

HEALTHCARE

# POLICY

## Politiques de Santé

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

**Volume 6 + Special Issue**

*“Going for the Gold”:  
Celebrating 20 Years of Experience in  
Population-Based Research in Manitoba and Beyond*

*« À la recherche de l’or » :  
célébrer 20 ans d’expérience en recherche fondée  
sur la population au Manitoba et ailleurs*

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*Healthcare Policy/Politiques de Santé* seeks to bridge the worlds of research and decision-making by presenting research, analysis and information that speak to both audiences. Accordingly, our manuscript review and editorial processes include researchers and decision-makers.

We publish original scholarly and research papers that support health policy development and decision-making in spheres ranging from governance, organization and service delivery to financing, funding and resource allocation. The journal welcomes submissions from researchers across a broad spectrum of disciplines in health sciences, social sciences, management and the humanities and from interdisciplinary research teams. We encourage submissions from decision-makers or researcher–decision-maker collaborations that address knowledge application and exchange.

While *Healthcare Policy/Politiques de Santé* encourages submissions that are theoretically grounded and methodologically innovative, we emphasize applied research rather than theoretical work and methods development. The journal maintains a distinctly Canadian flavour by focusing on Canadian health services and policy issues. We also publish research and analysis involving international comparisons or set in other jurisdictions that are relevant to the Canadian context.

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*Healthcare Policy/Politiques de Santé* cherche à rapprocher le monde de la recherche et celui des décideurs en présentant des travaux de recherche, des analyses et des renseignements qui s'adressent aux deux auditoires. Ainsi donc, nos processus rédactionnel et d'examen des manuscrits font intervenir à la fois des chercheurs et des décideurs.

Nous publions des articles savants et des rapports de recherche qui appuient l'élaboration de politiques et le processus décisionnel dans le domaine de la santé et qui abordent des aspects aussi variés que la gouvernance, l'organisation et la prestation des services, le financement et la répartition des ressources. La revue accueille favorablement les articles rédigés par des chercheurs provenant d'un large éventail de disciplines dans les sciences de la santé, les sciences sociales et la gestion, et par des équipes de recherche interdisciplinaires. Nous invitons également les décideurs ou les membres d'équipes formées de chercheurs et de décideurs à nous envoyer des articles qui traitent de l'échange et de l'application des connaissances.

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## A Shining Light in Canada's Health Information System

**I**N MARCH 2010, SEVERAL HUNDRED PEOPLE GATHERED IN WINNIPEG TO CELEBRATE the 20th anniversary of the Manitoba Centre for Health Policy (MCHP). This international conference ranged from reminiscences of the founding of the Centre to prospects for the future, and from the Manitoba Ministry of Health and a broad policy perspective to more technical and academic matters. All in all, this diversity was a fair reflection of the breadth and depth of MCHP's many accomplishments over the years.

The core idea of MCHP, founded by Noralou and Leslie Roos, both professors at the University of Manitoba, is in one sense very simple. But at the time, it required a unique mixture of both small and large "P" political savvy, and strong knowledge ranging across computing, databases, healthcare policy and medicine. This simple idea was akin to making art from found objects. In this case, the found objects were the electronic records kept routinely by the Manitoba Ministry of Health of patients' encounters with the healthcare system – such as hospital stays, doctor visits, drug prescriptions and admissions to nursing homes. The art was in seeing the tremendous analytical potential of these data if they were used in a more epidemiological manner rather than only in routine administrative processes. Indeed, the brilliant construction was seeing all these data elements as not only a heterogeneous set (a bagful) of data on discrete healthcare encounters, but rather as linked patient trajectories.

With appropriate (but not that easy, initially) software, the discrete encounters could be linked together, patient by patient, in order to tell stories of how the healthcare system was working (or not) from the patient's perspective, not just from the provider's. For the providers, such as hospitals, the data were already well suited to keeping track, for example, of how many surgical procedures of various sorts were being performed. But these data said nothing about how well patients were doing, beyond quite rudimentary indicators such as whether the patient was readmitted after a hospital procedure. And even this latter indicator, as shown in one of MCHP's early seminal analyses, could be grossly misleading.<sup>1</sup> In this study, Winnipeg hospitals' post-operative complication rates, signaled by subsequent hospital readmissions, almost doubled when, in addition to readmissions to the hospital where the procedure had been done, admissions to other hospitals elsewhere in the province were added. This latter step became feasible only when the data were linked on a patient basis for the entire province, and not only within each hospital.

Evidence such as this was critical to establishing both the feasibility and the importance of this kind of analysis. And in doing so, MCHP became not only a Canadian leader, but also a world leader. But undertaking analyses such as these was not typical of the kinds of health

research funded in Canada – it was not “basic” research with test tubes or mass spectrometers, but it still required infrastructure costs well beyond the means of the typically sized grants of the day. The gestation and birth of MCHP, in addition to the core analytical idea, therefore required the understanding and support of a broader group. In particular, this involved the Manitoba Ministry of Health – both the minister at the time, Donald Orchard, and the deputy minister, Frank Maynard, as well as the president and founder of the Canadian Institute for Advanced Research (CIAR, now CIFAR), Fraser Mustard. The Ministry of Health was the prime user of MCHP’s analytical results, and had the resources to provide the core long-term funding needed. CIFAR, especially its program in population health, provided a broader intellectual milieu and framework, especially in the recognition of the fundamental importance of focusing on entire populations, and not only on highly selected (and typically unrepresentative) subpopulations.

There is one more key ingredient in MCHP’s success – its continuing allocation of skill and effort in communicating and engaging with those most likely to be able to make use of their analytical findings. The Centre has long recognized that academic publications are necessary, but by no means sufficient. MCHP’s current director, Pat Martens, has exemplified this by her award-winning work and direct contacts with healthcare providers and regional health authorities across the province as well as with ministry staff.

One major signal of MCHP’s success is the expanding ambit of the data its analyses encompass. From the perspective of the framework developed by CIFAR’s population health program, this is entirely natural given its seminal work in explicating the broader social determinants of health. From the perspective of the Manitoba government, the growing span of linked data is an indication that other ministries – education, social services, justice – have also come to appreciate the potential and power of analyses from the individual or client’s perspective, rather than only the perspective of the service provider. And not to be minimized is the implicit acceptance of the increasingly extensive linkage of personal records from the perspective of those charged with privacy protection. The data held by the Centre, while all anonymized, are still extremely sensitive. MCHP’s policies and practices, ranging from physical security to regular training and sensitization of all staff, to security audits, accreditation processes and regular meetings with the provincial Ombudsman’s Office, have all served to endow MCHP with the confidence needed for it to undertake and expand its record linkage-based analyses.

The five main conference papers plus the 12 brief workshop reports in this special issue of *Healthcare Policy/Politiques de santé* provide a wonderful tour of the history and prospect for MCHP. They also bring in new perspectives, in particular, similar work in other centres.

The accounts of MCHP’s work featured in this special issue also signal an important challenge. We have clear evidence in the Centre’s accomplishments, both of their great importance and the critical success factors. But we still do not have in Canada similar high-quality capacities across the country, nor an integrated pan-Canadian capacity. Of course, Canada’s constitutional structure means that developments in each province and territory will follow their own paths. National initiatives by Health Infoway, the Canadian Institute for Health Information (CIHI) and Statistics Canada are also important. Still, progress in expanding and building upon the Manitoba example has been disappointingly slow.

Where are the impediments? MCHP (among other centres) has shown that privacy concerns are not the issue; nor is it anything to do with the potential power of the analytical results. Perhaps it is this very power, though, that is at the root of the lack of progress. Data and resulting analyses that enable citizens and governments to understand better what is working in the healthcare system – and, more importantly, what is not working – pose a threat to those who benefit from the status quo. The benefits of a healthcare system that works smarter rather than harder are diffuse – lower, or more slowly growing, healthcare costs benefit the public generally, but each person to only a small degree. But for the fewer who will not have to work as hard (or not have as much work), there will be a more concentrated drop in their incomes.

Another impediment is the scale of funding needed for sustained intensive analyses of linked personal data with the kinds of massive data sets at the foundation of MCHP's work. While Canada's research granting councils recognize the fundamental importance of basic infrastructure in the form of telescopes and particle accelerators, and more recently in multi-centre clinical trials and primary data collection from large-scale cohort studies, this recognition is not as well acknowledged in the case of secondary data analysis. That being said, MCHP is again showing its leadership. It has twice been successful in obtaining substantial CFI funding for the data laboratory – once in 1999, and most recently in 2010. These successes indicate a growing acceptance of the critical importance of this type of infrastructure. Hopefully, the accounts in this special issue celebrating the 20th anniversary of the Manitoba Centre for Health Policy will be a harbinger for further diffusion and growth of this kind of best practice across Canada and internationally.

MICHAEL WOLFSON  
*Guest Editor*

NOTE

<sup>1</sup> Wennberg, J.E., N. Roos, L. Sola, A. Schori and R. Jaffe. 1987 (February 20). "Use of Claims Data Systems to Evaluate Health Care Outcomes. Mortality and Re-operation Following Prostatectomy." *Journal of the American Medical Association* 257(7): 933–36.

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ÉDITORIAL

## Signaux lumineux dans le système d'information sur la santé au Canada

**E**N MARS 2010, PLUSIEURS CENTAINES DE PERSONNES SE SONT RÉUNIES À WINNIPEG pour célébrer le 20<sup>e</sup> anniversaire du Centre des politiques de santé du Manitoba (Manitoba Centre for Health Policy, MCHP). Ce colloque international abordait des

sujets allant de la commémoration de la fondation du MCHP aux promesses d'avenir, en passant par le ministère de la Santé, un vaste éventail de points de vue politiques et des sujets plus techniques ou scientifiques. En tout, cette diversité était un fidèle reflet de l'ampleur et de la profondeur des nombreuses réalisations du MCHP au cours des années.

L'idée principale du MCHP, fondé par Noralou et Leslie Roos, tous deux professeurs à l'Université du Manitoba, est d'une certaine façon une idée très simple. Mais à l'époque, il fallait posséder un ensemble particulier de connaissances pratiques *des* politiques et *de la* politique ainsi qu'une bonne connaissance de l'informatique, des bases de données, des politiques de santé et de la médecine. Cette idée ressemblait aux œuvres d'art créées avec des objets trouvés. Dans ce cas, les objets trouvés étaient les dossiers électroniques compilés de façon routinière par le ministère de la Santé du Manitoba, qui documentait l'interaction des patients avec le système de santé, par exemple, les séjours à l'hôpital, les consultations auprès du médecin, les médicaments sur ordonnance et les admissions dans les maisons de soins infirmiers. L'œuvre d'art était de voir l'extraordinaire potentiel analytique que permettaient ces données si elles étaient utilisées selon une approche plus épidémiologique plutôt que simplement comme un processus administratif routinier. En effet, l'idée brillante consistait à voir tous ces éléments non seulement comme un ensemble (un panier) hétérogène de données sur les interactions individuelles avec le système de santé, mais plutôt comme les trajectoires des patients qui pouvaient être liées entre elles.

