



Received Wisdoms:

How health systems are using
evidence to inform decision-making

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Foreword

What you are about to read is a draft of a book profiling case studies of health management and policy organizations that have implemented evidence-informed decision-making. The aim is to capture successful and not-so-successful efforts. The final version will be released later this year, as the Canadian Health Services Research Foundation's 10th anniversary legacy document.

This collection of stories complements a previous publication which focused largely on dissemination by researchers to decision makers and their organizations. It was produced by the Canadian Institutes of Health Research's Institute of Health Services and Policy Research and called *Evidence in action, acting on evidence: A casebook of health services and policy research knowledge translation stories* (www.cihr-irsc.gc.ca/e/documents/ihspr_ktcasebook_e.pdf).

The stories in this book have roots in the health system itself, and they come from some of the many individuals and organizations trying to better use evidence as part of their decision-making.

We are circulating this draft at the conference “Past, Present, and Future of Evidence-Informed Decision-Making” in the hope of eliciting feedback, either about the case studies or the general issues raised. The case studies were selected last year after we called for submissions of “successful and not-so-successful” efforts to encourage evidence-informed decision-making (see section on selection criteria).

If you think there are other instructive case studies which should be included in the book, we want to hear from you. Please do not hesitate to contact Elise Comtois (elise.comtois@chrsf.ca). We are particularly interested in hearing more examples of managers or policy makers transforming their local cultures to routinely use evidence in decision-making.

This draft was prepared by health writers Melissa Sweet and Ray Moynihan. Melissa Sweet is attending the conference, so please feel free to contact her at the conference or by e-mail (melissa@sweetcommunication.com.au). Ray Moynihan and his partner, camerawoman and editor Miranda Burne, also produced a short electronic video documentary (eVD) to accompany the book.

As well as acknowledging the achievements and hard work of the past decade, the book will anticipate the challenges and opportunities of the next 10 years. We look forward to hearing your thoughts on how the foundation, together with the policy, health services, and research communities, should be advancing into that future.

Jonathan Lomas

Founding CEO,
Canadian Health Services Research Foundation

Introduction

It is less than 20 years since the term evidence-based medicine was coined,¹ signalling a paradigm shift in healthcare which has come both quickly and not quickly enough. As Prof. Murray Enkin and colleagues recently pointed out,² the rise of evidence-based medicine has been meteoric. Relative to other eras in medicine, some of which lasted for more than 1,000 years, it seems the evidence-based movement arose almost overnight. It has expanded beyond the boundaries of medicine to influence all sectors and disciplines of the healthcare industry, from management to allied health and nursing. Evidence is increasingly informing clinical and public health practice and policy-making.

And yet the impacts of the evidence-based meteor have been less dramatic than many would have liked. The growing complexity and expense of healthcare, along with the need to ensure quality and safety of care, are demanding a greater role for evidence in informing decisions of policy, management, and practice. But many barriers remain. Organizational, cultural, professional, logistical, and resource issues often impede the application of evidence.³ These are issues which are only too familiar to Murray Martin, president and chief executive officer of Hamilton Health Sciences in Hamilton, Ontario. He finds it ironic that evidence-informed decision-making is far from being entrenched in his organization, despite its proximity to McMaster University, where the term “evidence-based medicine” was coined.

“This is supposedly the evidence-based capital of the world,” he says. “Yet within Hamilton itself and Hamilton hospitals, we certainly are far from being leaders of evidence-based practice. There’s not been a cross-fertilization, even with the proximity of the evidence-based research group that is here, in terms of influencing the culture of the hospital. There are so many variables and so many reasons why people won’t practise evidence-based practice.”

Nor is the use of good evidence a panacea for the complexity of problems and issues arising in modern healthcare systems. The stories in this book illustrate that many factors other than evidence are critical in informing policy and practice.

Ten years ago, the Canadian Health Services Research Foundation was almost alone in its goal of improving the health system through better use of evidence; now there are 20 like-minded organizations in Canada, with many more around the world. The foundation’s formative years focused on building research capacity and developing new research programs, and in more recent times it has focused more strongly on supporting decision makers with knowledge transfer and exchange. The support is about more than disseminating research findings to them. It is also about better equipping them to use research and encouraging their efforts at evidence-informed decision-making. Helping to achieve this have been initiatives such as the Executive Training for Research Application (EXTRA) program, which aims to develop managers’ capacity and leadership in using research evidence in their decision-making.

This document tells some of the stories of those working to enhance the role of evidence in policy, management, and on the front lines of healthcare, whether clinical or public health. Their experiences document the rewards, challenges, and obstacles involved. The stories are likely also to produce a sense of frustration: despite the vision and commitment to change, there is still little hard evidence to show these transformations are bringing improvements to human health.

The stories take us from Southend Hospital in the U.K., where attempts to introduce evidence-based changes met resistance, to Ontario, where researchers and policy makers caution about the importance of formalizing expectations and arrangements when working together,

to Montérégie, where a passionate and visionary management team is working to seamlessly integrate clinical medicine and public health strategies. Other examples, from Montreal and Oregon, illustrate how evidence can help policy makers facing tough resource allocation decisions, specifically in the area of new drug and technology assessments. Meanwhile, Vancouver yields an important case study about the potential benefits of teaching managers to evaluate their programs.

This book is an attempt to look at the current reality of evidence-informed decision-making, and we are immensely grateful to those who were willing to share their stories, warts and all. The book not only highlights the positive aspects but also explores the negatives and the challenges. It is, we hope, a realistic assessment. We also hope these stories will both inform and inspire others to investigate ways of enhancing the role of evidence in their work while acknowledging the reality that evidence is but one player in our complex world.

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1. Guyatt G. 1991. "Evidence-based medicine." *ACP Journal Club*; 114-A-16.
 2. Enkin MW et al. 2006. "Beyond Evidence: The Complexity of Maternity Care." *Birth*; 33(4): 265-269.
 3. Lomas J. 2007. "The in-between world of knowledge brokering." *BMJ*; 334(7585): 129.

1. Montreal: Helping hospitals make better decisions about new technology

Summary: Deciding how to spend scarce health dollars is one of the biggest challenges for managers. Local technology assessment units can help to make hospitals' decisions about spending on technology more rigorous, fair, and transparent.

Hospital managers often find themselves stuck between a rock and a hard place thanks to the conflicting pressures of finite budgets and an ever-increasing array of health and medical technologies.

Investment in new technology – whether it be a drug, a device, an intervention aimed at prevention or rehabilitation, or a medical or surgical procedure – inevitably has an opportunity cost, meaning fewer resources will be available elsewhere in the hospital.

Poorly considered investment in new technology is not only wasteful, it can have an adverse impact on patient care.

Traditionally, hospital managers have lacked access to timely, evidence-based assessments of new technology and to systematic mechanisms for incorporating local values and needs into their decision-making.

While health technology assessment has been conducted by national and provincial organizations for some decades, the results are not always relevant to an individual hospital's situation, and questions have been raised about their impact.¹

However, a trailblazing unit at the McGill University Health Centre, a network of five teaching hospitals in Montreal, Quebec, has pioneered a local approach to health technology assessment. It's a strong example of healthcare managers routinely incorporating evidence into their decision-making.

The McGill Technology Assessment Unit was established in 2001 to advise the hospital network on difficult resource allocation decisions, using an approach based on sound, scientific technology assessments and a transparent, fair decision-making process.²

The process has two arms: one for assessing the evidence about a technology's economic impact, effectiveness, and cost-effectiveness; and one for providing policy advice which incorporates the scientific evidence with budgetary, legal, and ethical issues along with local values and needs.

Administrators are not compelled to follow the unit's advice, but its recommendations and the data and reasoning upon which these are based are made public and posted on the web.

By the end of 2006, the unit had provided 28 assessments. Of the first 25 technologies considered, seven were recommended, 11 were rejected, and seven were recommended for limited use.

