Data in Ontario: Census 2000." Ottawa. http:// www.statscan.ca>.

Statistics Canada. 2001c. "Labour Force Participation Rates in Canada." Ottawa. .

Waiting Time for Radiation Therapy in Breast Cancer Patients in Quebec from 1992 to 1998

Temps d'attente pour la radiothérapie chez les femmes atteintes de cancer du sein au Québec de 1992 à 1998

A study of surgically treated breast cancer patients in Quebec documents and helps to explain increased waiting times for radiation therapy.



by BERNARD FORTIN, MD, FRCPC

Department of Epidemiology, Biostatistics, and Occupational Health, McGill University Department of Radiation Oncology, Centre Hospitalier de l'Université de Montréal

MARK S. GOLDBERG, PHD

Department of Epidemiology, Biostatistics, and Occupational Health, McGill University
Division of Clinical Epidemiology, McGill University Health Centre
Department of Medicine, McGill University
Department of Oncology, McGill University

NANCY E. MAYO, PHD

Department of Epidemiology, Biostatistics, and Occupational Health, McGill University
Division of Clinical Epidemiology, McGill University Health Centre
Department of Medicine, McGill University

MARIE-FRANCE VALOIS, MSC Department of Medicine, McGill University

SUSAN C. SCOTT, MSC Division of Clinical Epidemiology, McGill University Health Centre

JAMES HANLEY, PHD

Department of Epidemiology, Biostatistics, and Occupational Health, McGill University
Division of Clinical Epidemiology, McGill University Health Centre
Department of Medicine, McGill University

Abstract

Background: This study was conducted among surgically treated breast cancer patients in Quebec to determine waiting time between surgery and post-operative radiation therapy and factors influencing it.

Methods: Records of fee-for-service claims and hospitalizations were obtained for all women who, between 1992 and 1998, underwent an invasive procedure for non-metastatic breast cancer. Waiting time was defined as the time between either the last surgical procedure or the last cycle of chemotherapy and the initiation of radiation therapy. Hierarchical linear regression models were used to identify predictors of waiting time.

Results : Over seven years, 29,072 episodes of breast cancer treatments were identified, of which 17,684 included radiation therapy. The number of cases increased by 5.5% per year, but concurrent broadening of indications for radiation therapy led to an increase in the number of breast cancer patients receiving radiation therapy of 9% per year. In hierarchical linear modelling, comparing 1998 to 1992, median waiting time increased by 63% (95% confidence interval [CI] 35%–97%) in patients not receiving chemotherapy and by 35% (95% CI 3%–88%) in patients receiving chemotherapy. Other predictors of shorter waiting times were localized cancer stage, breast-conserving surgery, early consultation with a radiation oncologist, having surgery in a centre with a radiation therapy facility, living close to a radiation therapy facility and living in a higher socio-economic area.

Interpretation : Using administrative databases to evaluate waiting times is feasible. Explanations of the increased waiting time include increased demand, insufficient resources and changes in the indications for breast-conserving surgery and radiation therapy.

Résumé

Contexte: Cette étude a été menée auprès de femmes atteintes du cancer du sein et qui ont reçu un traitement chirurgical au Québec en vue de déterminer le temps d'attente entre la chirurgie et la radiothérapie postchirurgicale, ainsi que les facteurs influençant le temps d'attente.

Méthodes: Nous avons obtenu les données sur les demandes de paiement d'honoraires à l'acte et les hospitalisations pour toutes les femmes qui ont subi une intervention chirurgicale invasive pour un cancer du sein sans métastase entre 1992 et 1998. Le temps d'attente a été défini comme étant le délai entre la dernière intervention chirurgicale ou le dernier cycle de chimiothérapie et le début du traitement de radiothérapie. Des modèles de régression linéaire hiérarchique ont été utilisés pour déterminer les facteurs de prédiction du temps d'attente.

Résultats: Sur une période de sept ans, 29,072 épisodes de traitement contre le cancer du sein ont été répertoriés, dont 17,684 comportaient une radiothérapie. Le nombre de cas a augmenté de 5,5 % par an, mais une hausse concomitante des recommandations de traitement de radiothérapie a entraîné une augmentation de 9 % du nombre de femmes atteintes du cancer du sein qui reçoivent un tel traitement. Lorsqu'on compare 1998 à 1992, le temps d'attente moyen a augmenté de 63 % (intervalle de confiance [IC] de 95 % : 35 à 97 %) chez les patientes n'ayant pas besoin de chimiothérapie et de 35 % (IC de 95 % : 3 à 88 %) chez celles qui reçoivent des traitements systémiques. Parmi les autres facteurs permettant de prédire un temps d'attente plus court, citons le cancer localisé, le traitement chirurgical conservateur, la consultation précoce d'un oncoradiologiste, la chirurgie dans un centre offrant des traitements de radiothérapie, le fait de résider à proximité d'un centre de radiothérapie et l'appartenance à un milieu socio-économique plus favorisé.