Avec les logiciels appropriés (mais, au début, avec quelques difficultés), les interactions individuelles pouvaient être liées entre elles, patient par patient, de façon à dégager l'historique du fonctionnement (bon ou mauvais) du système de santé, et ce, du point de vue du patient, non seulement du point de vue du fournisseur. Pour les fournisseurs de services, tels les hôpitaux, ces données pouvaient déjà servir à connaître, par exemple, le nombre de diverses chirurgies qui étaient pratiquées. Mais ces données ne révélaient presque aucune information sur l'état des patients, mis à part quelques indicateurs rudimentaires concernant, par exemple, la réadmission d'un patient après une intervention à l'hôpital. Et même, cet indicateur pouvait mener à de mauvaises interprétations, comme l'a démontré une analyse de fond menée au tout début de l'existence du MCHP<sup>1</sup>. Dans cette étude, les taux de complications postopératoires dans les hôpitaux de Winnipeg, signalés par les réadmissions subséquentes, doubleraient presque quand, en plus des réadmissions à l'hôpital où l'intervention avait été pratiquée, on tenait aussi compte des réadmissions à d'autres hôpitaux dans la province. Cette constatation n'a été possible que lorsque les données ont été couplées, sur la base du patient, pour toute la province et non seulement pour chacun des hôpitaux.

De telles observations étaient cruciales pour établir la faisabilité et l'importance de ce genre d'analyses. Ce faisant, le MCHP est devenu non seulement un leader au Canada, mais aussi dans le monde. Mais ce type d'analyses n'était pas habituel dans le cadre de la recherche en santé financée au Canada – il ne s'agissait pas de recherche « fondamentale », avec des éprouvettes ou des spectromètres de masse; cette recherche nécessitait, malgré tout, des coûts d'infrastructure qui allaient bien au-delà des moyens accordés par les subventions typiques de l'époque. La naissance du MCHP, de même que de l'idée analytique principale, néces-

sitait donc la compréhension et le soutien d'un groupe plus grand. En particulier, il fallait compter sur le ministère de la Santé du Manitoba – à l'époque, il s'agissait du ministre, Donald Orchard, du sous-ministre, Frank Maynard, et de Fraser Mustard, président et fondateur de l'Institut canadien de recherches avancées (ICRA). Le ministère de la Santé était l'utilisateur principal des résultats des analyses du MCHP et avait les ressources pour en assurer les besoins financiers de base à long terme. Pour sa part, l'ICRA, et en particulier son programme « Santé des populations », offrait un milieu intellectuel et un cadre de travail plus ouvert, spécialement pour la reconnaissance de l'importance fondamentale d'étudier des populations entières au lieu de sous-groupes soigneusement choisis (et habituellement non représentatifs).

Un autre élément clé du succès du MCHP réside dans le talent et les efforts constants pour communiquer les résultats analytiques et, par le fait même, impliquer ceux qui sont les plus susceptibles de les utiliser. Depuis longtemps, le MCHP reconnaît l'importance des publications scientifiques, mais elles restent insuffisantes en soi. La directrice actuelle du MCHP, Pat Martens, a mis en pratique cette approche par son travail (qui a reçu des prix) et par ses contacts directs avec les fournisseurs de services de santé, avec les offices régionaux de la santé de toute la province et avec les employés du ministère.

Un des principaux signes du succès du MCHP est l'expansion de la portée des données sur lesquelles portent les analyses. Du point de vue du programme « Santé des populations » de l'ICRA, cela est tout naturel étant donné son travail de base qui cherche à mieux connaître les grands déterminants sociaux de la santé. Pour le gouvernement du Manitoba, l'envergure croissante des données couplées indique que d'autres ministères (Éducation, Services sociaux ou Justice) reconnaissent le potentiel et l'importance des analyses portant sur le point de vue de l'individu ou du client et non seulement sur celui du fournisseur de services. Et il ne faut pas négliger non plus l'acceptation implicite, de la part de ceux qui sont responsables de la protection de la confidentialité, d'un couplage de plus en plus généralisé à partir de dossiers personnels. Bien qu'elles soient anonymes, les données traitées par le MCHP sont extrêmement délicates. Les politiques et les pratiques du MCHP, allant de la sécurité du matériel à la conscientisation et à la formation continue du personnel, en passant par les audits de sécurité, les procédures d'accréditation et les réunions régulières avec le Bureau de l'ombudsman de la province, ont permis au MCHP d'acquérir la confiance nécessaire pour mener et accroître ses analyses fondées sur le couplage des dossiers.

Les cinq principaux articles de la conférence et les 12 courts résumés des ateliers présentés dans ce numéro spécial de *Politiques de Santé/Healthcare Policy* offrent un excellent aperçu de l'histoire et de l'avenir du MCHP. Ils apportent également un nouvel éclairage sur le travail semblable que font d'autres centres.

L'état des travaux du MCHP présentés dans ce numéro spécial fait également voir d'importants défis. Nous avons des preuves solides des réalisations du MCHP, tant de leur importance que des facteurs liés au succès. Mais il n'existe toujours pas une capacité de même qualité dans l'ensemble du pays ou dans ses différentes parties. Bien sûr, la structure constitutionnelle du Canada conditionne les provinces et les territoires à suivre leurs propres cheminements. Les initiatives nationales d'Inforoute Santé du Canada, de l'Institut cana-

dien d'information sur la santé (ICIS) et de Statistique Canada sont importantes. Encore là, l'expansion et la mise à profit de l'exemple du Manitoba se font malheureusement très lentement.

Quels en sont les empêchements? Le MCHP (parmi d'autres centres) a démontré que les préoccupations en matière de confidentialité n'en sont pas la raison; pas plus que ne l'est le potentiel des résultats analytiques. Peut-être que ce potentiel même est à la source du manque de progrès. Les données et les analyses connexes qui permettent aux citoyens et aux gouvernements de mieux comprendre ce qui fonctionne dans le système de santé – et, sans doute plus important, ce qui ne fonctionne pas – représentent une menace pour ceux qui tirent profit du *statu quo*. Les avantages d'un système de santé qui fonctionne aisément plutôt que difficilement sont diffus : des coûts plus bas ou qui augmentent lentement sont avantageux pour le grand public, mais seulement à un faible degré pour chacun des contribuables. Mais pour les quelques personnes qui ne devront pas travailler aussi fort (ou qui n'auront pas autant de travail), il y aura un plus grand apport dans leurs bénéfices.

Un autre empêchement est le taux de financement nécessaire pour effectuer des analyses détaillées de longue haleine portant sur des données personnelles et utilisant le type d'ensemble de données massives qu'on trouve au MCHP. Alors que les organismes subventionnaires canadiens reconnaissent l'importance fondamentale des infrastructures de base, telles que les télescopes ou les accélérateurs de particules, et plus récemment les essais cliniques multicentriques ou la collecte de données primaires provenant d'études à grande échelle sur des cohortes, cette reconnaissance n'est pas encore pleinement accordée aux analyses de données secondaires. Cela dit, le MCHP continue de démontrer son leadership. À deux occasions, il a su obtenir un important financement de la part du FCI pour le laboratoire de données (en 1999 et en 2010). Ces faits indiquent une acceptation grandissante de l'importance de ce type d'infrastructure. Espérons que les travaux présentés dans ce numéro spécial à l'occasion du 20<sup>e</sup> anniversaire du Centre des politiques de santé du Manitoba serviront de signe avant-coureur pour une plus grande diffusion et pour l'accroissement de ce genre de pratiques d'excellence au Canada et à l'échelle internationale.

MICHAEL WOLFSON

*Éditorialiste de collaboration spéciale*

NOTE

<sup>1</sup> Wennberg, J.E., N. Roos, L. Sola, A. Schori et R. Jaffe. 1987 (20 février). "Use of Claims Data Systems to Evaluate Health Care Outcomes. Mortality and Re-operation Following Prostatectomy." *Journal of the American Medical Association* 257(7): 933–36.

IT HAS BEEN AN HONOUR AND A PRIVILEGE TO HAVE PARTICIPATED IN THE DEVELOPMENT of both the scientific program for the 20th Anniversary Conference of the Manitoba Centre for Health Policy (MCHP) and this supplementary issue of *Healthcare Policy/Politiques de santé*. The conference was intended to be a combination of a celebration of the Centre's success and a brief overview of the work that has contributed to this success. This supplement provides the opportunity for those who were not there to share the learning from the conference.

MCHP's mission statement describes the work of the Centre as three pillars: support and development of the Population Health Research Data Repository ("the Repository"); the research done with this series of over 90 linkable databases; and knowledge translation (i.e., transforming research into action). The conference agenda shared our experience in all three aspects of MCHP's work. This supplement is a small contribution to our multifaceted, award-winning knowledge translation activities.

There has been so much ground-breaking work at the Centre over the last 20 years that it was a challenge to decide what to include. The inclusion of the work of colleagues and collaborators from across Canada in the conference ensures that we have presented a broad range of the current innovative data linkage research.

The Repository, developed under co-founding director Leslie Roos, has turned into a unique resource for Manitoba-based population health research. Through his work on creating the Concept Dictionary, this has turned into a widely respected international resource. Such development required vision, expertise and an ongoing collaborative relationship with those who manage the multiple data sources.

These relationships have become a hallmark of MCHP's success. Relationships with the end users of the research are fundamental to the model of knowledge translation promoted by MCHP and exemplified by the work of current director Patricia Martens with *The Need To Know Team*. The nature of these relationships is reflected in the attendance of the premier, the minister of health, numerous deputy ministers and Regional Health Authority executives at the celebration dinner held at the conference.

Finally, MCHP is foremost a research centre, and one that has set the standard for policy-relevant population health and health services research in Canada. From the ground-breaking early work of founding director Noralou Roos looking at the small area variation in the provision of tonsillectomies in Manitoba, to the wide variety of studies describing the impact of social determinants on both the health of Manitobans and the health services they use, MCHP scientists continue to explore new methodologies to produce the evidence needed to provide Manitoba's residents with the best possible health services.

Thank you to all who have contributed to this supplement: guest editor Dr. Michael Wolfson, all the contributing authors and managing editor Ania Bogacka.