A driving force behind the unit is Maurice McGregor, professor emeritus and a cardiologist with a long-standing interest in technology assessment. He was founding president of the Conseil d'évaluation des technologies de la santé du Québec (1988-94) and a member of the first board of the Canadian Coordinating Office for Health Technology Assessment (now the Canadian Agency for Drugs and Technologies in Health).

He set up the McGill unit after a "corridor query" from a hospital administrator about the merits of expensive new implantable defibrillators versus older, cheaper models.

Prof. McGregor recalls, "I said to him, 'give me six weeks and I will try to give you an answer – better than that, I will set up an organization in your hospital to answer all those questions.'"

The unit, he says, ensures decisions about technology investment are evidence-informed, fair, and transparent. “In the past, those decisions were made by the hospital administration *in camera* and their reasons were not made public.”

With an annual budget of \$300,000, the unit’s work is estimated to have resulted in annual savings of \$3 million, according to Prof. McGregor. “But we have also recommended some treatments which are quite expensive,” he adds. “Our prime objective isn’t saving money but is to make the best use of the money we’ve got.”

Integral to the unit’s success and credibility has been ensuring the involvement of relevant stakeholders – including clinicians working in the area – throughout the assessment and decision-making process. Timeliness is also a priority, with most reports completed within three months.

The unit’s impact is spreading well beyond McGill’s boundaries and has attracted interest from hospitals across the country, especially in light of concerns that health technology assessment in Canada needs to be expanded.³

Prof. McGregor believes any hospital with more than 100 beds could profit by the information coming out of a technology assessment unit, and any hospital with more than 600 beds could set up its own unit.

“Our prime objective isn’t saving money but is to make the best use of the money we’ve got.”

Interest in the unit’s work has also been stimulated by Prof. McGregor’s teaching with the foundation’s Executive Training for Research Application (EXTRA) program, which aims to develop managers’ capacity and leadership in using research evidence in their decision-making.

Meanwhile, Prof. McGregor says his long experience in health technology assessment has taught him a number of lessons, including that good decisions don’t depend on evidence alone.

“Policy that reflects values is better accepted,” he says. “There is seldom a decision that is absolutely right and just. The best we can do is make sure the process is fair and transparent.”

Insights

- A systematic, inclusive approach to health technology assessment can help hospital managers with difficult resource allocation decisions.
- Recommendations are more likely to be credible if relevant stakeholders have been engaged in the process.
- Decision makers need advice quickly.
- Analysis of the scientific evidence is only one component of what is needed for health policy decisions. Also important are legal and ethical issues as well as an understanding of local values and needs.

1. Roehrig C and Kargus K. 2003. *Health technology assessment in Canada and the G-7 countries: A comparative analysis of the role of HTA agencies in the decision making process*. Working Paper, Health Care System Division, Health Canada.

2. Technology Assessment Unit, McGill University Health Centre – web site. Accessed January 2007. www.mcgill.ca/TAU

3. Roehrig C and Kargus K. 2003. *Health technology assessment in Canada and the G-7 countries: A comparative analysis of the role of HTA agencies in the decision making process*. Working Paper, Health Care System Division, Health Canada.

... challenging accepted wisdom on needle stick prevention

In recent years, devices to prevent needle stick injuries have become widely used in hospitals throughout North America. Their use is mandatory in some places.

On the surface, questions about the merits of such devices might seem a “no brainer,” according to Prof. Maurice McGregor, chair of the Technology Assessment Unit at McGill University Health Centre. At roughly 57 cents apiece, the cost of devices to prevent needle stick injuries associated with intravenous lines seems insignificant compared with the benefits of preventing potentially serious infections such as hepatitis C, hepatitis B, and HIV.

But when the McGill team investigated further, the results were surprising. By their assessment, under the conditions in their hospitals, the devices would cost \$137,699 per year and could be expected to prevent one case of hepatitis B and one case of HIV approximately every 130 years, as well as one case of hepatitis C every 19 years.

The devices could also be expected to save 20 staff from the need to be tested and the associated anxiety about a needle stick injury each year, and the need for prophylactic treatment for seven people.

On the other side of the ledger, if the hospital decided to invest in the devices, the opportunity cost each year would be roughly equivalent to two acute medical beds.

And if the other potential benefits are ignored, the cost of preventing one case of hepatitis C infection every 19 years was estimated at \$2.642 million.

The hospital is considering the report’s findings as part of its decision-making process. Its final decision is not yet known.

2. Cape Breton Island: A model for implementing the evidence on diabetes

Summary: Developing an evidence-based approach to diabetes management led to a chronic care model of practice and policy

Cape Breton Island, which has been described as one of the world's most beautiful islands, has another claim to fame which is not so glamorous.

The island, whose rugged landscapes and remote settlements present health planners with considerable challenges, is also distinguished by a diabetes burden which exacts a considerable toll on the health of its residents.

People who live on Cape Breton are more likely to develop diabetes than other Nova Scotians. They are also more likely to have poorly controlled disease and to suffer complications as a result.¹

When Lindsay Campbell, director of rural health for the Cape Breton District Health Authority, was looking for a project to engage evidence with policy, it seemed improving diabetes management was an obvious choice.

She undertook the project in 2004 as part of the Executive Training for Research Application (EXTRA) program, led by the Canadian Health Services Research Foundation in partnership with the Canadian Medical Association, the Canadian Nurses Association, the Canadian College of Health Service Executives, and a consortium of 12 Quebec partners. The program aims to develop managers' capacity and leadership in using research evidence in their decision-making.

"I probably would have looked at it anyway without the EXTRA project, but that helped me focus on it a bit more and approach it a bit differently," says Ms. Campbell.

Ms. Campbell embarked on a search for the best evidence about diabetes management. As well as trawling through the medical literature, she spoke with experts throughout Canada and the United States in search of a framework to suit the island's needs.

After investigating strategies such as physician contact and follow-up, referral to disease-specific education centres, and clinical care guidelines, she settled upon a chronic care model, which incorporated an emphasis on patient self-management, a reorientation of health services, decision support, and information systems.²

The model provided a clear definition of optimal care, a roadmap for changing the system, and strategies for implementation. Ms. Campbell was encouraged by evidence showing the model was associated with improved diabetes management and reductions in deaths, heart attacks, strokes, amputations, and renal failure. Other benefits included improved patient satisfaction and quality of life, increased satisfaction of care providers, and fewer hospitalizations.

As Ms. Campbell investigated the model, she realized some of its components were already in place on the island. The challenge was in adapting existing systems to the chronic care framework; ensuring, for example, the information systems also supported patients' self-management.

The model also had to be adapted to the needs of different sites. "For example, one of our remote sites had staff shortages, so there we had a combined cardiac and diabetic clinic," says Ms. Campbell. "We had to build on what we had."

Ms. Campbell's work on the model is now helping inform a review of the district's diabetes care and will also guide its application to other chronic conditions. And a similar chronic care model is likely to be adopted by the province.

Nova Scotia has a diabetes registry, which will enable the model's impact on indicators such as hospital admissions, amputations, and blindness rates to be evaluated.

While it is too early to assess the model's impact on population health, the project has certainly had an impact at a number of other levels. "For me personally, it's meant the opportunity to pause before you jump in and develop something, to make sure you've considered the multiple sources of information that might be out there," says Ms. Campbell, who is now interim vice-president of population health and research.

“It probably gave me more confidence to ask questions and to encourage other people to inquire about evidence, to ask why we are doing things one way when the evidence might suggest something different. It’s also given me a wonderful network across the country, amongst both the faculty and the fellows.”

More recently, Ms. Campbell was involved in another project involving community health boards and public health services, which aims to incorporate evidence into policy-making. In 2005-06, a telephone survey of 3,500 residents was undertaken to provide information, both about health and local values, to guide planning and decision-making.

“The really neat thing is the commitment we have as a district to evidence,” Ms. Campbell says. Much of this, she adds, can be traced to the leadership of the authority’s chief executive officer John Malcom.

He encourages other decision makers to ask one simple question before acting: what is the evidence?