Interprétation: Il est possible d'utiliser des bases de données administratives pour évaluer le temps d'attente. Parmi les raisons pouvant expliquer l'augmentation du temps d'attente, citons la demande accrue, les ressources insuffisantes et les changements dans les recommandations de traitement chirurgical conservateur et de radiothérapie.

URING THE LAST 20 YEARS, THE MANAGEMENT OF BREAST CANCER HAS changed dramatically. With screening, tumours are smaller, and randomized controlled trials have shown equivalence between mastectomy and breast-conserving surgery followed by radiation therapy (Verkonesi et al. 1990; Sarrazin et al. 1989; van Dongen et al. 1992; Blichert-Toft et al. 1992; Jacobson et al. 1995; Fisher et al. 2002). This, combined with the aging of the population (Wiener and Tilly 2002; Gouvernement du Québec 2001), has generated a continually increasing demand for

radiation therapy in treating breast cancer. There are concerns that this increasing demand will reduce the availability of radiation treatments (Mackillop et al. 1995; Benk et al. 1998; Mackillop et al. 1994; Mayo et al. 2001).

Increased waiting times may be important, as the local recurrence rate after conservative surgery and radiation therapy appears to be about 5% but is 20% to 50% after conservative surgery alone (Fisher et al. 2002). However, there is no consensus as to the optimal time to offer radiation.

... researchers surveyed major radiation centres in the United States and in Canada ... the median waiting time before radiation therapy was 40 days in the United States and 73 days in Canada.

We knew from a recently published study (Mayo et al. 2001) that waiting times for the surgical component of breast cancer treatment were increasing in Quebec. An earlier report from Ontario on wait times for radiotherapy also depicted a situation that was deteriorating over time (Mackillop et al. 1994). In 1991, the median time between the

completion of surgery and initiation of post-operative radiation for breast cancer was 57.8 days – an increase of 102.7% compared to 1982. In 1994, the same researchers surveyed major radiation centres in the United States and in Canada (Mackillop et al. 1995). Their study showed that the median waiting time before radiation therapy was 40 days in the United States and 73 days in Canada. A report from a single centre in Quebec in 1992 showed a median waiting time of 68 days (Benk et al. 1998). Some literature from Europe suggests that waiting times are comparable to those seen in the United States, with a Spanish report showing an overall maximum waiting time of only 60 days for all cancer types and centres in that country (Esco et al. 2003).

Because of the concerns about availability of services, we conducted the present study to estimate secular trends in waiting time for radiation therapy after breast cancer surgery and to identify factors that may influence waiting time.

Subjects and Methods

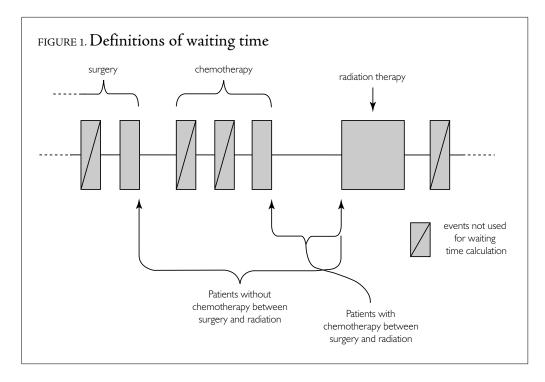
This study was approved by the McGill University Faculty of Medicine Institutional Review Board and by the Commission d'accès à l'information du Québec. It was population based and included all women aged 20 years and over who had an invasive procedure for the diagnosis or treatment of breast cancer in the province of Quebec between 1992 and 1998.

We used the database of physician fee-for-service claims maintained by the Régie de l'Assurance Maladie du Québec (RAMQ) to obtain data on diagnostic and surgical procedures related to the breast including chemotherapy, radiotherapy and visits to radio-oncologists. This was possible because all these procedures have specific codes and are performed by specific specialists, namely, surgeons, oncologists and radiation oncologists, who have unique specialty identifiers. The validity of the RAMQ database has been verified and shown to be high in another setting (Tamblyn et al. 2000). Since no radiation therapy facility in Quebec is private and doctors must bill specific procedure codes to the RAMQ in order to get paid, completeness of the data was expected to be high. During the study period, all breast cancer related procedures were performed in day surgery, thus requiring hospitalization. For that reason, the hospital discharge file (MedEcho) was used to capture additional details concerning the treatments and any missing breast cancer episodes. MedEcho is a mandatory database concerning all the procedures performed during hospital stays. For confidentiality reasons, the only personal patient information provided in the dataset from RAMQ was the women's age in 1992, in five-year categories.