ALAN KATZ  
Project Editor

C'EST UN HONNEUR ET UN PRIVILÈGE D'AVOIR PARTICIPÉ AU DÉVELOPPEMENT DU programme scientifique pour le colloque du 20<sup>e</sup> anniversaire du Centre des politiques de santé du Manitoba (MCHP) ainsi qu'à la parution de ce numéro spécial de *Politiques de Santé/Healthcare Policy*. Le colloque était à la fois une célébration des succès du Centre et un aperçu du travail qui y a contribué. Ce numéro spécial est l'occasion, pour ceux qui n'étaient pas présents au colloque, de prendre connaissance des sujets abordés.

L'énoncé de mission du MCHP décrit le travail du Centre en fonction de trois piliers : le maintien et le développement du Registre de données de recherche sur la santé de la population (le « Registre »); la recherche effectuée à partir de cette série de plus de 90 bases de données qui permettent un couplage entre elles; et le transfert de connaissances (c'est-à-dire, la transposition de la recherche en actes concrets). Le programme du colloque nous a permis de partager l'expérience dans les trois aspects du travail du MCHP. Ce numéro spécial est une petite contribution à nos activités polyvalentes de transposition de connaissances, lesquelles ont d'ailleurs remporté des prix.

Au cours des 20 dernières années, il y a eu tant de travaux novateurs au MCHP qu'il était difficile d'arrêter un choix pour le colloque. Les travaux de collègues et de collaborateurs de partout au Canada inclus au programme du colloque représentent un vaste éventail de la recherche novatrice effectuée à partir de données couplées.

Le Registre, développé sous la direction du cofondateur Leslie Roos, est devenu une ressource unique pour la recherche en santé fondée sur la population au Manitoba. Son travail pour la création du « dictionnaire de concepts » en a fait une ressource grandement respectée à l'échelle internationale. Un tel travail a nécessité une vision, une expertise et une relation de collaboration continue avec ceux qui gèrent les sources multiples de données.

Ces relations sont devenues le sceau du succès du MCHP. Les relations avec les utilisateurs finaux de la recherche sont essentielles pour le modèle de transposition de connaissances favorisé par le MCHP; le travail de la directrice actuelle, Patricia Martens, avec l'équipe *Need to Know* en est un excellent exemple. La présence du premier ministre, du ministre de la Santé, de nombreux sous-ministres et responsables d'offices régionaux de la santé au dîner de célébration, organisé lors du colloque, témoigne de la nature de ces relations.

Le MCHP est avant tout un centre de recherche, un centre qui a su établir les standards canadiens d'une recherche pertinente sur la santé de la population et sur les services de santé. Depuis les premiers travaux novateurs du directeur fondateur, Noralou Roos, qui étudiait les variations régionales de l'amygdalectomie au Manitoba, jusqu'à la grande variété d'études qui décrivent l'impact des déterminants sociaux tant sur la santé des Manitobains que sur leur utilisation des services, les chercheurs du MCHP continuent de mettre à profit de nouvelles méthodologies afin de produire les données scientifiques nécessaires pour offrir aux résidents du Manitoba les meilleurs services de santé possibles.

Merci à tous ceux qui ont contribué à ce numéro spécial : l'éditorialiste de collaboration spéciale, Michael Wolfson, tous les auteurs des articles ainsi que Directrice de rédaction, Ania Bogacka.

ALAN KATZ  
Directeur de projet

# Administrative Data and the Manitoba Centre for Health Policy: Some Reflections

## Données administratives au Centre des politiques de santé du Manitoba : réflexions



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### Abstract

The authors review their 30 years' experience in determining the best research applications for routinely collected data from ministries of health, education and social services. They describe the rich research opportunities afforded by 40 years of data on health – i.e., every patient contact with hospitals, physicians, drugs and more – from the problems encountered in convincing an academic journal that meaningful findings could be culled from information collected on paying bills and tracking patients, through studies on education (enrolment, grades, stand-

ardized tests for grades 1 to 12), family characteristics (residential moves, marital formation and breakdown, number and timing of births) and social services (welfare recipients, children taken into care, protection services offered children in the family). They also detail how and why the Manitoba Centre for Health Policy was founded, and how it has continued through multiple ministerial, deputy and government changes.

## Résumé

Les auteurs ont examiné leurs 30 années d'expérience dans le recensement des meilleurs applications de recherche que permet la collecte routinière de données auprès des ministères de la Santé, de l'Éducation et des Services sociaux. Ils décrivent les riches possibilités de recherche que permettent les données de santé recueillies pendant 40 ans – soit chacun des contacts des patients avec l'hôpital, le médecin, les médicaments ou autres – et ce, allant des problèmes qui surgissent au moment de convaincre une revue scientifique que des résultats significatifs peuvent découler de l'information recueillie sur les factures payées et le suivi des patients, en passant par les études sur l'enseignement (inscriptions, classes, tests normalisés pour les classes de niveaux 1 à 12), les études sur les caractéristiques familiales (déménagements, mariages et séparations, taux et fréquence de natalité) et les études sur les services sociaux (bénéficiaires d'aide sociale, enfants pris en charge, services de protection offerts aux enfants dans une famille). Les auteurs expliquent également comment et pour quelles raisons a été fondé le Centre manitobain des politiques en matière de santé, et comment il a continué ses activités en dépit de plusieurs changements de ministères, de délégués et de gouvernements.

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**B** EING OFFERED 4,500 WORDS TO REFLECT UPON AND REVIEW OUR PROFESSIONAL lives is a privilege – and also a challenge. This offer gave us the opportunity to go back through files, datebooks and dusty folders, coming across long-lost memories and events.

Because creating a history of the Manitoba Centre for Health Policy (MCHP) and its work with administrative data is central to this exercise, we'll start there. The historical review identified a whole series of "highlights" – events that were particularly important, memorable and fun to recount. The review also prompted a focus on "lessons learned" – insights that may resonate with others trying to work in similar circumstances. The review also revealed a series of challenges that we faced and mostly survived. Finally, all this reflection underscores what remains to be done – the opportunities for the next generation of those working with administrative data and setting up policy centres.

## Our History of Working with Administrative Data

Meeting Paul Henteleff, Assistant Executive Director, Health Services at the Manitoba Health Services Commission, who was responsible for the data section, and becoming aware of the remarkably rich, routinely collected electronic hospital and physician records for the Manitoba population, was unquestionably where everything started. We had recently arrived

from the United States, where Noralou had conducted a series of interviews to determine the problems with a fractious, stalled merger of the Northwestern teaching hospitals. The potential for conducting research with anonymous data already collected on all Manitobans who existed in the past and present was most attractive.

We started working with tonsillectomy both because it was a clinical issue of some interest to Paul Henteleff and the Manitoba Health Services Commission at that time, and because the American Academy of Pediatrics guidelines based its assessment of appropriateness on the *number* of episodes of respiratory illness a child experienced. The number of times a child had been seen by a physician for such problems in the period before surgery could be counted using claims data. The first paper submitted for publication was rejected because reviewers doubted the validity of the diagnoses entered on physicians' claims. Fortunately, the next month the *New England Journal of Medicine* published a paper assessing the validity and reliability of clinical judgments (Koran 1975). Koran reported both intra-observer agreement (agreement of a physician with himself/herself regarding repeated observations) and inter-observer agreement (agreement of two or more physicians with one another). The same approach could be used for assessing the validity of diagnoses on physician claims. We compared the two diagnoses received by patients who had a respiratory diagnosis and who had a second physician visit with a respiratory diagnosis within one week following their first visit. Agreement rates on these two visits were almost as high as Koran found in his research (Roos, Henteleff et al. 1977). Because some of the mismatches included such complaints as injuries or broken bones (which clearly could have reflected a new accurate diagnosis), reviewers were convinced that the administrative data were a valid research resource – and we had our first two major publications (Roos, Henteleff et al. 1977; Roos, Roos et al. 1977).

In the 1980s we continued with surgical procedures that are easy to study with administrative data, including cholecystectomy, hysterectomy, prostatectomy and hip replacement. There was little disagreement about whether a surgical procedure had occurred, and complications, particularly when they involved revisions (hip replacement) and re-operation (prostatectomy), were interesting and easy to track. The administrative data showed real strengths: revision rates for prostatectomy over an eight-year follow-up period were more than double the highest estimate available from the published literature (Wennberg et al. 1987). Several reasons were found for the discrepancies between our findings and those published in the literature. Patients were sometimes unavailable for follow-up, and in some cases there were shorter periods of follow-up. When patients had complications following a procedure, they often didn't go back to the same surgeon and hence were being missed in the published data, which focused on one group's or one hospital's patients.

A major innovation came when Les decided we could and should use the health system registration data to track whether someone did not have a complication following surgery because he or she was healthy and had no problems, or because the patient had left the province and hence was lost to follow-up. Noralou was miffed at the time because this meant completely reanalyzing a set of hysterectomy outcomes data – and made little difference to the results. But the concept of the research registry and our ability to track an individual's

presence (or absence owing to moves or death) over long periods of time greatly expanded the questions that could be addressed.

Each of these clinical issues was approached working with a clinical specialist in the area – often the head of the department. We focused on hip replacement because an orthopaedic surgeon, David Lyttle, was concerned about quality-of-care issues and thought the administrative data could be used to look at re-operation rates. We found that 2.7% of patients required re-operation within two years and 4% of patients were readmitted to hospital with other surgical complications (Roos and Lyttle 1985). Our first non-surgical focus involved mortality rates associated with acute myocardial infarct (AMI) and working with a cardiologist, Andrew Morris, who was interested in standards of care in rural Manitoba (Morris et al. 1983). Concerned that out-of-hospital deaths might not be recorded in the Ministry of Health database with which we were working, we met with the local office of Vital Statistics and started a relationship resulting in the annual transfer of mortality data (including cause of death) from their offices to us at the university. This addition significantly improved the database, providing both a check on the registry and independent information on cause of death.

We also accomplished our first merger of administrative data with survey data – a representative cohort of elderly Manitobans interviewed as part of an initiative by the provincial gerontologist, Betty Havens (Mossey et al. 1981). This merger allowed us to address such important questions as, “Are those patients who are *not* accessing care, or not visiting physicians, individuals who are very sick and isolated and in need?” As we found using the survey data, the non-users in a universally funded healthcare system were basically healthy individuals (Shapiro and Roos 1985).