“It’s not uncommon for him to send me journal articles related to an area I’m working on,” she says. “He’s constantly finding some of that evidence and making sure it gets to the right people.”

After 30 years in healthcare administration, Mr. Malcom has a heartfelt appreciation for the value of evidence as a tool for decision makers.

“In our system there are many powerful interests and there is much emotion around many of these issues,” he says. “The only way I know how to deal with those two challenges is to make sure we’ve got as much evidence as possible to support our decisions.”

He encourages other decision makers, including board members, to ask one simple question before acting: what is the evidence?

Mr. Malcom says Canada has been fortunate to have groups such as the foundation dedicated to bridging the divide between researchers and decision makers, and he believes programs such as EXTRA are creating important cultural change.

“Those are shifts that don’t happen overnight,” he says. “We’ve made progress but there’s still a way to go. I’d say we’re 50 percent or better now compared to where we used to be 10 years ago, but there are still too many decisions that are informed by emotion, the identifiable victim, and not enough consideration of the evidence.”

Insights

- Areas where there is significant room for improvement in patient and population health outcomes can benefit from an evidence-informed approach to practice and policy.
- Organization leaders have a vital role in fostering an evidence-conscious culture.
- Awareness is growing about the potential benefits of evidence-informed policy, but there is considerable scope to further enhance the role of evidence in decision-making.

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1. Malcom J and Campbell L. 2006. *Hospitalization for Ambulatory Care Sensitive Conditions, Reduction in Diabetes Admissions to Rural Hospitals through Implementation of a Chronic Care Model*. PowerPoint presentation to EXTRA program.
 2. Wagner EH. 1998. “Chronic disease management: What will it take to improve care for chronic illness?” *Effective Clinical Practice*; 1: 2-4.

3. Montérégie: Marrying research and policy

Summary: A major restructuring of health and social services in a Quebec region provided an opportunity to create cultural and system changes promoting evidence-informed policy-making.

For a public health physician, Denis Roy has a job title which is most unusual. He is “chief knowledge officer” at the Agence de la santé et des services sociaux de la Montérégie in southwestern Quebec.

His position signifies the priority which his organization places on incorporating research evidence into the policy process. “There are not very many other people with my title,” says Dr. Roy.

Dr. Roy is head of the agency’s Information and Knowledge Directorate, which has played a key role in knowledge brokering and driving cultural and structural changes to facilitate the use of evidence in decision-making.

The agency’s move towards a greater emphasis on evidence-informed policy began in 2003, when its chief executive officer, Luc Boileau, recognized a restructuring of the region’s health and social services was an opportunity for developing closer linkages between research and policy.

He felt increasing the role of evidence in decision-making would help the agency better manage a number of difficult challenges, including issues arising out of the restructuring.

The restructuring, which merged health and social services and also mandated a strong focus on population health, raised many questions about how best to deliver services. “This was a radical change for us,” says Dr. Boileau, “to be responsible, not only for the clients who come to our institutions, but for our broader population.”

As well, like health agencies in many places, the combination of an aging population and budgetary constraints meant Montérégie had to make the best possible use of its health resources.

Around the same time he was grappling with these issues, Dr. Boileau joined the foundation’s Executive Training for Research Application (EXTRA) program, which aims to develop managers’ capacity and leadership in using research evidence in their decision-making.

The experience was invaluable, he says, in helping him develop strategies for enhancing the role of evidence in his organization. Dr. Boileau and other key managers at the agency, including Dr. Roy, decided to take advantage of useful resources offered by the foundation.

Key strategies used by Dr. Boileau include:

- Creating a strategic committee, which included the chief executive officers of all organizations within the agency, as a platform for systematically engaging decision makers with research evidence. Researchers are regularly invited to contribute to the committee’s meetings, and when the committee identifies gaps in the evidence its members jointly fund both primary research and systematic reviews.
- Creating networks to bring together groups of people in charge of similar areas at the different organizations, and supporting them to use evidence to inform their decision-making, priority-setting, needs assessment, skills development, and service provision. Networks were created, for example, for those working in youth, mental health, and cancers. They focus on acute care as well as prevention and promotion. Networks were also established for general managers and those working in information technology, finance, and human resources.
- Establishing the Information and Knowledge Directorate, with knowledge brokers who provide information in a timeframe and format that is useful to policy makers. “They are responsible for making sure our decisions are supported by evidence when

it is possible,” says Dr. Boileau. “Sometimes we have only a few hours or a few days, and it’s amazing how they can bring some information that helps us make the decisions.” As well as communicating research findings to policy makers, the directorate also communicates policy makers’ needs and priorities to the research community.

- Developing close ties and collaborative projects with the University of Montreal. One such project, for example, is developing quality indicators for the agency’s health services. Another is the creation of a full-time research position at the university, funded by the agency, devoted to working on the research needs of agency managers.

Many of those involved in the agency’s transformation into an evidence-informed organization believe the close personal and professional relationships between key leaders in the policy and research communities have been vital.

Dr. Roy says his background, as both a clinical academic and public health official, means he straddles both communities, which has helped him engage leading health policy researchers in change management at the agency.

Dr. Boileau and Dr. Roy are also long-standing colleagues of Renaldo Battista, director of the department of health administration in the faculty of medicine at the University of Montreal. Their shared interest in knowledge translation has been invaluable in forging collaboration.

“The fact we’ve known each for a number of years is important,” says Prof. Battista. “It means you have trust and understanding and that you have champions in both organizations who communicate and work to overcome obstacles.”

While it is too early to measure the impact of developments at the agency, Prof. Battista is confident significant cultural change has occurred among both policy makers and academics.

“At the university, it has made the researchers much more aware of the needs of the health authority,” he says. “It reinforces the conviction that there is a mutually beneficial interest. We hope that in the medium and longer terms it will have a major impact on the way we conceptualize problems and research.”

Close personal and professional relationships between key leaders in the policy and research communities have been vital.

Prof. Battista envisages that the Montérégie model may eventually become widely adopted within the Quebec health system.

For other organizations considering a similar path, Dr. Boileau advises being realistic about the difficulties of changing entrenched habits among managers. Leadership and systems to bring evidence to the decision-making table are important for helping overcome such resistance, he adds.

Dr. Roy has found it can be difficult for those attempting to drive change to maintain enthusiasm for their message. “One of the obstacles for me was that you have to repeat very often the same thing. Sometimes it gets boring and disappointing; you have the sense that you’re not well-understood and that you’re teaching in a desert.”

In retrospect, he believes a more explicit effort should have been made to engage physicians in the change process. “One of the weaknesses of the Canadian health system is the level of accountability of individual physicians,” he says. “The medical profession by and large is isolated – it’s our strength and it’s a major weakness.”

More also could have been done to spell out the implications of the changes for the general public and their associated responsibilities, he adds.

Dr. Roy believes it is important not to let resource constraints be used as an excuse for avoiding change. He says while Quebec's health services are relatively underfunded, they are also exceptionally productive, creative, and collaborative.

"If you want to make these changes, it's a matter of leadership and will, it's not a matter of resources," he says.

Insights

- The restructuring of an organization or services can be an opportunity for introducing systems and structures to promote evidence-informed decision-making.
- Influential and respected champions are vital for driving change.
- Close personal and professional relationships can help build collaboration between research and health system organizations.
- Change management processes are more likely to be effective if all relevant stakeholders are engaged.

4. Oregon: How evidence can help deal with vested interests

Summary: An influential collaboration is providing policy makers across the United States and Canada with evidence-based information comparing the effectiveness and safety of drugs within the same class.

It is no coincidence that Oregon, the state which is famous for pioneering innovation in health financing, also gave birth to a groundbreaking project in pharmaceutical evaluation.

John Kitzhaber, a medico-turned-politician who in the late 1980s helped author the Oregon Health Plan to foster equitable resource allocation, was also instrumental in establishing the Drug Effectiveness Review Project (DERP) as a tool for maximizing returns on investment in pharmaceuticals.