We made use of prior (1980–1991) and subsequent (1999) data to avoid truncating episodes that spanned administrative time periods. The 1996 Canadian census database was used to obtain, for each Forward Sorting Area (first three characters of the postal code), the median income (categorized as high if the median income was higher than the 75th percentile), the proportion of households in which one or more persons had completed high school (categorized as "educated" if more than two-thirds of households in the area included at least one person with a high school diploma) and the distance of the patient's residence to the nearest radiation therapy facility (categorized as 0–100 km, 101–400 km and \geq 401 km because the often very wide geographical area covered by each Forward Sorting Area did not permit finer stratification). There were 10 radiation therapy centres in Quebec in 1991, and three new centres were opened in the province during the study period.

Since routine mammograms are usually spaced at intervals of at least six months, we considered consecutive surgical procedures to the breast that were separated in time by five months or less to be related to a single breast cancer that was operated on more than once (e.g., the biopsy, the definitive surgery and then a re-excision for positive surgical margins) and not to multiple breast cancers. Any non-surgical treatments delivered later than one year after breast cancer surgery were considered not to be related to that surgical procedure but rather to another cancer event. Topography and morphology codes listed in the hospital discharge database were used to estimate the stage of breast cancer.

Only episodes including breast surgery followed by adjuvant radiotherapy were retained. Excluded were episodes with a diagnosis of disseminated disease, with localized breast cancer occurring after an episode for metastatic cancer and where radio-



therapy was begun before surgery.

For patients who did not receive chemotherapy between their surgery and radiation therapy, waiting time was calculated as the number of days between the last surgery in an episode (accounting for possible multiple surgeries) and radiotherapy. For patients who received chemotherapy, the time before the end of the chemotherapy was considered as part of planned treatment and, thus, the waiting time was calculated as the time from the last post-operative chemotherapy code to the initiation of radiation therapy (Figure 1).

Statistical methods

Secular trends were analyzed using simple linear regression and logistic regression. To evaluate factors associated with waiting time, hierarchical linear regression models were used. We used the natural logarithm scale for waiting time because it was lognormally distributed. We used hierarchical models because waiting times may be more similar for patients treated in a given hospital (Bryk and Raudenbush 1992). We used a two-level hierarchical model to try to isolate the effects of individual-level variables on waiting time (e.g., tumour stage, type of surgery) from the variation in waiting times explained by the radiation therapy centres' differing waiting lists. This model allowed each radiation therapy centre to have its own median value for waiting time. The effect of any individual-level variable was then analyzed according to that centrespecific median.

All statistical tests were two-sided. The reported confidence intervals (CI) were evaluated at the 95% level, and all covariates were adjusted for the others in the retained model.

Results

Demographic characteristics

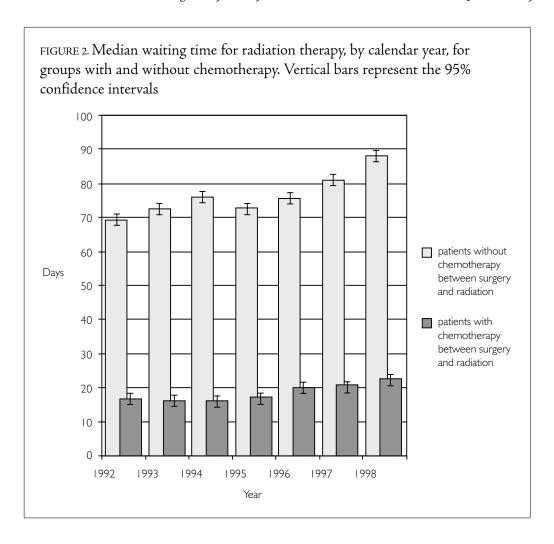
Between 1992 and 1998, there were 30,446 episodes of surgically treated breast cancers among 27,734 patients. Of these, 1,374 episodes were metastatic, thus leaving 29,072 cancer episodes for analysis.

Table 1 shows that the distributions of age and stage of breast cancer were fairly stable during the study period. Apparent changes in the age distribution over time are