In 1984 the University of Manitoba and the Manitoba Health Services Commission exchanged letters, and the university accepted responsibility for housing the anonymized database. Over these early years we had little contact with the owners of the data, the Manitoba Health Services Commission, except with regard to new data requests. We spent little time with anyone in the Ministry of Health. Every three to five years when we wanted to add to or update our data sets, we would invite a prominent researcher (John Bunker came from Stanford University in 1986) to speak to key individuals in the ministry about how important the research was. Such advocacy helped us maintain access to the data. We also did little with the press. After one bad experience with a headline, whenever called by a reporter, Noralou would be as boring and dry and brief as possible.

All the work was supported by external funding agencies on topics that we, as researchers, identified as interesting and doable. In the mid-80s our funding level had grown from \$300,000 to \$400,000 per year. We focused on publication in high-profile journals.

## The Academic–Ministry Interface

Then, in 1988 we were asked to join Fraser Mustard’s and Bob Evans’s population health group at the Canadian Institute for Advanced Research (CIAR). This major change led to the founding of the Manitoba Centre for Health Policy (and Evaluation) in 1990. The CIAR group was struggling to develop a new approach to understanding the full range of determinants of health. The

kinds of data and analysis being done in Manitoba were seen as both innovative and strategic.

The early years of the MCHP meant a steep learning curve. Noralou spent the first six months trying to determine who in the ministry used data for making decisions because she assumed we could provide whatever they needed. This simplistic view was quickly abandoned. She then thought that we would figure out the best set of “indicators” that could be developed from each type of data (hospitals, physicians, nursing homes), and we would then update these indicators annually. This step was important in deciding how to work with the data (and research on such indicators continues with each new data set). But it became clear that, if we were to be useful, we needed to focus on specific projects of interest to the most senior levels of the Ministry of Health. This, in turn, led to periodic meetings with the deputy minister and minister to discuss important issues facing the government, discussions that continue to this day and are central to maintaining the relevance of the MCHP’s work.

A major driver of the government’s agenda in the 1990s was the fiscal problems it and other provinces were facing, Manitoba was committed to cutting healthcare costs and particularly to closing hospital beds. Bed closures began in 1992; by 1996, 24% of the beds in Winnipeg hospitals had been closed. One of the early projects the MCHP took on was to monitor the effects of bed closures on mortality, readmission rates and access to care.

Our analyses showed that the system responded remarkably well. In the face of shortening lengths of stay and expanding outpatient surgery, we were able to detect no negative impacts on quality of care (Brownell et al. 2001). The minister wanted results as soon as possible, and we agreed to produce the first report on the first year of data available after closures began. (The MCHP typically receives the next year of data in the fall following the March 31 fiscal year-end.) With bed closures such a challenging issue (newspaper reports had predicted an increase of people dying in the streets), we were very concerned about the study’s accuracy. We wrote up the first year’s report (which found essentially no negative impact from the closures) and delivered it to the government, which planned to announce the results on a given date. One of our most uncomfortable periods was waiting for this announcement, because by then, we had the second year of data. We pulled out all stops to replicate our earlier analyses in case our early work was proven wrong. We knew the second year’s results would come in about three weeks before the announcement was due. Fortunately, the early “no negative impact” findings held.

One of our analysts (Ron Wall), on a visit in 1992 to the Manitoba Health Services Commission, noticed the collection of forms and files on cost data routinely reported by Manitoba hospitals. He suggested that we could use the cost data, combined with case-mix data created from the hospital files, to estimate comparative costs per hospital across the system. When then-Minister of Health Donald Orchard was asked at an early meeting if he would be interested in our working on these calculations, he was keen. We emphasized that this was a major job, because we would first have to demonstrate that all the pieces could be validly measured.

One of the first stages of the process compared lengths of stay for several types of patients at Winnipeg hospitals (Roos and Brownell 1994). Before the report was released, Manitoba’s Deputy Minister of Health, Frank Maynard, called together the CEOs of the hospitals to whom we presented the results. One hospital was an outlier on several of the conditions, with

its patients having the longest stays. When we got to one of the last groups of patients – those with a psychiatric diagnosis – the CEO of this “long-stay” hospital said (before he had seen the results), “Okay, I know we have a problem here; I have met with the head of psychiatry and we are trying to turn this around.” In fact, his hospital had one of the shortest lengths of stay for these patients. This interaction was helpful in convincing the group that they really didn’t know how their practice patterns compared with those of other hospitals. Our work, they somewhat grudgingly admitted, was potentially useful.

Our subsequent costing report focused attention on the high costs and high proportion of patients in Manitoba treated at teaching hospitals. As a result, teaching hospitals became a particular focus of bed cuts. Because we were not physicians, the MCHP – based in the Faculty of Medicine – was not always appreciated by other faculty members. At this time we were fortunate in having Nick Anthonisen as dean of medicine. While he didn’t always agree with our conclusions, he respected our work. As part of the release of our most controversial reports, the dean convened a faculty forum where we were able to present our results and respond to questions and criticisms.

As academics, we could bring the research of others to the attention of the deputy minister of health. During this period of bed closures, one of the vice-presidents of a teaching hospital claimed that every patient at his hospital needed to be there; there was no room for early discharge. We knew that studies of the appropriateness of acute hospital care had been done in the United States and in another Canadian province, using physician-developed measures of acuity derived from medical records. We suggested to the deputy minister that if he were interested in having us assess acuity levels, and was willing to pay extra for the necessary abstractions from hospital records, questions of appropriate hospital use could be answered. Following up on his interest, 51% of the admissions and 67% of the Winnipeg hospital days used by adults with medical conditions were assessed as non-acute (inappropriate) (DeCoster et al. 1997).

While much of our early focus was driven by the government’s cost-cutting agenda, and our results showing no negative effects were welcome, sometimes findings ran counter to government plans. The government committed early on to a strategy of redirecting rural patients, who occupied 20% of Winnipeg hospital beds, into less expensive rural hospitals. This decision seemed to make sense, as MCHP had shown how expensive care in the teaching hospitals was. In addition to saving money, such a policy appealed to the Progressive Conservative government’s strong rural base. We were asked to determine which rural hospitals needed to be expanded to absorb the patients displaced by Winnipeg hospital closures. We were reluctant to take on this project, as we were fairly sure the answer would not be what was expected. We were right; our report showed essentially no rationale for expanding rural hospitals. However, we kept the minister and his deputy briefed on our early results. To give the minister, Don Orchard, particular credit (the hospital in his constituency would have benefited from this expansion), he understood the results and gave us the opportunity to brief caucus members and explain these unwanted findings.

How we thought about what needed to be done was much influenced by our association with the CIAR Population Health Group. This group changed the dialogue across Canada,

focusing on the role played by socio-economic status and education as key determinants of health. Our research – showing the relatively high proportion of non-acute care patients in Winnipeg hospitals, the variations in surgical rates across the province and the inefficiencies in the current system – correspondingly helped to reorient thinking about the healthcare sector. In joining these two strands together, our work on acuity also showed that despite their higher rates of hospital use, hospital stays for patients who lived in the poorest neighbourhoods did not represent “social admissions,” as some suggested; patients admitted from the poorest areas had acuity levels at least as high as those of individuals from the wealthier areas.

## Key Insights Gained Over the Years

### *Organize the data infrastructure*

Les had the insight to insist on several strategies:

1. Force the use of one programming language throughout the operation – in our case, SAS. While there were a few problems and cases were made for adding other capabilities, this policy undoubtedly gave us a more efficient and more unified programming structure. New features have allowed SAS to be used in MCHP’s Remote Access Sites (secure terminals located elsewhere at the University of Manitoba).
2. Write generalized, probabilistic record linkage software using SAS. This request provided a flexible capability for putting various files together, allowing needed additions to the program to be made in a timely manner. A more recent version of the software is being used at several sites (including the Manitoba Ministry of Health), both nationally and internationally.
3. Force a centralized documentation system of definitions and code to describe how things are defined and operationalized. Our concept dictionary and research resources were made Internet-accessible in the 1990s.
4. Develop a population registry to provide a flexible way of generating population denominators. We could then understand not just who was getting health services, but who was not; not just who was enrolled in grade 12 and wrote exams, but who should have been writing them (i.e., those who had remained in Manitoba since birth and weren’t writing because they had dropped out of school or had been held back) (Roos et al. 2010).

### *Ask for all the data*

When we were first working with ministry staff to identify which data would be transferred to the university, staff asked us to specify which fields we wanted. Since we didn’t know which fields they had, and record layouts were considered confidential, this was a painful process. Eventually we realized that blank hospital discharge forms and physician claim forms would provide information on the fields potentially available. Our current approach when acquiring new files is to ask for all valid data fields (other than names and street addresses); fields once thought to be irrelevant have often proved essential for a project. These rich data files form the backbone of the repository and can be accessed when the next study is designed.

*Organize areas by health or socio-economic status*

Typically, reports organize presentation of data on areas by geographic location or alphabetically, to make the specific areas easier to find. We started early on by organizing the areas from best to worst, according to the health status of area residents (using the premature mortality ratio – i.e., rate of deaths occurring before age 75). More recently, when data on outcomes for high-risk children are presented, findings are organized by socio-economic status of the areas. We have found that multiple indicators of health and socio-economic status result in similar area rankings. (Spearman correlation between our routinely used health measure – the premature mortality ratio – and our routinely used socio-economic factor index was 0.91,  $p < 0.0001$  across 80 areas.) Such organization ensures a focus on whether access to care reflects the needs of area residents and how strongly socio-economic status is related to health and educational outcomes.

Our most compelling evidence for demonstrating the relationship of socio-economic status to health came after looking at Manton's (1991) US study estimating the life expectancy that could potentially be gained by eliminating all types of cancer – 2.8 years. We were at the time (Roos et al. 2004) producing results showing that the potential life expectancy gains to those in the lowest-income neighbourhoods would be several times as large (as the gains from eliminating cancer) if they could achieve the health status of residents of high-income neighbourhoods – i.e., 11.3 years would be potentially gained by males and 7.7 years by females.

*Data (if they are seen and understood) can change the dialogue (a bit)*

Originally, the government had pledged that all care displaced from closing hospital beds would be replaced and equivalent care would be found for these patients elsewhere in the system. With our work on acuity levels in different hospitals, unexplainable differences in lengths of stay and the variations in surgical rates found across different areas of the province, the dialogue began to focus on the potential for making the acute care sector more efficient.