Against a backdrop of growing anxiety over unsustainable increases in drug costs and inappropriate industry influence, the Drug Effectiveness Review Project stands out as a model of rational evidence-informed policy-making. Since its establishment in 1999, the project has evolved into an influential collaboration involving 13 states and the Canadian Agency for Drugs and Technologies in Health.¹

It analyses the best available evidence on effectiveness and safety comparisons between drugs in the same class and produces systematic reviews to guide policy decisions about pharmaceutical financing. These are freely available through the web site of the Center for Evidence-Based Policy of the Oregon Health and Science University, where the project has been based since 2004.

All collaborators on the project are involved in key decisions, including which drug classes to review, and participating organizations all contribute the same amount – \$96,600 a year – to fund each three-year term of the project.

Mark Gibson, the centre's deputy director and previously health advisor to Gov. Kitzhaber, recalls the difficulty of establishing the Drug Effectiveness Review Project in Oregon in the face of political resistance and heavy lobbying by the pharmaceutical industry.

“The governor sponsored the legislation, but the industry had it so completely bottled up that we were unable even to get a hearing in committee, which is the normal route for legislation,” says Dr. Gibson.

“Finally, the governor, the day before the legislature was set to adjourn for the session, called in the speakers of the two houses and said if he didn't get this bill passed he would veto the entire human services budget, which would throw the budget out of balance, and that he would call them back into session in two weeks' time after he had explained to every community why he was doing that.

“And, lo and behold, the legislation went through and was passed that day, on the eve of the adjournment.”

Dr. Gibson says the governor's commitment to the project arose out of his experience with the Oregon Health Plan, which had made him acutely conscious of the opportunity cost of health spending. “He realized the explicit decision to fund one thing is an implicit decision not to fund another – that if we're paying millions of dollars more than we need for the therapeutic benefit we can get from a medication, that's funding we can't apply to other services.”

The Drug Effectiveness Review Project aims to provide policy makers with evidence-based information to help them ensure the maximum return from spending on pharmaceuticals. It provides policy makers with an objective counter-balance to the pharmaceutical industry's influence, says Dr. Gibson.

“You could call me the master of understatement if I said the industry is well-resourced and knows how to use those resources in every possible way to affect public policy,” he says. “They have good relationships with many advocacy groups by virtue of their willingness to fund some of these groups.

They play a very influential role in legislative politics because they have very capable lobbyists.”

Because of the powerful interests at stake in pharmaceutical policy, transparency is a critical element of the Drug Effectiveness Review Project’s process and reviews.

Drafts of key questions to be addressed by planned systematic reviews are posted on its web site, and these are sometimes amended in response to feedback. Draft reports are sent for review by experts whose specialty is relevant to the review topic and are also posted on the web site for public feedback. Reviews are regularly updated, and everyone engaged in the review process and the project’s governance is asked to declare conflicts of interest.

Dr. Gibson says the reports are used to *inform* rather than dictate policy, and local decision makers use the findings in different ways and sometimes with different results. For some states, they are the major source guiding policy on Medicaid drug lists, and several states use them in determining public employees’ pharmaceutical coverage.

The Drug Effectiveness Review Project’s reviews also help inform a web site, Consumer Reports Best Buy Drugs, launched by the Consumers Union (www.crbestbuydrugs.org) to provide the general public with evidence-based information about medications.²

According to Dr. Gibson, some of the key review findings revealed:

- A dearth of reliable, comparable data on long-acting opioids, despite huge price differentials between products. As a result, some states made considerable savings by funding the cheaper drugs.
- Newer antidepressants are similarly efficacious, but patient responses can be idiosyncratic. “Most states decided that if someone was stabilized on a particular drug, it didn’t make sense to move them onto a lower-cost drug as there was a chance it may not work,” says Dr. Gibson. “On the other

hand, if a patient is naive to the class and hasn’t used an antidepressant before, it makes sense to start off with the low-cost drug.”

- Concerns about unexplained cardiac problems associated with rofecoxib were identified by a Drug Effectiveness Review Project review long before they hit the international headlines. As a result of this review, most members of the project did not list it as a preferred drug. “Two to three years later, when it was taken off the market, they felt pretty good about that decision,” says Dr. Gibson. “Not only had they been saved from buying a more expensive drug that had not demonstrated superior pain relief effectiveness, but they also weren’t buying a drug with this cardiac risk factor and didn’t have to pay the costs of treating cardiac complications.”

The original idea for the Drug Effectiveness Review Project grew out of discussions between policy makers attending meetings of the Reforming States Group, which includes health policy leaders from across North America, who meet and share experiences and work on practical solutions to pressing healthcare problems. Alongside the tangible benefits that flow from the reviews, state and provincial policy makers also find their involvement with the project provides a welcome opportunity for interaction and discussion with peers.³

“It’s one of the few sources of highly credible academic information about new drugs.”

Bob Nakagawa, who is now assistant deputy minister of pharmaceutical services in the British Columbia Ministry of Health, remembers the meetings well. “We got into discussions about how not all drugs are created equal and how it’s very important to look beyond the information provided by manufacturers in order to make good policy decisions,” he says.

“Our responsibility, as stewards of the tax dollar, is to ensure there’s good value and that returns on tax investment and funding are worthwhile. If we’re spending a million dollars on a drug, it’d better give us a million dollars of great health outcomes.”

While Canada has a national agency to review individual drugs, Mr. Nakagawa says the Drug Effectiveness Review Project’s work has been extremely useful in providing information on drug classes. In a previous job, running pharmaceutical services for the Fraser Health Authority, he used a review concluding proton pump inhibitors were of equal value to create price competition among manufacturers. This resulted in “substantial savings,” he says.

“If someone says we really need a drug class review, the first thing I say is, have you looked at what DERP has done?” he adds.

Mr. Nakagawa says there is significant room to improve awareness of the Drug Effectiveness Review Project in Canada, and he also believes more could be done to market the project internationally.

“There’s tremendous potential still for it to be expanded in terms of its membership,” he says. “It’s an incredibly valuable resource. When so much information about drugs comes from industry, DERP stands alone. It’s one of the few sources of highly credible academic information about new drugs.”

The project has not lacked critics, however. The pharmaceutical industry has lobbied state legislators against it, while some professional and patient advocacy groups have viewed it as a cost-containment exercise whose findings are being used to restrict access to new therapies.

Concerns have also been raised about its decision not to examine cost-effectiveness. “The DERP decision to ignore cost-effectiveness considerations reveals a society still unable to consider economic factors openly in evidence reviews, even in a program led from Oregon, the most willing of all states to push health policy limits,” wrote Peter J. Neumann, director

of the Center for the Evaluation of Value and Risk in Health at the Institute for Clinical Research and Health Policy Studies at Tufts-New England Medical Center.⁴

Meanwhile, the Drug Effectiveness Review Project is now signing up collaborators for the second of its three-year terms and is likely to expand its horizons. The project’s future agenda may include class-to-class comparisons, combination therapies, and off-label use, says Dr. Gibson.

Insights

- Policy makers value access to independent, evidence-based information about the effectiveness and safety of drugs.
- Collaboration enables states and other concerned organizations to pool resources to achieve access to such information.
- Consumers may also benefit from access to evidence-based information about pharmaceuticals.
- Efforts to ensure the best return on investment in pharmaceuticals are likely to meet resistance from vested interest groups.

1. The Drug Effectiveness Review Project – web site. Accessed January 2007. www.ohsu.edu/drugeffectiveness
2. Findlay SD. 2006. “Bringing the DERP to consumers: ‘Consumer Reports Best Buy Drugs.’” *Health Affairs*; 25(4): W283-W286.
3. Hoadley J et al. 2006. *Understanding key features of the Drug Effectiveness Review Project (DERP) and lessons for state policy makers*. Issue Brief, National Academy for State Health Policy, Portland, ME. www.nashp.org
4. Neumann PJ. 2006. “Emerging Lessons From The Drug Effectiveness Review Project.” *Health Affairs*; 25(4): W262-271.