TABLE 1. Selected								
episodes among 1992 and 1998	the 27,734	patier	its sur	gically	treate	d in Q	uebec	between
	Total (%)	1992	1993	1994	1995	1996	1997	1998
Women's age in 1992		%	%	%	%	%	%	%
20–34	1488 (5.1)	2.6	3.6	3.9	4.8	5.9	6.2	7.5
35–49	8968 (30.9)	25.4	28.4	28.9	30.5	31.6	34.1	34.6
50–64	10 092 (34.7)	33.5	33.7	34.6	34.8	35.1	34.8	36.0
65–79	7364 (25.3)	31.3	28.3	27.6	25.7	24.5	22.5	20.3
≥ 80	1160 (4.0)	7.3	6.1	4.9	4.2	2.9	2.4	1.6
Cancer stage								
Benign In situ	199 (0.7)	0.6	0.8	0.9	0.7	0.6	0.5	8.0
Localized	19 336 (66.51)	66.2	67.0	66.8	65.4	66.6	66.5	67.0
Regional	7431 (25.6)	28.4	26.8	26.7	26.4	24.8	24.1	23.1
Unspecified Surgery in a centre	2106 (7.2)	4.8	5.3	5.7	7.5	8.1	8.8	9.1
with a radiation therapy service Highest quartile	8420 (29.0)	29.9	29.5	28.2	28.3	29.8	29.0	29.1
for median income	5846 (24.8)	22.9	24.2	24.9	24.2	25.6	26.0	28.3
Residential distance								
from a radiation								
therapy centre								
0–100 km	25 960 (89.4)	88.5	89.8	89.8	88.8	89.0	89.6	89.9
101–400 km	2933 (10.1)	10.9	9.8	9.6	10.6	10.4	10.0	9.7
≥401 km	158 (0.5)	0.5	0.4	0.7	0.7	0.6	0.5	0.5

TABLE 2. Distribution of the number of cases by type of treatment and calendar year								
	1992	1993	1994	1995	1996	1997	1998	Average absolute annual change (95% CI)*
Total number of cases	3532	3675	3904	4062	4231	4503	5165	5.5% (3.7 to 7.4)
Proportion with breast-conserving surgery	78%	78%	78%	80%	81%	80%	82%	0.7% (0.3 to 1.1)
Number receiving radiotherapy, any surgery	1966	2125	2306	2393	2592	2886	3398	9.0% (5.7 to 12.4)
Proportion receiving radiotherapy, any surgery	56%	58%	59%	59%	61%	64%	68%	1.8% (1.2 to 2.4)
Radiotherapy given, breast-conserving surgery episodes only	1783 (65%)	1963 (68%)	2125 (70%)	2217 (68%)	2410 (70%)	2681 (75%)	3279 (77%)	1.8% (1.0 to 2.6)
Radiotherapy given, mastectomy episodes only	183 (23%)	162 (20%)	181 (21%)	176 (22%)	182 (22%)	205 (22%)	219 (24%)	0.3% (-0.3 to 0.8)
Proportion receiving chemotherapy	27%	26%	25%	25%	25%	27%	28%	0.3% (-0.4 to 1.0)
*Modelled using simple linear regressi	ion							

explained by the fact that age was provided in the database as the patient's five-year age category in 1992 rather than when she was diagnosed. Table 2 shows that there was a statistically significant average increase in the number of breast cancer cases (5.5% per year, 95% CI 3.7%–7.4%), in the proportion of patients treated with breast-conserving surgery (average of 0.7% per year, 95% CI 0.3%–1.1%) and in the number of patients receiving radiation (9% per year; 95% CI 5.7%–12.4%). For patients treated with breast-conserving surgery, the proportion of subjects receiving radiation increased from 65% to 77% (annual increase of 1.8%; 95% CI 1.0%–2.6%). The overall use of chemotherapy (26% of patients) and radiation therapy for patients treated with mastectomy (22%) was stable.



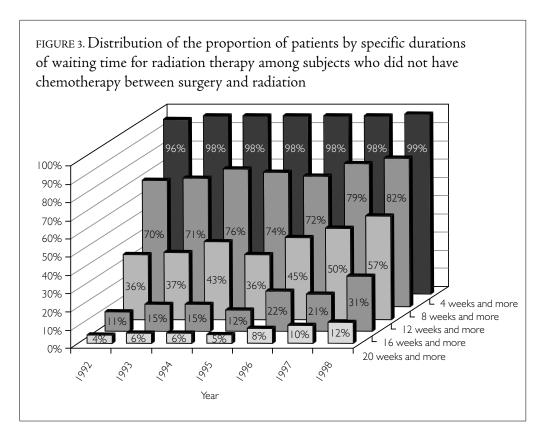
Waiting time for radiation therapy

Post-operative radiation therapy was provided in 17,684 (60.8%) of the cancer episodes. Of these, 4,821 contained an indication that chemotherapy was received after surgery and before radiation.

Figure 2 shows the median and 95% CI of the waiting time, by year of treatment, for the group without chemotherapy and for the group with chemotherapy. For the former group, the median waiting time was 69 days in 1992 and 88 days (28% longer) in 1998; for the group receiving post-surgery chemotherapy, the median waiting time was 17 days in 1992 and 22 days (32% higher) in 1998.

For patients not receiving chemotherapy, the unadjusted proportion of patients having to wait more than eight weeks before radiation therapy increased from 70% in 1992 to 82% in 1998 (Figure 3). If a 12-week cut-off is used, the proportion increased from 36% in 1992 to 57% in 1998.