However, we have been less successful in attempts to review quality of care. A great deal of outcomes research, often resulting in hospital or physician “report cards,” has been published (Robinowitz and Dudley 2006). We did early work evaluating surgical outcomes in Manitoba compared with other jurisdictions (Roos et al. 1990, 1992). Overall findings were highly favourable to Manitoba surgeons and hospitals, but the outcomes of one particular procedure performed in Manitoba hospitals (repair of hip fracture in the years 1979–1992) were worse than those in New England (Roos et al. 1996). Engaging the specialists involved in discussion of these data, or in the routine monitoring of such outcomes, proved impossible. Another project focusing on developing quality-of-care indicators for hospital comparisons proved divisive and raised serious issues with local physicians (Bruce et al. 2006). The most recent projects to succeed in monitoring quality of care have been led by a physician (Katz et al. 2006). Physician leadership may be a prerequisite for influencing the local system on quality concerns.

*Interaction between academics and policy makers is a complex process*

Policy making is clearly more complex than academics realize. We have been effective when evidence could be used in support of shifting the agenda or implementing policies that some-

one in the bureaucracy had already been working on. Often the evidence does not come as a surprise, but our making it public makes it harder to ignore; the evidence can then potentially be used to galvanize action.

Those in the Ministry of Health did not always welcome what we considered compelling data on system inefficiencies, information that we somewhat naively thought should have made their job easier. Evidence-based decision-making may require more political will than decision-making without such information. The real world is also complicated. While data may suggest that a given hospital discharges patients rapidly – a practice that would appear to be more efficient – we were also providing data showing that hospitals sometimes admit patients who do not really require acute care.

Often academics will work with information in ways that the data owners could not or would not have considered. To calculate an outcomes score across all students taking language arts exams, we combined the scores from similar tests given in different settings (to students in French immersion, those in French-language schools and those in English-language schools). This had not been done before. We could also use the health data (hospital and registry) to develop birth cohorts, ascertaining the enrolment status of each cohort member not taking a language arts test even though they were still in the province and, if they had stayed in school and continued with their cohort, should have been writing. We understood why the ministry didn't do this routinely; they could see the value in our efforts to develop population-based measures of educational achievement.

### *Ground rules for academics working with government*

On the advice of university lawyers, our first contract stated that we would have the right to publish our findings. We also agreed to take on projects that the government requested but – after an early meeting with the deputy when he made two small requests with which Noralou was uncomfortable – agreed we would not “fire-fight” (do quick studies on government request). During the early years, Noralou would always take Evelyn Shapiro (who established the provincial home care program) or Brian Postl (the head of Community Health Sciences when the MCHP was established) to meetings with the minister and his deputy. Both were highly experienced in political interactions. Noralou wanted someone there who could help sort out what we could or should, as well as what we couldn't or shouldn't, do. She was also fortunate to have a very helpful government-based liaison, Tom McCormack. He advised us on when we needed to get the deputy minister involved in dealing with the bureaucracy, when asking for a “comfort” letter or memorandum of understanding was appropriate, and so forth.

### *Working across ministries*

Working with the CIAR Population Health Group and focusing on the broader determinants of health led us to successfully seek Canadian Foundation for Innovation funding to bring education and social services databases into the repository. Work across the databases of different ministries creates high-payoff research insights. In conjunction with Marni Brownell,

we have been able to understand the “overlap” across ministries in the high-risk populations they serve: how many teen mothers have parents receiving income assistance; how many were at one point in “protection” or in care of Family Services (Roos et al. 2010). As we started working with education and Family Services data, we had a breakfast meeting with the deputies from the various ministries before our MCHP Advisory Board meeting both to report back to them on progress and to gain insight into their priorities.

### *Timelines will likely be long*

We completed our first project working with Family Services information in the mid-1990s but didn't do a second, or achieve the regular transfer of Family Services data to the MCHP, for another 10 years.

### *Challenges will occur*

The province implemented an electronic system for tracking all out-of-hospital prescription drug purchases on a patient-specific basis. Noralou was a member of the committee setting this up, and joined others in arguing for not allowing the system to be owned and run by a private company. When the lead member of this system left government to work in the private sector for a company expecting to receive the prescription data, he wrote the deputy minister warning that the MCHP's security was lax and that there were breaches of confidentiality. Subsequently, the ministry and auditors conducted a six-month review of the MCHP's operations; we came out squeaky clean, and prescription drug data were eventually transferred to the MCHP.

When the Canadian Institute for Health Information (CIHI) was established in 1994, the new director met with the deputy minister, suggesting that the MCHP was no longer needed; the ministry should just cancel our contract and depend on CIHI for needed information. Fortunately our deputy minister at the time, John Wade, appreciated the strengths of the MCHP and said “thank you, no.”

### *Working with the press*

Most academics avoid the press. However, from the time the MCHP was founded, several of us decided we needed to work with the media to ensure that our research was accurately communicated to the public. We hired a media consultant to coach our authors to ensure that they knew how to interact with media representatives (for example, always have a series of sound bites ready to get across). Because the government seemed to pay attention to us (several of the first reports were released by the deputy or minister with us in attendance at the Legislature), the press paid attention to our reports. And because the press gave extensive coverage to these reports, stakeholders (hospitals, physicians) were also forced to look closely at our analyses and respond to them. The press and stakeholder response in turn influenced how the government saw us. We have subsequently tried, and changed, many approaches – press conference versus none, op-ed opinion pieces when reports were released versus none – but working with the media to communicate key findings has remained a priority.

### *Locating a centre with external “deliverable” responsibilities*

The government was straightforward when setting up the MCHP: the funding came with the stipulation that payment was being made for services to be delivered – hence the concept of the “deliverable” projects agreed upon every year – something quite different from typical “curiosity-driven” investigator-initiated research. While initially we worked only with the Manitoba Ministry of Health, with the expansion of the repository several ministries became involved; currently, five deputy ministers serve on the MCHP Advisory Board. The MCHP is located in the Department of Community Health Sciences within the Faculty of Medicine. This arrangement has worked well when the department head and the dean are “hands off” and appreciate the unconventional academic role of the director. Over the last 20 years, MCHP Advisory Board members have sometimes questioned the reporting lines, suggesting that the director should be independent of an individual faculty and should instead report through the vice-president of research. We never pursued this suggestion. However, it has become clear in recent years that a centre such as ours must have support at the highest levels of the university, both for research that is multidisciplinary (not strictly healthcare-focused, somewhat unusual for a centre sited in a medical faculty) and for the director’s role, which involves different demands than academics typically face.

### *National and international linkage*

Linkages with researchers outside Manitoba have been attempted in several ways. We have frequently brought in speakers from elsewhere in Canada and hosted visitors (sometimes for up to a year) from other universities and centres. Arrangements have been made for timely reports to support such national efforts as the Romanow Commission (*On the Future of Health Care in Canada*). Work using the data repository with Canadian and US investigators outside Manitoba has been particularly successful; the analysis has been done on-site at the MCHP with supervision by a local researcher. Such work has led to some of our most highly cited and policy-relevant studies (Fedson et al. 1993; Forget et al. 2002; Romano et al. 1993).

Studies involving joint or cooperative data analysis across two or more provinces have had mixed success. The hurdles have included inadequate documentation of variables and differing provincial rules regarding data access and handling (Kephart 2002). Relatively simple comparative analyses using Ontario and Manitoba data have been successful (Tu et al. 2001).

Projects with Statistics Canada have suffered from “midstream” policy changes promulgated in response to federal issues. Nonetheless, important papers have resulted from such collaboration, and the potential remains great (Mustard et al. 1999).

## **Challenges for the Future**

### *Introducing new perspectives*

The possibilities for tracking health and other histories of family members across now 40 years of repository data have led to several proposals by various researchers. New data sets, such as those on housing and justice, offer unique opportunities.

*Routinizing evaluation and using administrative data to track outcomes*

We were big fans of the work of Duncan Neuhauser (1991, 1992), described years ago at Case Western Hospital, where patients entering the hospital were routinely randomized to different wards in order to compare patient outcomes and assess the effect of different staffing levels, treatments, medication approaches and more. We always thought we could and should implement something similar in the Winnipeg hospitals, using the administrative data to track outcomes; however, this has never been achieved.

*Informing the public*

We were told by deputy ministers that they “got” our messages, but our real challenge was to shape the public view. There isn’t sufficient public understanding to permit government to use our findings to set a political agenda. This shortcoming may reflect the lack of relationship between healthcare spending and health, the inefficiencies in the healthcare system or the long-term pay-offs from investing in high-risk children. Academics can say things that those in government cannot. Several of us have recently received research support to try working with the media on exactly these issues.

Another suggestion has been that we need an updated version of a Misery Index (an old idea in economics that combines the inflation rate with the unemployment rate), or, more kindly, a Social Deficit or Social Balance Sheet, to monitor progress. Gauging society’s success by growth in GDP alone needs to be challenged in informed ways. Ongoing work with the United Way and the City of Winnipeg has the potential to provide data to support efforts at improving society.

We look forward to working on some of these issues and contributing what we can to others. It has been fun!

*Correspondence may be directed to: To come...*

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# The Manitoba Centre for Health Policy: A Case Study

## Centre des politiques de santé du Manitoba : une étude de cas



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### Abstract

*Context:* The Manitoba Centre for Health Policy (MCHP) is a university research centre with a long-standing contractual arrangement with government.

*Objective:* The purpose of this project was to examine the facilitators and challenges in the development, establishment and continuation of MCHP.

*Methods:* In-depth, semi-structured interviews with 28 participants selected purposefully and a document review were conducted and analyzed using qualitative methods.

*Results:* Although a unique confluence of factors facilitated MCHP's establishment, participants viewed safeguards to credibility (arm's-length from government; guaranteed academic freedom) along with powerful advocates as key to longevity. Other factors that participants discussed as important to sustainability included excellence in scholarship; thorough protection of privacy; stable funding; incremental growth; teamwork; leadership; nurturing of relationships; and authentic partnerships.

*Conclusions:* MCHP has demonstrated that using local administrative data to address policy-related research questions is of enduring value to local and provincial communities, and also has national and international relevance.

## Résumé

*Contexte* : Le Centre des politiques de santé du Manitoba (Manitoba Centre for Health Policy, MCHP) est un centre de recherche universitaire qui compte sur une entente contractuelle à long terme avec le gouvernement.

*Objectif* : Le but de ce projet était d'examiner les facteurs facilitants et les défis liés au développement, à l'établissement et à la continuité du MCHP.

*Méthodologie* : Les renseignements recueillis par des entrevues semi-structurées en profondeur, menées auprès de 28 participants choisis expressément, et par une revue de documents ont été analysés au moyen de méthodes qualitatives.