5. Southend, U.K.: The challenges of change in an outpatient rehabilitation service

Summary: Introducing an evidence-based approach to the management of back pain and musculoskeletal problems required significant changes to service structures and practices – and caused some pain of its own along the way.

Implementing evidence-based changes in established services is tough work involving many obstacles, but it can also yield significant dividends for patient care and service delivery.

That, at least, has been the experience of two consultant physiotherapists who have been engaged in evidence-based reform of an outpatient rehabilitation service at Southend Hospital in Essex, eastern England.

Hubert Van Griensven and Billy Fashanu are clinical leaders, meaning their positions combine managerial and clinical responsibilities. They were appointed with a brief to implement evidence-based practice in their respective areas of back pain and musculoskeletal problems affecting the upper and lower limbs.

Mr. Van Griensven recalls that when he began at the service in 2004, he found many examples of entrenched practices in the treatment of back pain which did not reflect current knowledge.

One-to-one physiotherapy was common despite doubts about its effectiveness as a first-line treatment, while a fitness class was used mainly as a last resort despite evidence suggesting it should be a front-line treatment for chronic, non-specific back pain.¹

Mr. Van Griensven says because patients tended to be referred to the fitness class only after all other treatment options had been tried, it was less likely to be effective.

“If the class had been sold properly right from the start, with patients being told ‘there is no pathology, nothing we need to investigate, and that what really works for your sort of back pain is this sort of exercise,’ it would have worked much better,” he says.

“The other advantage of the evidence-based approach is that treating people in groups is more cost-effective than one-on-one physiotherapy consultations.”

Mr. Van Griensven developed a new clinical pathway for back pain, asking therapists to consider the interventions with the strongest evidence base first. He also developed an assessment tool to identify patients whose distress was likely to reflect underlying psychological problems so they could be referred elsewhere for more appropriate treatment.

After revising his proposals in response to staff feedback, the new approach was implemented in February 2005. Within a few months, the use of one-to-one treatment for non-specific back pain was cut in half.

However, the changes then hit turbulent waters. Staff members revolted against the use of clinical pathways, saying they didn’t want to be told what to do.

As well, a psychologist launched an attack on the use of the assessment tool, a psychological questionnaire, by non-psychologists. She was concerned it could trigger emotional reactions that non-psychologists may not be able to manage appropriately.

Mr. Van Griensven felt confident this would not be a problem but could not identify any reliable evidence to allay the psychologist’s concerns, and the use of the questionnaire was abandoned. “This experience showed a real gap in clinical evidence,” he says.

Staff members’ unhappiness eventually resolved after they were given the opportunity to design their own assessment forms. After budgetary cutbacks were imposed by hospital management, most therapists eventually accepted clinical pathways as a way to improve efficiency without sacrificing quality of care.

Sharing an office with Mr. Van Griensven during the tumultuous months of opposition to his reforms, Mr. Fashanu was facing similar challenges in his own efforts to introduce evidence-based clinical pathways to the management of shoulder pain.

Both felt at least some of the opposition reflected staff’s general discontent with the pace of change in the National Health Service and a broader suspicion of management. Mr. Van Griensven says staff members were dealing with other changes they felt

reduced their autonomy, such as the introduction of an electronic diary system.

“My introduction of clinical pathways became part of that, so their reaction was, ‘why should we be told what to do? We’re clinicians and we’ve got a lot of experience,’” says Mr. Van Griensven.

In retrospect, both Mr. Van Griensven and Mr. Fashanu say they’ve learned valuable lessons. If attempting similar changes again, they would make greater efforts to communicate to everyone who might be affected.

“I’d be more aware of the people and the bits of the organization that this could impact on and make absolutely sure that I kept them in the picture,” says Mr. Van Griensven.

And rather than developing the new assessment tool himself with staff input, he would ask staff to develop the new tool to ensure they felt greater ownership. “What I’ve learned is that asking people for feedback may not be the same as asking them to do something and steering them in the right direction,” he says.

There is a need for wider education about the principles and benefits of evidence-based care.

Both reforming managers believe their experiences also illustrate the need for wider education about the principles and benefits of evidence-based care.

“Lots of people have very little knowledge about research,” says Mr. Fashanu. “They think evidence-based practice is a way of people controlling them. They don’t see the positive side, they see the negative side.”

He is pleased that in-service training now helps rehabilitation therapists learn how to analyse the evidence behind their practices. It would also have been useful, he adds, to have respected outside experts on evidence-based practice come in to speak with staff before the reform process began.

The process also identified the difficulties that non-medicos can face in engaging doctors in change.

“Medical consultants have the power to do what they like,” says Mr. Van Griensven. “It’s one of my enduring frustrations that there isn’t a level of management that says to all the people involved in musculoskeletal practice that ‘this is what you are going to do.’ It’s awkward to say to staff that ‘we need to do evidence-based practice’ because they only have to walk a few hundred yards to the orthopedic surgeons to see that that doesn’t apply to everyone.”

Both reformers feel vindicated that their changes eventually led to improvements in patient care and service efficiency, including dramatic reductions in waiting lists.

But the process has taken a personal toll. “I’ve learned a lot out of it but it has been quite painful and in a way still is,” says Mr. Van Griensven.

Insights

- Implementing evidence-based clinical pathways can pay significant dividends for patient care and service efficiency.
- Efforts to change health services and practices inevitably meet resistance.
- Effective communication is vital, and involving staff in the change process helps smooth implementation.
- Improving staff members’ knowledge and understanding of evidence-based concepts may facilitate change.
- Managers and clinicians responsible for driving evidence-based reforms also require support.

1. Airaksinen O et al., on behalf of the COST B13 Working Group on Guidelines for Chronic Low Back Pain. 2004. *European Guidelines for the Management of Chronic Non-Specific Low Back Pain*. www.backpaineurope.org

6. Halifax: The infuriating case of the beige baseboards

Summary: Designing an eye care centre to meet patients' needs required a visionary approach, determination, and perseverance.

After many years working in a leaky, rodent-infested building at the old Halifax Infirmary, staff members at the Nova Scotia Eye Centre were delighted when in 1997 they finally got the go-ahead to move elsewhere.

Upon inspection of their proposed new home, an old neurosurgery ward at the Victoria General Hospital, they realized a major redesign would be needed to make it suitable for their ambulatory patients.

Rather than rushing into any decisions, a broadly based working group was formed to seek out the best available evidence on the optimum design of eye centres. Senior staff members travelled to Vancouver, Portland, Seattle, San Diego, and Iowa City to investigate what designs had worked, or not worked, elsewhere.

They also sought advice from experts at the local branch of the Canadian National Institute for the Blind.

Several teams were developed to consider different aspects of the project, with each group incorporating end users – nurses, doctors, clerical staff, research co-ordinators, and patients.

The result, says Susan Smith, who at that time was the ophthalmology department's administrator, was a design strategy based on what had been learned from the evidence and interpreted for the local situation.

The centre was to be divided into units clearly delineated by different colours to help guide patient flow. The unit with red walls, floors, and signs, for example, was for problems related to the front of the eye, while the green unit was for those with retina problems, and the blue unit for those with low vision and/or glaucoma.

The centre was also to incorporate some visual cues to help patients find their way along hallways without bumping into walls. Critical to this was having highly contrasting colours between the wall and floors to help people distinguish where one ended and the other began.

“We were very pleased with the progress on the building until I went in one Monday morning and my heart sank,” remembers Ms. Smith. Instead of finding the contrasting baseboards she had expected, they were all beige, while both the flooring and walls were off-white. The contractors had been instructed to cut costs.

“People should be encouraged to consider use of evidence in a very broad context.”

Despite protests from unhappy staff, the state-of-the-art centre opened in July 1998 with beige baseboards and considerable concern for the safety of patients.

“It was really only a matter of a day or two before we started getting complaints from patients about walking into the walls,” Ms. Smith remembers. After official complaints from the Canadian National Institute for the Blind, management finally had a change of heart, and the contractors were called back in.