Tables 3 and 4 show the predictors of waiting time, expressed as the percentage



change in the median. The effect estimates of the patient-specific covariates are provided in the first column and the estimated between-centre variation in the patientspecific covariates effects is presented in the second column.

In the non-chemotherapy group (Table 3), waiting times between 1992 and 1998 increased on average by 63%. There was considerable variation by radiation centre, explaining 30% of the variability in waiting times. For example, the 95% confidence interval for the mean change (63%) between 1992 and 1998 in median wait times across centres was -11% to +199%. The large variability is due partly to the opening of radiation centres (with shorter waiting times) in the later years. Individual-level factors associated with waiting time were regional cancer spread (9% increase), having had a mastectomy instead of breast-conserving surgery (25% increase), living farther than 100 km from a radiation therapy centre (10% increase), seeing a radiation oncologist before having surgery (30% decrease), having surgery in a centre where there is a radiotherapy service (13% decrease) and coming from an area in which the average level of education is higher (3% decrease). The individual-level variables in the model explained a small part (15%) of the variation in waiting times. The only centre-specific variable that contributed to the model was the proportion of patients from a highincome area (2% decrease for each 10% increase). The number of patients that the centres treated per year did not influence waiting times.

TABLE 3. Predictors of waiting time for radiotherapy in the group not receiving chemotherapy

	Hierarchi	cal modelling
Patient-level predictors:	% change in median waiting time (95% CI)	•
1993 vs. 1992	9% (2 to 16%)	-10 to 31%
1994 vs. 1992	10% (1 to 21%)	-16 to 45%
1995 vs. 1992	5% (-8 to 20%)	-30 to 59%
1996 vs. 1992	12% (0 to 24%)	-20 to 55%
1997 vs. 1992	14% (-4 to 37%)	-36 to 103%
1998 vs. 1992	63% (35 to 97%)	-11 to 199%
Regional cancer spread	9% (4 to 14%)	-5 to 25%
For mastectomy vs. breast-conserving surgery	25% (15 to 36%)	-3 to 61%
If seen pre-op by a radio-oncologist	-30% (-37 to -23%)	-48 to -6%
If surgery done in a centre where there is a radiotherapy service	-13% (-17 to -8%)	-25 to 2%
Living more than 100 km from a radiotherapy centre	10% (4 to 17%)	-8 to 32%
Living in an area where at least one person completed high school in 2/3 of households	-3% (-5 to −1%)	–6 to 1%
Missing information for household education	-20% (-32 to -4%)	-53 to 39%
Hospital-level predictors:		
Proportion of patients from high median income area, per 10% increase	-2% (-3 to -1%)	n.a.
n.a.: not applicable; CI: confidence interval		

For the chemotherapy group (Table 4), the radiation therapy centre at which a given patient was treated explained only 2% of the variation in waiting times, while the patient-level variables explained 10% of that variation. The association between individual-level variables and waiting time in this group was similar in direction to what was found in the non-chemotherapy group: regional cancer spread (28% increase), having had a mastectomy instead of breast-conserving surgery (31% increase) and having surgery in a centre with a radiotherapy service (-18%). A trend towards longer waiting times was found in the later years (35% longer in 1998 than in 1992). The parameters estimates in the chemotherapy group are less stable because the cohort was smaller.

TABLE 4. Predictors of waiting time for radiotherapy in the group receiving chemotherapy

	Hierarchical modelling						
Patient-level predictors:	% change in median waiting time (95% CI)	95% CI for mean change in median waiting times across RT centres					
1993 vs. 1992	5% (-10 to 23%)	-21 to 39%					
1994 vs. 1992	-5% (-27 to 24%)	-55 to 100%					
1995 vs. 1992	-3% (-29 to 31%)	-60 to 135%					
1996 vs. 1992	25% (-14 to 82%)	-60 to 287%					
1997 vs. 1992	19% (-17 to 72%)	-60 to 259%					
1998 vs. 1992	35% (-3 to 88%)	-50 to 269%					
Regional cancer spread	28% (15 to 43%)	-4 to 72%					
For mastectomy vs. breast-conserving surgery	31% (16 to 48%)	3 to 67%					
If surgery done in a centre where there is	-18% (-35 to 4%)	-61 to 74%					
a radiotherapy service							
CI: confidence interval							

Discussion

The main findings from this study are that waiting times for receiving radiation therapy after surgery for breast cancer increased over the study period. The increase in the group receiving chemotherapy is disturbing, because there should have been sufficient time to schedule radiotherapy during the planned delay of three to six months.