*Résultats* : Bien qu'une confluence particulière de facteurs aient facilité l'établissement du MCHP, les participants estiment que la longévité du centre est tributaire de mesures de sauvegarde de sa crédibilité (autonomie face au gouvernement; garantie de la liberté de recherche) ainsi que de la présence de puissants porte-parole. Parmi les autres facteurs que les participants ont jugé importants pour la durabilité se trouvent l'excellence de la mission professorale, une protection rigoureuse de la confidentialité, un financement stable, une croissance incrémentielle, le travail d'équipe, le leadership, l'entretien des relations et la présence de partenariats authentiques.

*Conclusions* : Le MCHP a démontré que l'utilisation des données administratives locales pour traiter les questions de recherche sur les politiques présente une valeur durable pour les communautés locales et provinciales et est également pertinente aux niveaux national et international.

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**T**HE MANITOBA CENTRE FOR HEALTH POLICY (MCHP; "THE CENTRE") IS A research centre located in the Department of Community Health Sciences in the University of Manitoba's Faculty of Medicine in Winnipeg, central Canada. Research scientists and their collaborators at the Centre study health services, population and public health and the social determinants of health using population-based data. Formally established in 1991 with funding from the Manitoba government, it maintains a strong focus on answering questions of interest to local policy makers. The Centre has had both an academic and a policy thrust from its first contract with Manitoba Health. It now has formal associations with five government departments and 11 regional health authorities (RHAs) to address research questions aimed at improving the health of Manitoba's citizens.

MCHP's success in research endeavours has attracted national and international attention as demonstrated by multiple speaking invitations and visitors wanting to learn more about the Centre (Martens 2008; MCHP 2007a,b, 2008). Previous papers on the Centre's use of administrative databases have been cited as often as 700 times (Lewis et al. 2009).

The purpose of this project was to examine the facilitators and challenges in the development, establishment and continuation of MCHP through documenting the perspectives of people involved with the Centre as it evolved. It adds further perspectives to previously published reports by MCHP investigators (Roos et al. 2007; Roos 1999; Roos and Shapiro 1995; Bowen et al. 2005).

## Methods

A case study is both a process for learning and a choice of object to be studied (Patton 2002). It is a useful approach when the research goal is to appreciate the uniqueness and complexity of an organization within its context (Baxter and Jack 2008; Stake 2005). I used qualitative methods, including a document review and semi-structured interviews.

### *Document review*

I reviewed publicly available documents and in-house records (such as annual reports, newsletters, meeting minutes, external reviews and other materials) to inform and complement interview data.

### *Individual interviews*

In-depth, semi-structured interviews were used because a major goal was to elicit participants' accounts of the Centre's development. Questions concerned each participant's role with MCHP, challenges encountered and how they were met, key issues, events, successes and failures, other influences and – as is usual in qualitative research – follow-up questions to clarify responses.

I selected participants purposefully from a list compiled with MCHP's executive management team, the founding directors and an early mentor, Evelyn Shapiro. The individuals named most frequently were associated with the Centre's formative years.

The response rate to interview invitations was 100%. Eight of the 28 participants requested anonymity; the others explicitly agreed to mentioning their names. I interviewed the founding and current directors (3), a university department head, deans (2), a past president, a health minister, deputy ministers (3), advisory board chair and members (2), people associated with government (9), current (10) and former (4) MCHP staff (including support staff, data analysts and researchers) and others (2). Some participants had more than one role.

Interviews were audio-recorded and transcribed, and I solicited participant feedback on both records and, for some, on interview summaries prepared for a more extensive report available from MCHP (Marchessault 2010). Quotations have been edited to improve readability.

### *Analysis*

Analysis involved reviewing transcripts, coding and categorizing text to identify topics and patterns that could be developed into themes, using N-Vivo to assist with organizing data (version 8, QSR International Pty Ltd., Cambridge, MA 2009).

### *Ethical approval*

The University of Manitoba Health Research Ethics Board provided ethical approval for this project.

## Results

### *Pre-Centre events*

Although the Centre was formally created in 1991, its story begins in 1973, after Drs.

Leslie and Noralou Roos moved to Winnipeg to take positions in the business school at the University of Manitoba. Dr. Noralou Roos met Dr. Paul Henteleff, Assistant Executive Director of Health Services at the Manitoba Health Services Commission (MHSC) from 1972 to 1974, a meeting that led to the population approach to the study of healthcare in Manitoba. Dr. Roos discovered both the existence of the administrative health database, with physician and hospital billing claims for virtually all Manitobans, and an enthusiastic research collaborator. Dr. Henteleff suggested an investigation of physician visits and surgeries for tonsillectomy to evaluate against guidelines for medical care, and he facilitated access to the data.

Using computers for health research was a relatively new methodology; however, the Rooses had worked with them in the mid-1960s while completing their doctorate degrees in political science at the Massachusetts Institute of Technology. Manitoba's geography and relatively small size also facilitated this research. Records for both physician and hospital claims were held in one place by one organization. This endeavour helped build relationships and establish trust, a pre-condition for sharing personal health information concurrent with working out methods to protect confidentiality.

The tonsillectomy study was published (Roos et al. 1977a,b), and two years later a journalist's report, "End to Unneeded Surgery Sought" (Rubin 1979), got the attention of the Manitoba Legislature and the College of Physicians and Surgeons. This first research experience with MHSC data raised some important issues, such as access to data in a way that protects confidentiality but allows tracking of services to individuals; the impact of the media's presentation of research findings; and difficult relationships with physicians affected by research results who questioned the validity and relevance of the data. Centre researchers have worked to resolve these challenges, for example, by partnering with physicians to increase their receptivity to research results.

Many interviewees discussed the "terrific database" as fundamental to the Centre's success. Les Roos remarked that the Repository gave them a comparative advantage early on when competition was minimal. MCHP added data sources incrementally, going from three databases initially to about 10 when the Centre was established, to 90-plus at the 20th anniversary. "Start small and build slowly" was discussed as a success factor. Current linkages in such areas as education, social services and housing provide the ability to address many new research questions in population health. The data sets and the research scientists' innovative use of them provide the Centre's current comparative advantage.

Another early decision was to have all researchers use the same statistical analysis system (SAS), which permitted sharing of code among projects and over time. Documentation efforts such as the Concept Dictionary and Glossary (MCHP 2010) further facilitated sharing resources.

For the next 15 years, the Rooses obtained external funding to continue their research using anonymized extracted MHSC data. In the process, they pioneered a new way of doing health services research.

### *Establishment of the Centre*

On August 3, 1990, Donald Orchard, then Minister of Health in Premier Gary Filmon's

Progressive Conservative government, announced the creation of a \$3.5-million health research centre to be funded over three years (Campbell 1990). The expectation, stated within the contract, was that the Centre would become self-sustaining (Maynard and Naimark 1991: 3). As Noralou Roos pointed out, they had been self-sufficient and could easily continue to operate independently; however, if they were not funded they could not produce deliverables, the government-funded research projects.

Orchard is widely credited with making the Centre happen, and along with then-Deputy Minister of Health Frank Maynard, initiated the contacts that led to this long-lasting government–university partnership. Both said the primary factors behind their initiative were the government’s need for information to make good policy decisions in a challenging fiscal and political climate, and learning of the relevance of the Roose’s work to filling this need. They highlighted the influence of Dr. Fraser Mustard, founder of the Canadian Institute for Advanced Research, in stimulating their interest in population health and for promoting a shared understanding about the potential of the proposed research centre through meetings with the premier and members of the Manitoba Cabinet.

University leaders Dr. Arnold Naimark, president of the University of Manitoba, Dr. John Wade, dean of the Faculty of Medicine and Dr. Brian Postl, head of the newly formed Department of Community Health Sciences, each highlighted the social context of the 1970s and 1980s as sparking their interest in population health and inspiring their support. They were receptive to the government’s proposal despite its novelty and widespread concerns about academic freedom and possible perceptions of bias.

Maynard said the government shared these concerns because the value of the research rested on the Centre’s credibility with the public. Consequently, the Centre was positioned within the university, and the role of government was limited to participating in choosing projects and assisting with fact-finding, with no right to influence the content of reports.

The advisory board was initially structured to protect academic needs while assuring the government that projects would be timely and relevant to decision-makers. Maynard and Noralou Roos co-chaired the board initially with membership including internationally renowned researchers and local representatives of government and the business community. This wide-ranging membership increased the Centre’s visibility and enhanced its credibility. As the Centre’s reputation grew, board membership shifted to reflect increased intergovernmental involvement, viewed as helpful in expanding the databases and promoting sustainability.

The first contract included the Centre’s right to publish findings after 180 days (now 60 days), and several interviewees remarked that no government has tried to embargo a report or interfere with the interpretation of findings, even when results were unfavourable.

Because governments are often protective of their information sources, funding the Centre and having it outside the control of government was potentially risky. However, Orchard said there was nothing to fear from negative reports because informing the public about the evidence behind policy recommendations would increase support for needed change. He said, “We absolutely, on a number of issues, took the rat-pack politics out of healthcare. And it was to everybody’s benefit to do that because we ended up making good policy decisions.” At the

same time, he added that he was able to use the Centre as a resource to “politically neutralize” his critics by inviting the opposition, the media and the public to meet with the researchers.

This close working relationship did not mean that MCHP researchers supported the party in power, as pointed out by Dr. Norman Frohlich, a long-term research associate and political scientist with Treasury Board experience. He explained that the researchers’ role was to provide policy support in the form of clearly articulated research results rather than policy advice. Avoiding policy recommendations was a way to protect the public’s perception of the Centre as independent by keeping MCHP distinct from the government of the day. Tom Carson, a deputy minister who worked with about 20 ministers, recommended annual presentations to all caucuses and developing relationships with a policy adviser in each political party. He also stressed political neutrality: “It’s absolutely important that the Centre never be seen as being more supportive of one party than another. That’s death.”

Maynard said working with the Centre marked a huge change in the way government did business. He said that despite sometimes uncomfortable results, the Centre survived years of constraint and several changes in government because its research was helpful, both for determining policy and for defending decisions.

In retrospect, the actual founding of the Manitoba Centre for Health Policy and Evaluation, as it was initially named, seems both remarkable and almost effortless. Orchard said he obtained funding approval on his first request. The Conservative government deserves credit for its willingness to assume the risk of investing in a research centre that could potentially expose flaws in its operations. It was perhaps fortunate for the Centre that early research results supported sound decisions that saved money.

Although the context in which the Centre evolved is unique, the 15 years of research preceding its establishment is an important part of the story. The Roosees’ and their colleagues’ high standards of research, success in publishing and obtaining grants and their unblemished record of protecting privacy provided a sound foundation for building the Centre. As would be anticipated, these important attributes continued to underpin the success of the Centre over the next 20 years. Table 1 outlines key events after the Centre’s founding. Participants discussed these events in ways that conveyed challenges, success factors or both.