When the unit was finally completed as intended, patient flow noticeably improved compared with their previous location, says Ms. Smith. “Often at our old centre, we would find that patients would come to the front desk and they might be standing there waiting for ages when they just needed to go to another area to have their particular needs met.”

Raymond LeBlanc, who headed the department of ophthalmology at the time of the redesign and is now vice-president, research and academic for the Capital District Health Authority where the eye care centre is located, says the effort which went into planning the new centre was a wise investment.

“If I were to design a new eye care facility tomorrow, I would do a lot of the things exactly the same again, as time has proven them to be really good decisions,” he says.

Ms. Smith, who is now a consultant and a graduate of the foundation’s Executive Training for Research Application (EXTRA) program, looks back on the centre’s redesign as a landmark.

“It’s kind of a silly, strange story, but it’s an important story. It’s about being persistent. Sometimes I don’t think we realize that we use evidence in our management decision-making for everyday stuff. People should be encouraged to consider use of evidence in a very broad context.”

Insights

- The design of health services can affect patient care and well-being.
- Evidence can come from many different sources and inform many different types of decisions.
- Implementing evidence can require persistence and determination, especially in the face of cost pressures.

7. Vancouver: Learning to evaluate, on the job

Summary: Training health professionals and managers how to evaluate their programs may result in improvements to service efficiency and patient care

“We need to evaluate what we’re doing but we’re not sure how to go about it.” The sentiment was heard so often from staff at the Vancouver Coastal Health Authority it sounded like a cry for help.

It was also recognized as an opportunity by leaders at the authority and the Vancouver Coastal Health Research Institute, which was established in 2003 as a partnership between the authority and the University of British Columbia with a mission to support research and its links with practice.

The institute runs workshops training researchers and health professionals about practical aspects of doing research. But staff’s interest in developing evaluation skills led to the development of a unique course teaching on-the-job evaluation.

When designing the course, which ran for the first time in 2005-06, organizers felt it was important to make it as user-friendly as possible, knowing participants were certain to already have demanding clinical loads. The course required a team of at least two people to attend a class one day a month over a seven-month period, to work on a specific project.

At the end of the first course, participants, who included managers, nurses, and allied health professionals but no physicians, presented their findings to a meeting of colleagues and invited guests. They also wrote reports making recommendations for their programs.

Participants were overwhelmingly positive in their evaluation of the course, with most indicating they would make changes to their program in response to their project’s findings. Many were also keen to do further evaluation projects.

For Linda Peritz, associate director of the Vancouver Coastal Health Research Institute, the beauty of the course is that it is making a difference on the front lines. “All the projects are related to daily patient care. It’s the people who are delivering the care who see the issues. These are the questions they face in their practice on a daily basis. They’re now able to answer the questions they have and improve their practice at a very elemental level.”

“The biggest value for me in taking the course was learning how to look at our program objectively, our weaknesses and our strengths and where we needed to be able to focus.”

Among the first graduates were Deborah Jeske, manager of Vancouver Hospital’s pre-admission clinic, and Kelly Barr, co-ordinator of the blood utilization program. The program had started three years earlier and was struggling to meet increasing demand from patients wanting to conserve their blood before surgery as an alternative to transfusion.

“We were crazy busy but we didn’t have the resources to look at how effective we were, where we could streamline, and how we could be more effective,” says Ms. Barr.

“The biggest value for me in taking the course was learning how to look at our program objectively, our weaknesses and our strengths and where we needed to be able to focus. We needed to be able to articulate that, especially as we knew we’d have to advocate for more resources.”

The project identified that patients were being referred too close to their operation. As a result of this finding, referral forms have been revised, and patients must now be referred at least 10 days before surgery.

As well as its impact on service delivery, Ms. Jeske says the course has been helpful in changing mindsets. “You learn to think differently,” she says.

“In nursing we have a tendency to develop patterns of behaviour in how we work with our patients. We’re not always very good at going back and looking at those patterns of behaviour and whether we’re getting the outcomes we want. The course teaches us to be a little more analytical, to look at what you and other nurses are doing.”

Judith Krajnak, an evaluation consultant who taught the course, is widely credited with being a key reason for its success. “Judith was fabulous because she had the right mix,” says Peter Quick, a quality leader who joined the first class. “She knew the theory of evaluation and she also knew the clinical reality for all of us, that people didn’t want to be careerist researchers, that this was something they did on the side.”

Dr. Krajnak is equally complimentary about her students. “I’m so impressed by the quality of the projects that they come forth with,” she says. “I find it particularly gratifying that they have recognized areas of need in their workplaces. They are so enthusiastic and so independent once you give them the tools to carry out an evaluation. I’m just amazed at what they were able to produce.”

For other agencies considering establishing similar courses, Dr. Krajnak advises one of the obstacles was the difficulty of obtaining ethics committee approval. Ethics committees are still struggling with how to review a project that is an evaluation project rather than a research project, she says.

“The students had to go through the ethics review if they wanted to present their findings outside at conferences. The forms are fairly tedious and not that easy for those filling them out for the first time, so that took a bit longer than any of us might have expected.”

The course is relatively inexpensive to run, and organizational leaders are thrilled with its results and committed to finding resources to continue it, according to Dr. Peritz.

Will the two courses that have already been run have a lasting impact on the Vancouver Coastal Health Authority? “Yes and no,” says Mr. Quick. “Yes, because some people got into it and carried it forward. No, because I don’t think the organization is good at sustaining change.”

He believes the organization needs to do better at identifying champions for change. “With most organizations, the champions tend to be positional. We tend to follow the hierarchy and we’re not effective at unleashing those other champions.”

Through his work accrediting hospitals across Canada, Mr. Quick has observed many organizations could also do more to enhance their capacity to deliver quality care. “I often witness that someone may be really willing to do something but may not be capable of doing it because they don’t have the right equipment or the right statistical package. We need to do a better job of matching up willingness with capabilities.”

Mr. Quick has also come to realize that many health providers and services are doing well but need help to demonstrate this. “I keep seeing people missing the opportunity to celebrate that they’re doing best practice,” he says.

Insights

- Many health professionals and managers would like to improve their skills in program evaluation without leaving their workplace.
- Evaluating health services and programs can lead to efficiencies and improvements in patient care.
- Being involved in evaluation projects can encourage health professionals and managers to develop an interest in evidence.
- Organizational support is needed to sustain the changes which may flow from such projects.

8. Ontario: Setting the stage for effective partnerships

Summary: An organization-level initiative promoting linkage and exchange between a research unit and a policy branch brought both challenges and benefits.

Those who attempt to build bridges between the worlds of research and policy may find the task rewarding but also more strenuous, time-consuming, and resource-intensive than they expect.

That has been a key lesson for those involved in developing and maintaining a formal partnership between mental health academics and policy makers in the provincial government of Ontario over the past several years.

The partnership originated between the Health Systems Research and Consulting Unit at the Centre for Addiction and Mental Health and the former Mental Health Rehabilitation and Reform Branch of the Ontario Ministry of Health and Long-Term Care.

It resulted from the awarding of a chair, funded by the Canadian Health Services Research Foundation and the Canadian Institutes of Health Research, to the Health Systems Research and Consulting Unit's director, Paula Goering, who is a professor at the University of Toronto.

The 10-year award is part of a strategy to build capacity for evidence-informed decision-making within research, policy, and management communities. It differs from many endowed chairs because of its explicit focus on training, knowledge exchange and linkage, and its requirements for accountability to external parties.

The award required Prof. Goering, a nurse with a PhD in medical science and a long-standing interest in applied research and knowledge transfer, to have the support of a policy partner. She saw this arrangement as a way of creating ongoing opportunities for

collaboration with the government branch at a time of mental health reform in Ontario. Likewise, policy makers appreciated the opportunity to get help with evaluation.

"It was a good, innovative model," says Darryl Sturtevant, then director of mental health reform within the ministry and a driving force behind the partnership. "I really wanted to link with the world of evidence, to inform policy work on the reforms and help build the new community-based mental health system."