Most of the variation in waiting times cannot be explained by the available data. This result is not surprising given that this study is based on administrative databases that contain very little data on personal characteristics, medical histories and limited contextual variables. This should not, however, affect the validity of the findings. It was troubling to find an increase in waiting time by distance from the nearest radiation therapy centre. This finding may have been due to difficulties in communication between the treating surgeon and the radiation oncologist. Supporting this observation was a favourable effect on waiting time for patients who had surgery in a centre with a radiation therapy facility on site. These centres are located mainly within large tertiary centres. Some possible explanations for this effect include improved communication between specialists, faster access to diagnostic tests and higher volumes of patients treated by these surgeons.

Other factors adversely affecting waiting time were having had a mastectomy and having regional disease spread. The longer waiting time could have been due to longer

healing time after a more extensive surgery or to more thorough investigation and treatment for a more severe disease.

In addition, the effect of socio-economic status and education on waiting time, though small, was surprising considering the universal health insurance coverage in the province of Quebec. This finding may reflect an ability of some women to influence more timely treatment.

... physicians are paid on the basis of services rendered ... completeness and accuracy of reporting have monetary incentives attached.

Some radiation therapy centres performed better than others. Because each hospital designation code was encrypted, it is difficult to explore possible causes such as total radiation therapy workload, staff shortages and case mix. However, it is likely that some of the radiation centres were newly

created and thus may not have had the same backlog as the older ones. It also demonstrates that during the study period, patients could have waited less if they had been transferred from centres with long waiting lists to centres with shorter ones.

A strength of this study is that it is population based and that the data are robust: physicians are paid on the basis of services rendered, and completeness and accuracy of reporting have monetary incentives attached. Because of the universality of medicare, very few procedures would have been performed at private clinics and, thus, coverage of the data is close to 100%. The waiting times for radiation therapy reflected in this study are thus a precise depiction of the situation in Quebec between 1992 and 1998.

A limitation of this study is that these results cannot be used to distinguish system delays from patient delays, as our data sources contain only records for procedures performed by physicians. Nevertheless, in an oncology setting, the delay for which the patient is responsible is often only the time from the appearance of symptoms until the first contact with a healthcare professional, as subsequent diagnostic and therapeutic procedures are usually scheduled on behalf of the patient.

There are no data to suggest an optimal waiting time. As treatment decisions involve major life-altering choices for women, an "appropriate" amount of time is required to choose the best treatment approach (Coates 1999), and this may vary considerably among women. On the other hand, women and their families may face considerable anxiety because of delays. What is of more concern is that long waits may also affect recurrence and survival, as suggested by theory and experience with other cancer sites (Robertson et al. 1998; van der Voet et al. 1998; Petereit et al. 1995; Fortin et al. 2002).

There is only one randomized clinical trial (Recht et al. 1996) and few retrospective studies investigating the effects of delays on breast cancer control (Buchholz et al. 1993; Clarke et al. 1985; Nixon et al. 1994; Buzdar et al. 1993; Vujovic et al. 1998; Froud et al. 2000; Slotman et al. 1994; Recht et al. 1991; Hartsell et al. 1995). In the randomized trial, 244 patients with early breast cancer were assigned, after breastconserving surgery, to receive a 12-week course of chemotherapy given either before or after breast radiotherapy. There was lower overall survival (73% vs. 81%) and a higher incidence of distant metastasis (36% vs. 25%), but a lower rate of local recurrence (5% vs. 14%), in the group receiving radiotherapy early (thus delaying chemotherapy). These observations have led to the practice of prioritizing chemotherapy over radiation therapy for patients who require it.

A pooled analysis of the retrospective studies (Huang et al. 2003) compared local breast cancer recurrence rates for patients treated later than eight weeks to those receiving their post-operative radiation therapy within eight weeks. The pooled odds ratio of recurrence among patients treated later compared to those treated within eight weeks was 1.62 (95% CI 1.21-2.03), representing a 62% higher risk of recurrence among those receiving radiation more than eight weeks after surgery.

The existing data do not show a relationship between local cancer recurrence rates and survival. The usually slow tumour kinetics of breast cancer (which lead to underdetection of late recurrences in studies with short observation periods) and the option to perform a mastectomy in patients with local recurrence after breast-conserving surgery are possible explanations for this lack of obvious relationship between local recurrences and cancer death.

Because waiting time usually reflects accessibility to services, some measures have been implemented in the province since 1998 to address this issue - for example, centralized management of the waiting lists of all radiation therapy centres and transfer of patients to centres with shorter waiting lists, opening of new radiation therapy units and a significant increase in admissions to the radiation oncology residency program and the radiation technologist training programs.

One has to remain conscious, though, of the unrelenting increase in the total number of breast cancer cases over the years, as shown in this study. As a consequence, we believe that the problem of waiting lists must be kept under close scrutiny if we want to maintain the highest standards of cancer treatment for our population, and the available administrative databases provide a tool to do so.