### *Perspectives from Manitoba Health*

The current executive director of the Health Information Branch at Manitoba Health, Deborah Malazdrewicz, who has a 27-year history of working with health information, is well positioned to reflect on the government’s relationship with MCHP. She stressed that the Centre’s detailed and thorough privacy policies, security audits, technical infrastructure and protocols for researcher access to data give the public a sense of security that their information is being protected, and that this is key to the Centre’s sustainability. Manitoba Health strips nominal information from the data sets before supplying them to the Centre, providing fundamental protection.

Malazdrewicz said that the Centre’s research has become integral to the healthcare system. In addition to providing important information to assist with decision-making, the reports

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help Manitoba Health better understand healthcare system issues and provide opportunities to develop alliances across departments around program development.

**TABLE 1.** Key events at the Manitoba Centre for Health Policy: 1990–2010

<b>First 10 Years: Manitoba Centre for Health Policy and Evaluation (MCHPE)</b>	
1990	<ul style="list-style-type: none"> <li>• August 3: Donald Orchard, Minister of Health, announces the creation of a \$3.5-million health research centre to be funded over three years.</li> </ul>
1991	<ul style="list-style-type: none"> <li>• Noralou Roos is director, MCHPE.</li> <li>• Leslie Roos is director of the Population Health Research Data Repository.</li> </ul>
1992	<ul style="list-style-type: none"> <li>• Data Dictionary maintained in-house, rather than mainframe computer.</li> </ul>
1993	<ul style="list-style-type: none"> <li>• First Rural and Northern Healthcare Day.</li> <li>• First five-year contract (\$1.9 million per year).</li> <li>• MCHPE goes online.</li> <li>• Implementation of Populis – a residence-based data repository linking Manitoba population's health to healthcare use, economic and social factors.</li> </ul>
1993–94	<ul style="list-style-type: none"> <li>• First fellowships for students conducting research using the database.</li> </ul>
1994	<ul style="list-style-type: none"> <li>• Communication firsts: "four-pagers," website, op-eds.</li> <li>• First external review by Steven Lewis and Maurice McGregor.</li> </ul>
1995	<ul style="list-style-type: none"> <li>• Cost-cutting by provincial government; MCHPE is protected.</li> <li>• Medical Care Supplement (Roos and Shapiro 1995).</li> <li>• Concept Dictionary on Web.</li> </ul>
1996	<ul style="list-style-type: none"> <li>• Co-directorship starts: Noralou Roos and Charlyn Black.</li> <li>• Charlyn Black uses premature mortality ratio (PMR) to order graphs and data.</li> <li>• First website project: "Health Reform in Three Provinces."</li> </ul>
1997	<ul style="list-style-type: none"> <li>• Six-month government audit.</li> <li>• <i>Personal Health Information Act (PHIA)</i> legislation passed.</li> </ul>
1998	<ul style="list-style-type: none"> <li>• New five-year contract, now renewable every three years.</li> </ul>
1999	<ul style="list-style-type: none"> <li>• Continuity with change of government.</li> <li>• Interactive format introduced for Rural and Northern Healthcare Day.</li> <li>• Medical Care Supplement (Roos and Shapiro 1999).</li> <li>• Canadian Foundation for Innovation (CFI) grant: Data Infrastructure for Improving Health and Human Capital to fund Brodie Centre, acquisition of new data sets (\$2.7 million over five years).</li> </ul>
2000	<ul style="list-style-type: none"> <li>• Second review by John Hamerton, Greg Stoddart and Michael Dector.</li> </ul>
<b>Second 10 Years: Manitoba Centre for Health Policy (MCHP)</b>	
2001	<ul style="list-style-type: none"> <li>• New name: Manitoba Centre for Health Policy.</li> <li>• The Need to Know Team is funded.</li> <li>• MCHP awarded Health Services Research Advancement Award by Canadian Health Services Research Foundation.</li> <li>• October 1: First day in new premises; merging two campuses to form Brodie Centre.</li> <li>• November 2: Grand opening of state-of-the-art data laboratory at Brodie site.</li> </ul>

TABLE 1. Continued

2002	<ul style="list-style-type: none"> <li>• Healthcare Management Forum Supplement (Lix 2002).</li> <li>• <i>Canadian Journal of Public Health</i> supplement (Brownell et al. 2002).</li> <li>• Data acquired from Family Services and Education.</li> </ul>
2003	<ul style="list-style-type: none"> <li>• First Manitoba Health Day.</li> <li>• First Winnipeg Regional Health Authority Day.</li> <li>• Royal Bank of Canada grant to research children's health (\$750,000 over five years).</li> <li>• Evelyn Shapiro Award for Health Services Research established.</li> <li>• January 2003 to May 2004: Leadership model experiment: co-acting, co-directors.</li> </ul>
2004	<ul style="list-style-type: none"> <li>• May 31: Noralou Roos steps down as director.</li> <li>• June 2004 – June 2005: Patricia Martens is appointed acting director; implements new organizational structure.</li> </ul>
2005	<ul style="list-style-type: none"> <li>• <i>Canadian Journal of Public Health</i> supplement (Martens et al. 2005).</li> <li>• <i>Canadian Journal on Aging</i> supplement (Menec 2005).</li> <li>• June 2005 to date: Patricia Martens is director.</li> <li>• Lupina Foundation grant to support Web-based research knowledge translation through Concept Dictionary (started in 1990; \$625,000).</li> <li>• Patricia Martens, MCHP and The Need to Know Team awarded Canadian Institutes for Health Research (CIHR) Knowledge Translation Award.</li> <li>• Third external review by Jonathan Lomas, John Horne and Kevin Kavanagh.</li> </ul>
2006	<ul style="list-style-type: none"> <li>• CIHR report, <i>Privacy Best Practices for Secondary Data Use</i> (Collins et al. 2006).</li> </ul>
2007	<ul style="list-style-type: none"> <li>• Les Roos steps down as director of Repository.</li> <li>• Contract renewed at \$2.35 million a year; first increase (\$495,000) in 13 years.</li> <li>• Current strategic plan adopted.</li> </ul>
2008	<ul style="list-style-type: none"> <li>• Treasury Board of Manitoba commissions Steven Lewis to review MCHP impact (Lewis et al. 2009).</li> </ul>
2009	<ul style="list-style-type: none"> <li>• CFI grant, "The Manitoba Centre for Health Policy's LEADERS Initiative: Leading-Edge Access and Data Enhancement Research Strategy" to set up pilot for Repository Access Sites (RAS) and additional data sets (\$3.6 million).</li> </ul>
2010	<ul style="list-style-type: none"> <li>• March 8–9: MCHP 20th Anniversary Conference: Going for the Gold.</li> </ul>

Source: Adapted from table presented in *The Story of the Manitoba Centre for Health Policy* (Marchessault 2010).

Malazdrewicz stressed the importance of the relationship between the Centre and the deputies and ministers: "Transparency and open dialogue has allowed us to have difficult or challenging conversations if necessary, whether it's around a particular deliverable or sustainability of funding to the Centre." She added, "It's all about the relationships and open communication. ... And that's hard to get sometimes."

Malazdrewicz said the Centre faced a major challenge several years ago when the Treasury Board questioned whether continued investment in the Centre's research was providing adequate return on investment (ROI). The resulting review listed MCHP's numerous positive impacts, including "reputation, research revenues and productivity, varying influence on policy and system management, and a major cultural and intellectual influence on the Manitoba environment. The quantifiable ROI from research grants alone is close to 200%, but the real impact is likely to be far greater" (Lewis et al. 2009: A37).

The Centre also survived an earlier funding crisis. Dr. John Wade, who was the deputy minister of health in 1995, credited the Centre's placement within the university and strong support from influential people within government, naming four ministers and deputy ministers. Consequently, he said, the Centre "was maintained through the biggest cost cutting we've ever gone through."

Both Malazdrewicz and Louis Barré, who was director of health information management for 11 years prior to Malazdrewicz's appointment, discussed the involvement of five ministers and five deputies in a recent expansion of funding. Both stressed the Centre staff's commitment to producing high-quality research that met departmental needs as well as extensive efforts they and the Centre's directors made to keep people within government well informed.

Barré said the work the department did to support the Centre included transferring data files, establishing the annual research agenda, conducting briefings for report releases, and maintaining relationships with data providers, users and Centre staff. He said that in many respects, greater effort is required now than previously as contracts have become more complex due to privacy legislation and the expanded scope of engagement with the increase in data sets necessitating negotiations and feedback with multiple departments.

Malazdrewicz suggested that an appreciation for evidence-informed decision-making has spread throughout Manitoba. She credited Dr. Patricia Martens, MCHP's current director, the larger research community and funding bodies such as the Canadian Institutes of Health Research (CIHR) and the Canadian Health Services Research Foundation (CHSRF) for their promotion of knowledge translation. She specifically mentioned the Rural and Northern Healthcare Days and *The Need to Know Team* for foundational work with small regions.

Barré pointed out that the Centre researchers' external grant funding provides additional benefit to the province. He particularly stressed that the focused policy-based research using local data to address issues of local interest stimulates engagement and increases its relevance and likelihood of use throughout the province. In particular, the smaller rural RHAs find the training and information support invaluable in their regional planning process. Barré described the partnership approach to research problems: "The research that the Centre does about Manitoba is real to the Manitoba audience. ... There's a big difference when the focus of the research is local, and local people have been part of defining, executing and acting on the research. That relationship is a really important piece of it."

### *Lessons Learned: 1991–2010*

Many interviewees said that the Centre's success was due to the people who work there – leaders and team members with research proficiency but also the ability and willingness to work as partners with multiple stakeholders. They also remarked that stable, long-term funding was a necessary foundation for achieving these goals.

### ADEQUATE AND STABLE FUNDING

Several interviewees saw government support of a research centre as bypassing the peer review system and creating resentment outside the unit. However, they also said that core fund-

ing was essential to the timeliness of policy-relevant research. Some expressed doubts that these projects could be done through competitive grants. Manitoba Health's initial funding was sufficiently generous to enable setting up sound infrastructure. The first contract, for example, allowed the founders time to become knowledgeable about newly received data sets. Infrastructure costs continue, as maintaining the dozens of databases now requires extensive time and effort. Adequate and stable funding is needed to attract and retain highly qualified staff, essential to maintaining scholarship standards and academic credibility. Most years the Centre has been able to obtain additional grant funding to match that received from the Manitoba government. Base funding sufficient to support efforts to bring in other sources of revenue have been important to this success.