When Prof. Goering and colleagues reflect back on the first years of the partnership, they describe their experiences as a play with three acts – with the third act yet to come. In many ways, their experiences reflect the tensions, dramas, and resolution of difficulties that characterize many stories told on the stage.

Act 1 began in 2001, with the birth of the partnership and the two organizations agreeing to share a knowledge broker.

"The original proposal contained ideas about how this partnership would be conducted, but there was no formal agreement underpinning the understanding of each party," says Prof. Goering.

"In essence it would be a work in progress with each party bringing its own ideas to the table for how best to construct the partnership."

During the four years of Act 1, Prof. Goering says there were many notable accomplishments, including a research-to-policy forum, educational sessions for researchers and policy makers, and clearly articulated dissemination plans for ongoing research.

For Mr. Sturtevant, the partnership was critical to the government's reforms, and the link with research helped build the case to convince senior decision makers to fund some costly programs. "We had solid analysis to help make the case for what investment was required," he says, citing the example of early intervention programs for psychosis. According to Mr. Sturtevant, good research evidence helped inform policy decisions to fund programs to identify early

episodes of psychosis in kids and try to keep them out of the more formalized mental health system. “We didn’t achieve some of the big system reform, but there were investments in key program areas.”

However, the partnership was not without tensions and difficulties. The policy maker was seen by some external stakeholders to be unfairly favouring the research partner, which was perceived to compromise its neutrality.

The research unit faced similar issues regarding its perceived independence and research credibility, and there were concerns that an overly close relationship with the funder might compromise academic freedom and the reporting of results, especially if they were critical of government-funded programs.

Other problems reflected differing organizational cultures and practices. While policy makers sometimes criticize researchers for being slow to provide answers, Prof. Goering and colleagues were at times frustrated by the slowness of bureaucratic decision-making.

“We were surprised by how cumbersome it was to make things happen,” says Prof. Goering. “Sometimes in coming up with answers we’re slower than they’d like; sometimes in terms of coming up with action, they move slower than we’d expect.”

Mr. Sturtevant agrees with Prof. Goering that policy-making can sometimes happen very slowly, particularly with big reforms. At other times, however, “policy can happen in a flash and you need to solve problems quickly.”

Still a supporter of the innovative partnership, Mr. Sturtevant has since become assistant deputy minister, strategic policy and planning for the Children and Youth Services Ministry in the province of Ontario.

Another perspective comes from Dale Butterill, the knowledge broker employed by the partnership, who recalls that the partners agreed to change the term of their shared enterprise from “knowledge transfer” to

“knowledge exchange.” “The ministry was committed to seeing this as a two-way street and that both parties had knowledge to impart,” she says.

Act 2 began in 2005 when the policy makers needed urgent help with a second large-scale five-year research project to evaluate the impact of the government’s new investments in mental health reform. In this phase, both partners felt they needed to develop a new approach, to acknowledge the lessons learned from Act 1.

They agreed to establish a more formal relationship and to involve more internal ministry programs and external organizations. This resulted in an expanded partnership that was much more representative of major players in the field.

“We were surprised by how cumbersome it was to make things happen.”

A memorandum of understanding was developed between the ministry and the researchers, setting out the expectations for the business aspects of the relationship such as reporting requirements, conflict resolution, financial accountability, and communication pathways.

Prof. Goering says this document safeguarded the project from lack of accountability and role confusion. It also put a boundary around the “business” aspects of the relationship, freeing up the ministry to assume a different role with the larger group.

For the project as a whole, an executive advisory committee was created, comprising provincial organizations, consumer and family stakeholders, as well as the Ministry of Health. Over a number of meetings, members agreed to a set of partnership principles and practices that were incorporated into the terms of reference.

Prof. Goering is positive about the developments of Act 2 and the benefits of having more organizations involved, but adds the partnership is now more complex to manage as a result of the many organizations involved. The memorandum of understanding negotiations were also protracted, taking one and a half years to achieve sign-off.

“We’ve learned that a lot of partnership issues are sorted out in doing things together,” says Prof. Goering. “It’s in the action and the task that we get an opportunity to learn; you can only do so much when talking about the nature of the relationship.”

Prof. Goering and colleagues are finding Act 2 more secure than Act 1 because the formalizing of arrangements through the memorandum of understanding is helping to resolve one of their major obstacles to date: staff turnover at the ministry.

“There is only one person in the ministry branch now who was involved in part of Act 1,” says Prof. Goering. “Having a more formalized MOU means if we lose our current ministry contacts, we have some confidence that we will have an institutional memory in the relationship.”

“Everyone complains that it’s hard to find continuity in partners in government. Ontario is going through a major reorganization of its health system and that’s added to the extent of turnover.”

Carrie Hayward, director of the Mental Health and Addiction Branch, is sympathetic to these concerns, especially as she is herself moving to another job, but says it is a fact of life when working with government. “Building relationships is a continuous activity,” she says.

Ms. Hayward believes the partnership model created in Act 2 is working well, reflecting the time and effort that was invested in building relationships and creating a solid foundation. But she expects some issues may arise when it comes time to publish the project’s findings.

“In other projects where I’ve worked with researchers, there can be sensitivities about the way results are framed,” she says. “It can be caused by conflicting agendas but it can also be caused by conflicting perceptions.”

Ms. Hayward says researchers sometimes have unrealistic expectations. “I tell researchers you can tell me about all the research you want but I don’t have time to read it,” she says. “I have time to read the research relevant to the project I’m working on today. Senior decision makers tend not to read evidence unless they are very focused on something they are trying to learn about. That’s very hard for researchers to understand because they feel the value of their work is being ignored.”

She advises researchers to talk to policy makers before they begin their research. “Ask what’s relevant to us,” she says. “We don’t get those questions very often.”

Her partners at the Health Systems Research and Consulting Unit have gained many new insights into the realities of policy-making.

“I have a much better appreciation of the world of policy-making,” says Prof. Goering. “As soon as you understand it better, your expectations about what you can achieve in terms of research are somewhat modified. I don’t expect the immediate policy results that I might have before.”

“We do see a lot of uptake of our ideas and recommendations in ministry documents, but we have a much better understanding of why that doesn’t always happen.”

Prof. Goering also has a better appreciation of the value of the knowledge broker role and the time and energy it requires. “We now have two people filling that role on my research unit because I am so impressed with the investment that’s required to make all of this rhetoric a reality.”

Other important lessons from the partnership include the need to maintain open and ongoing channels of communication to help resolve problems of cultural differences; respect peer review processes; ensure a mutual commitment to publishing in and presenting at scientific venues; and anticipate and manage real and/or perceived conflicts of interest.¹

Both partners say they have been helped by supportive organizational environments. The corporate policy branch of the Ontario Ministry of Health has, for example, created a position for a research transfer advisor, while the University of Toronto's department of psychiatry has implemented promotion policies rewarding scientists for knowledge transfer activities.

Insights

- Having access to reliable evidence can help policy makers argue more effectively for government investment in effective interventions.
- Formalizing arrangements for partnerships between researchers and policy makers can help overcome some of the challenges inherent in such relationships.
- Maintaining open and ongoing formal and informal channels of communication can help resolve problems arising out of cultural differences between the worlds of policy and research.
- Discussing the need to respect peer review processes and ensuring a mutual commitment to publishing in and presenting at scientific venues at the beginning of the process is critical to the future resolution of these problems.
- Anticipating and managing real and or perceived conflicts of interest is vital.
- Policy makers and researchers engaging in partnership arrangements will benefit from support from their own organizations.

1. Goering P et al. 2003. "Linkage and exchange at the organizational level: a model of collaboration between research and policy." *Journal of Health Services Research and Policy*; 8(S2): 14-19.

Beware of success

In the mid 1970s, people living on two First Nations reserves in Manitoba were supplied with free dental floss as part of a comprehensive program to improve oral health by preventing dental disease.