Correspondence may be directed to: Dr. Bernard Fortin, Dept. of Radiation Oncology, Centre Hospitalier de l'Université de Montréal, 1560 Sherbrooke East, Montréal, QC H2L 4M1.

REFERENCES

Benk, V., V. Ho, P.R. Fortin, G. Zhang, C. Levinton and C.R. Freeman. 1998. "Predictors of Delay in Starting Radiation Treatment for Patients with Early Stage Breast Cancer." *International Journal of Radiation Oncology, Biology, Physics* 41(1): 109–115.

Blichert-Toft, M., C. Rose, J.A. Andersen, M. Overgaard, C.K. Axelsson, K.W. Andersen et al. 1992. "Danish Randomized Trial Comparing Breast Conservation Therapy with Mastectomy: Six Years of Life-Table Analysis." Danish Breast Cancer Cooperative Group. *Journal of the National Cancer Institute Monographs* 11: 19–25.

Bryk, A.S. and S.W. Raudenbush. 1992. Hierarchical Linear Models: Applications and Data Analysis Methods. Newbury Park: Sage Publications.

Buchholz, T.A., M.M. Austin-Seymour, R.E. Moe, G.K. Ellis, R.B. Livingston, J.G. Pelton et al. 1993. "Effect of Delay in Radiation in the Combined Modality Treatment of Breast Cancer." *International Journal of Radiation Oncology, Biology, Physics* 26(1): 23–35.

Buzdar, A.U., S.W. Kau, T.L. Smith, F. Ames, E. Singletary, E. Strom et al. 1993. "The Order of Administration of ChemoTherapy and Radiation and Its Effect on the Local Control of Operable Breast Cancer." *Cancer* 71(11): 3680–3684.

Clarke, D.H., M.G. Le, D. Sarrazin, M.J. Lacombe, F. Fontaine, J.P. Travagli et al. 1985. "Analysis of Local–Regional Relapses in Patients with Early Breast Cancers Treated by Excision and Radiotherapy: Experience of the Institut Gustave-Roussy." *International Journal of Radiation Oncology, Biology, Physics* 11(1): 137–145.

Coates, A.S. 1999. "Breast Cancer: Delays, Dilemmas, and Delusions. *Lancet* 353(9159): 1112–1113.

Esco, R., A. Palacios, J. Pardo, A. Biete, J.A. Carceller, C. Veiras et al. 2003. "Infrastructure of Radiotherapy in Spain: A Minimal Standard of Radiotherapy Resources." *International Journal of Radiation Oncology, Biology, Physics* 56(2): 319–327.

Fisher, B., J.H. Jeong, S. Anderson, J. Bryant, E.R. Fisher and N. Wolmark. 2002. "Twenty-Five-Year Follow-up of a Randomized Trial Comparing Radical Mastectomy, Total Mastectomy, and Total Mastectomy Followed by Irradiation." New England Journal of Medicine 347(8): 567–575.

Fortin, A., I. Bairati, M. Albert, L. Moore, J. Allard and C. Couture. 2002. "Effect of Treatment Delay on Outcome of Patients with Early-Stage Head-and-Neck Carcinoma Receiving Radical Radiotherapy." *International Journal of Radiation Oncology, Biology, Physics* 52(4): 929–936.

Froud, P.J., D. Mates, J.S. Jackson, N. Phillips, S. Andersen, S.M. Jackson et al. 2000. "Effect of Time Interval between Breast-Conserving Surgery and Radiation Therapy on Ipsilateral Breast Recurrence." *International Journal of Radiation Oncology, Biology, Physics* 46(2): 363–372.

Gouvernement du Québec. 2001. Surveillance de la mortalité au Québec 1977–1998.

Hartsell, W.F., D.C. Recine, K.L. Griem and A.K. Murthy. 1995. "Delaying the Initiation of Intact Breast Irradiation for Patients with Lymph Node Positive Breast Cancer Increases the Risk of Local Recurrence." *Cancer* 76(12): 2497–2503.

Huang, J., L. Barbera, M. Brouwers, G. Browman and W.J. Mackillop. 2003. "Does Delay in Starting Treatment Affect the Outcomes of RadioTherapy? A Systematic Review." *Journal of Clinical Oncology* 21(3): 555–563.