The campaign, developed by federal government dental services, focused on preventing gum disease in an attempt to avoid premature tooth loss in adults. It was hoped this would also reduce the need for treatment, which was difficult and costly to provide to remote locations.

When the campaign ended, efforts to evaluate its long-term impact in these remote communities included monitoring sales of dental floss through the local Hudson's Bay stores, according to Stephen Simmons, who was then assistant director of dental services for federal government programs in Manitoba.

Dr. Simmons was pleased when sales figures showed a strong and increasing demand for dental floss in areas targeted by the campaign but surprised an education campaign should result in such a rapid diffusion of

a new and quite complex skill through a population. Either the campaign had revealed an extraordinarily effective means of influencing health behaviour, or it was all too good to be true, he thought.

His caution was later vindicated when he moved to a reserve and discovered dental floss was not just being used to improve oral hygiene. It also came in very handy as a hard-wearing string for decorative beadwork and as a tough, thin fishing line that floated.

"I was very impressed by the ingenuity and practical survival skills of the local community in discovering new uses for floss," says Dr. Simmons, who is now clinical director and specialist in dental public health based at St. Ann's Hospital and the Haringey Teaching Primary Care Trust in London.

While these newfound uses probably also brought public health benefits – by improving incomes and diets – Dr. Simmons says the experience reminded him of the pitfalls of relying on proxy outcome measures in evaluation.

Tentative Conclusions

Here are some preliminary lessons learned from these stories. They are in draft form and will be expanded and modified for the final version of this book.

1. It's early days yet for evidence-informed decision-making.

In the last few years many organizations have become aware of the promise and practice of evidence-informed decision-making; they have become “predisposed” to it. Only a few, however, have gone as far as enabling it to actually occur. There are, therefore, few assessments yet of its impact on patient and health system outcomes. Such impacts are likely also to prove difficult to measure. Nevertheless there are many anecdotal reports of its value in highlighting needs, managing stakeholders, and informing resource allocation decisions.

2. Evidence-informed decision-making and change management are intertwined.

Evidence-informed decision-making frequently implies changes in the way things ought to be done. Successfully bringing about these changes usually requires involvement of those affected. Change management is, inevitably, an integral part of evidence-informed decision-making.

3. “Evidence” is more than research in “evidence-informed decision-making.”

The individuals and organizations in these stories use many types of evidence, including systematic data collection, formal research studies, research synthesis, observation, experienced judgment, and situational analysis. The ongoing challenge of evidence-informed decision-making is to maintain prominence for the systematically collected and most valid forms of evidence (often the research) over the anecdotal and less-valid forms.

4. Evidence-informed decision-making is sustained through personal relationships.

Single, episodic instances of evidence-informed decision-making are less difficult to realize than an ongoing and sustained commitment – the cultural change in an organization that leads to routine use of evidence in all important aspects of its work. Creating and maintaining personal relationships, especially between researchers and decision makers, and the personal factor of a leader who champions the concept, seem to be integral to establishing the cultural change inherent in ongoing evidence-informed decision-making.

5. There is a need for an evidence-informed decision-making infrastructure

There is a need for infrastructures to underpin evidence-informed decision-making initiatives. The infrastructures include evaluation programs such as the one developed in Vancouver; information systems, like the one expected by the Cape Breton District Health Authority; or a health technology assessment unit, as the one established in Montreal at McGill. Another example is the foundation's programs, such as EXTRA, which seem to be used as part of the infrastructure supporting evidence-informed decision-making.

The conclusions and recommendations will be finalized after the foundation conference “Past, Present, and Future of Evidence-Informed Decision-Making.”

We look forward to your suggestions and contributions to this section.

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- Ms. Lindsay Campbell, Interim Vice-President, Population Health and Research, Cape Breton District Health Authority
- Prof. Murray Enkin, Professor Emeritus, Departments of Clinical Epidemiology and Biostatistics, Obstetrics and Gynecology, Faculty of Health Sciences, McMaster University
- Mr. Billy Fashanu, Southend Hospital, U.K.
- Dr. Mark Gibson, Deputy Director, Center for Evidence-Based Policy, Oregon Health and Science University
- Prof. Paula Goering, Centre for Addiction and Mental Health, University of Toronto
- Dr. Jeremy Grimshaw, Ottawa Health Research Institute; University of Ottawa.
- Ms. Carrie Hayward, Mental Health Rehabilitation and Reform Branch, Ontario Ministry of Health and Long-Term Care
- Ms. Deborah Jeske, Vancouver Hospital
- Dr. Judith Krajnak, consultant, Vancouver
- Prof. Raymond P. LeBlanc, Dalhousie University
- Mr. John Malcom, Cape Breton District Health Authority
- Mr. Murray Martin, Hamilton Health Sciences Centre
- Prof. Maurice McGregor, McGill University Health Centre
- Mr. Bob Nakagawa, Assistant Deputy Minister, Pharmaceutical Services, Ministry of Health, British Columbia
- Dr. Linda Peritz, Vancouver Coastal Health Research Institute
- Mr. Peter Quick, Vancouver Coastal Health Authority
- Dr. Denis Roy, Agence de la santé et des services sociaux de la Montérégie
- Dr. Stephen Simmons, Haringey Teaching Primary Care Trust, London
- Ms. Susan E. Smith, Wayfinder Consulting Incorporated, Halifax
- Mr. Darryl Sturtevant, Assistant Deputy Minister, Strategic Policy and Planning, Children and Youth Services Ministry, Ontario
- Mr. Hubert Van Griensven, Southend Hospital, U.K.

Selection process and criteria

In the fall of 2006, the foundation launched a call for stories:

“We’d like to capture your stories of successful (and not-so-successful) efforts to encourage evidence-informed decision-making, as well as any unanticipated consequences you may have encountered.”

We invited stories of evidence-informed decision-making:

- highlighting innovative approaches;
- showing how organizations made it routine to acquire, assess, adapt, and apply research;
- demonstrating the value of using research to inform decisions; and
- describing the challenges and pitfalls.

The 30 stories received were reviewed by a panel of three foundation staff using the following criteria:

1. The initiatives profiled must be either initiated (or at least co-initiated) by a provider organization or a policy organization such as a ministry of health.
2. There is preference for initiatives aimed at improving/increasing the organization’s long-term capacity to use research.
3. Some evidence of success or other impacts are included.
4. There is some discussion of the factors that seem to have supported and/or hindered the organization’s capacity to use research.

In addition, the set of stories finally selected should include:

1. both successes and failures, as well as stories that provoked unanticipated consequences; and
2. some stories involving the programs offered by the foundation.

On the basis of these criteria, 12 stories were forwarded to the authors of this book for consideration, along with the contact details for those nominating the stories. They selected nine for inclusion in this draft edition, mindful of featuring case studies from across the provinces as well as outside of Canada.

About the Authors

Melissa Sweet, a freelance health writer, journalist, and adjunct senior lecturer in the school of public health at the University of Sydney, has been writing about the promises and pitfalls of evidence-informed healthcare for more than a decade. Together with Judy and Les Irwig, she published *Smart Health Choices* (Allen and Unwin, 1999), which gave readers some tools for critically assessing health information. Ms. Sweet recently published a non-fiction book, *Inside Madness* (Pan Macmillan, 2006), which combines a number of stories, including that of murdered psychiatrist Margaret Tobin, the difficulties of achieving change in complex health systems, and a history of mental health in Australia. This year, she will publish another health-related book (ABC Books).

Award-winning journalist, author, and documentary maker **Ray Moynihan** is an internationally recognized health writer, a visiting editor with the *British Medical Journal*, and conjoint lecturer at the University of Newcastle. He has a global reputation for writing critically about the dangers of modern medicine and how to reform it.

His 2005 book *Selling Sickness* has been successfully sold in many nations, including the United States, the U.K., Canada, and across Asia and Europe. It is being translated into Japanese, Chinese, Italian, Greek, and Spanish, among other languages, it has inspired several TV and radio documentaries, and it was short-listed for a Walkley and Queensland Premier's Award.

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