Jacobson, J.A., D.N. Danforth, K.H. Cowan, T. d'Angelo, S.M. Steinberg, L. Pierce et al. 1995. "Ten-Year Results of a Comparison of Conservation with Mastectomy in the Treatment of Stage I

- and II Breast Cancer." New England Journal of Medicine 332(14): 907-911.
- Mackillop, W.J., H. Fu, C.F. Quirt, P. Dixon, M. Brundage and Y. Zhou. 1994. "Waiting for Radiotherapy in Ontario." *International Journal of Radiation Oncology, Biology, Physics* 30(1): 221–228.
- Mackillop, W.J., Y. Zhou and C.F. Quirt. 1995. "A Comparison of Delays in the Treatment of Cancer with Radiation in Canada and the United States." *International Journal of Radiation Oncology, Biology, Physics* 32(2): 531–539.
- Mayo, N.E., S.C. Scott, N. Shen, J. Hanley, M.S. Goldberg and N. MacDonald. 2001. "Waiting Time for Breast Cancer Surgery in Quebec." *Canadian Medical Association Journal* 164(8): 1133–1138.
- Nixon, A.J., A. Recht, D. Neuberg, J.L. Connolly, S. Schnitt, A. Abner et al. 1994. "The Relation between the Surgery–Radiotherapy Interval and Treatment Outcome in Patients Treated with Breast-Conserving Surgery and Radiation Therapy without Systemic Therapy." *International Journal of Radiation Oncology, Biology, Physics* 30(1): 17–21.
- Petereit, D.G., J.N. Sarkaria, R. Chappell, J.F. Fowler, T.J. Hartmann, T.J. Kinsella et al. 1995. "The Adverse Effect of Treatment Prolongation in Cervical Carcinoma." *International Journal of Radiation Oncology, Biology, Physics* 32(5): 1301–1307.
- Recht, A., S.E. Come, R.S. Gelman, M. Goldstein, S. Tishler, S.M. Gore et al. 1991. "Integration of Conservative Surgery, Radiotherapy, and Chemotherapy for the Treatment of Early-Stage, Node-Positive Breast Cancer: Sequencing, Timing, and Outcome." *Journal of Clinical Oncology* 9(9): 1662–1667.
- Recht, A., S.E. Come, I.C. Henderson, R.S. Gelman, B. Silver, D.F. Hayes et al. 1996. "The Sequencing of Chemotherapy and Radiation Therapy after Conservative Surgery for Early-Stage Breast Cancer." New England Journal of Medicine 334(21): 1356–1361.
- Robertson, C., A.G. Robertson, J.H. Hendry, S.A. Roberts, N.J. Slevin, W.B. Duncan et al. 1998. "Similar Decreases in Local Tumor Control Are Calculated for Treatment Protraction and for Interruptions in the Radiotherapy of Carcinoma of the Larynx in Four Centers." *International Journal of Radiation Oncology, Biology, Physics* 40(2): 319–329.
- Sarrazin, D., M.G. Le, R. Arriagada, G. Contesso, F. Fontaine, M. Spielmann et al. 1989. "Ten-Year Results of a Randomized Trial Comparing a Conservative Treatment to Mastectomy in Early Breast Cancer." *Radio Therapy and Oncology* 14(3): 177–184.
- Slotman, B.J., O.W. Meyer, K.H. Njo and A.B. Karim. 1994. "Importance of Timing of Radiotherapy in Breast Conserving Treatment for Early Stage Breast Cancer." *RadioTherapy and Oncology* 30(3): 206–212.
- Tamblyn, R., T. Reid, N. Mayo, P. McLeod and M. Churchill-Smith. 2000. "Using Medical Services Claims to Assess Injuries in the Elderly: Sensitivity of Diagnostic and Procedure Codes for Injury Ascertainment." *Journal of Clinical Epidemiology* 53(2): 183–194.
- van der Voet, J.C., R.B. Keus, A.A. Hart, F.J. Hilgers and H. Bartelink. 1998. "The Impact of Treatment Time and Smoking on Local Control and Complications in T1 Glottic Cancer." *International Journal of Radiation Oncology, Biology, Physics* 42(2): 247–255.
- van Dongen, J.A., H. Bartelink, I.S. Fentiman, T. Lerut, F. Mignolet, G. Olthuis et al. 1992. "Randomized Clinical Trial to Assess the Value of Breast-Conserving Therapy in Stage I and II Breast Cancer, EORTC 10801 Trial." *Journal of the National Cancer Institute Monographs* 11: 15–18.



By invitation only.

To join us write Lina Lopez at llopez@longwoods.com

Breakfast with the Chiefs



Toronto • Vancouver



UNDERSTANDING THE PHYSICIAN WORKFORCE

CIHI provides a comprehensive portrait of Canada's physician workforce, describing demographics, supply and distribution, as well as service utilization and expenditure trends.

Learn more at www.cihi.ca/physicians.

CIHI—taking health information further www.cihi.ca



Policy is always in the making. This journal is designed to serve readers from diverse backgrounds including health system managers, practitioners, politicians and their administrators, educators and academics. Our authors come from a broad range of disciplines including social sciences, humanities, ethics, law, management sciences and knowledge translation. They want good policy — a foundation for best practices.

www.healthcarepolicy.net