Nevertheless, there was a 13-year period with no increase in funding levels that created a tense and clearly problematic situation as staffing roughly quadrupled over the same period. In an effort to improve the stability of financial support from government contracts, especially important to job security, the Centre has had five-year contracts with negotiations initiated three years into the contract. If negotiations are straightforward, another five-year contract is put in place at the end of three years, but should the contract require more complex changes, including the renegotiation of funding or updated legislative considerations, the old contract covers the remaining two years.

It is clear that the Centre would not succeed without the significant amount of work done at Manitoba Health to support MCHP efforts as discussed above. This work represents an administrative, financial and political commitment from the Manitoba government.

#### RECRUIT AND RETAIN GOOD PEOPLE

The Centre's reputation is a factor in attracting and retaining researchers, important given increased competition for researchers by similar centres elsewhere. The Centre's location in a relatively small city makes recruitment difficult. However, when it comes to retention of technical staff, this situation is advantageous because there is little nearby competition.

MCHP has a strong record in retaining staff. More than 40% of the original staff of 14 still worked at the Centre as of winter 2009 (Rach 2009). Approximately half of the current 60 full- and part-time employees have been with the Centre for 10 years or longer. Staff cited interesting and challenging projects with noticeable policy impact (which they found gratifying), a lot of autonomy, flexible hours, encouragement for a good work-life balance and the use of the lunchroom and celebratory events to promote bonding as contributing to their satisfaction. Appreciation was expressed for efforts to recognize individuals' contributions, to support learning and taking on new initiatives and to increase remuneration where appropriate and feasible. Frequent staff meetings and retreats were instituted when MCHP underwent major change, as for example when the two campuses merged in 2000, necessitating the blending of two very different work cultures.

Research scientists at the Centre described their work environment as collaborative and supportive. The assigned deliverables come with resources, including a research coordinator and programmer. Weekly meetings bring together experienced researchers to assist with

challenges encountered from conception through writing up results for submission to peer-reviewed journals. For new researchers, such massive support has obvious advantages for their careers and for the Centre's continued ability to attract funding.

Several participants commented that it takes a special kind of person to work at the Centre. Being personable with good communication skills was considered as important as having technical ability, given the emphasis on knowledge translation and sustaining relationships with stakeholders. Directors at the Centre, in particular, needed to be comfortable in both the academic and policy environments.

#### STRONG LEADERSHIP

Leadership is ultimately about motivating people to work together to accomplish goals. Great respect was expressed for both the past and current directors for their commitment to the health of Manitobans and the extensive time and energy they have devoted to communication with government and throughout the province. Both the current and past leadership actively support others to make use of administrative data for research purposes through setting up Remote Access Sites, Web-based resources and consulting locally, nationally and internationally. Interviewees described the directors as effective in representing the Centre to the external world and nurturing multiple relationships that stand the organization in good stead when support is needed.

Foremost among these groups is Manitoba Health, the core funder. Meeting the government's need for policy-relevant research is necessary but insufficient. MCHP's director meets with the Manitoba Health director biweekly and with the deputy minister of health every six to eight weeks to ensure mutual understanding. Established processes facilitate joint collaboration on research – from the selection of projects, to advising on research context, to broad dissemination of research results. The process is widely recognized as demanding, with participants within government and the Centre expressing appreciation for one another's support of the partnership. Managers from both areas work to keep people throughout the government, from high-level administrators to healthcare workers, informed about the benefits of MCHP research. This approach creates well-informed advocates, useful, for example, when the government changes.

As already mentioned, MCHP researchers are available to and brief the opposition as well as the party in power. The Centre also releases its reports to the public through press releases and reader-friendly four-page summaries of its research results, and again, researchers are available to discuss these results with reporters.

For over a decade, the Centre has implemented interactive workshops with regional planning teams. These knowledge translation events have been mutually beneficial, as the researchers learn more about programs and program people learn more about research. These workshops evolved into a genuine partnership when The Need to Know Team collaboration was funded in 2001 by CIHR's Canadian Alliance for Health Research program. This award-winning knowledge translation project involved MCHP researchers and data analysts, decision-makers and planners from Manitoba's 11 RHAs and Manitoba Health throughout the research process from the development of the research questions through ensuring use of the results. The team works collaboratively on research, capacity-building for all partners and

knowledge translation. The project has fostered strong relationships perceived as important to the Centre's survival through difficult economic times. Regional healthcare leaders have indicated to the government that the Centre's research is indispensable to their planning processes.

#### BUILDING PARTNERSHIPS AND NURTURING RELATIONSHIPS

At MCHP's 20th anniversary conference, Steven Lewis remarked that the Centre's success depended on its "pedestrian but ground-breaking" nurturing of relationships. Discussion of relationships came up, often repeatedly, in virtually all interviews, as for example in the following comments: "That relationship piece with government is so critically important" (MCHP manager); "Relationship management is a huge part of what it takes to make this work" (Manitoba Health manager); "The relationship the Centre has established throughout the province has been truly phenomenal" (external researcher).

Such comments suggest consensus on the importance of relationships. People talked about developing relationships at multiple levels – with politicians, with senior administrators, with data providers, between programmers in the government and in the Centre, with RHAs, physicians, other researchers, the media, the academic community and more. Participants mentioned the importance of trust, good communication skills and the ability to listen and respond to the needs of different constituencies. Many noted that relationships must be nurtured on a continual basis, and some commented that the Centre has had more than 20 years to develop meaningful relationships.

While most participants emphasized the care taken to ensure high-quality relationships, some referred to partnerships. In fact, as David Orchard described it, his original vision was based on a university–government partnership model. And Brian Postl, chair of MCHP's board, also said that keeping partnerships alive was the key to success but a continuing challenge.

Partnerships are close and cooperative relationships with shared responsibility and accountability for achieving goals. Much of the interview content about the Centre's relationship with Manitoba Health and The Need to Know Team reflect principles that the Community–Campus Partnerships for Health (CCPH 2010) has outlined as essential to authentic university–community partnerships. These principles stress the relationship among partners. The list includes such characteristics as mutual trust, respect, genuineness and commitment; the ongoing prioritization of clear and open communication among partners and efforts to understand one another's needs and interests; continuous feedback to stakeholders; and efforts at capacity-building by all partners.

Much of this seems obvious. However, successful partnerships are difficult to accomplish (CCPH 2010). MCHP's story involves several successful partnerships, and these have been an integral part of its success and longevity.

#### *Strengths and limitations*

Selecting interviewees in consultation with MCHP managers may have introduced a positive bias; however, it also ensured that participants were knowledgeable about MCHP's history. I selected participants to provide perspectives from a cross-section of former and current

MCHP employees, and personnel from government and external university departments. I also actively searched for critical comments and tried to incorporate the results in a way that respected the tone of participants' discussions. The use of multiple sources and interviews allowed cross-validation of some findings.

## Conclusions

The confluence of many necessary and enabling factors that allowed the Centre to become established is striking and included:

- The existence of the MHSC electronic hospital and physician records.
- The willingness of MHSC staff to support external research using these data.
- The Roosees' pioneering use of administrative record linkage for more than a decade with established international reputations in health services and population health research.
- The social context that stimulated interest in population health.
- Support from strong leaders in academia, government and respected national organizations.
- An environment of fiscal restraint in the late 1980s that prompted the government's search for evidence for decision-making in its most costly area – health.

These factors were mentioned as significant in prompting the Manitoba government to initiate discussions that eventually resulted in MCHP's establishment in 1991. While some components of this initial context are unique, other factors indicate generalizable lessons for sustainability. The arm's-length relationship with government and guarantees of academic freedom built into the first contract safeguard the Centre's credibility. Credibility is essential to its usefulness, and along with the presence of powerful advocates, viewed as key to longevity. A strong track record combined with continued excellence in scholarship, meticulous protection of privacy, stable funding, incremental growth of database resources, teamwork, leadership and a partnership approach with an emphasis on nurturing relationships were highlighted as important to sustainability.

MCHP has succeeded in making its research relevant nationally and internationally, simultaneously demonstrating that using local administrative data to address specific research questions is of lasting value to the local community and the provincial government.

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# Straw into Gold: Lessons Learned (and Still Being Learned) at the Manitoba Centre for Health Policy

## Changer la paille en or : leçons retenues (et qu'on continue d'apprendre) au Centre des politiques de santé du Manitoba



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### Abstract

What lessons have we learned at the Manitoba Centre for Health Policy (MCHP) about knowledge translation (KT) over the past 20 years, and what is our vision for the future? How does that KT interrelate with our other activities – research and the Population Health Data Repository? Who first noticed that “there’s gold in them thar hills,” and what did they do about it? How did we weave administrative database “straw” into gold, how have we panned for gold and how do we look for the pot of gold in the future? This paper describes how MCHP began with an integrated KT research relationship with government, and through *The Need to Know Team*, extended KT to regional health authority planners. It describes the various push–pull KT mechanisms that MCHP has used, including dissemination of research to planners through interactive workshops, and to other researchers through Web-based resources.

## Résumé

Quelles leçons ont été retenues au Centre des politiques de santé du Manitoba (Manitoba Centre for Health Policy) au sujet du transfert des connaissances au cours des 20 dernières années et quelle est la vision pour l'avenir? Comment le transfert de connaissances est-il lié aux autres activités du Centre, c'est-à-dire la recherche et le registre de données sur la santé de la population? Qui ont été les premiers à voir qu'« il y avait de l'or » et qu'en ont-ils fait? Comment a-t-on changé la « paille » des données administratives en or? Comment a-t-on extrait l'or et comment cherche-t-on les marmites d'or pour l'avenir? Cet article décrit comment le Centre des politiques de santé du Manitoba a établi une relation de recherche intégrée en transfert de connaissances avec le gouvernement et, grâce à l'équipe *Need to Know*, a élargi le transfert de connaissances aux planificateurs des autorités sanitaires régionales. L'article décrit les nombreux mécanismes de transfert de connaissances qu'a employés le Centre, notamment la diffusion de recherches aux planificateurs grâce à des ateliers interactifs, et à d'autres chercheurs grâce à des ressources en ligne.

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**W**HEN I WAS FIRST CHALLENGED TO THINK ABOUT THE HISTORY AND VISION of knowledge translation at the Manitoba Centre for Health Policy (MCHP) in conjunction with its 20th anniversary celebrations entitled "Going for Gold," I began by recalling all the possible phrases that come to mind when I think about the word "gold": going for the gold; digging for gold; pot of gold; gold standard; there's gold in them thar hills; Olympic gold; golden nuggets; straw into gold.

The 20th year of MCHP is a great vantage point from which to review the past, identify what works in the present and dream about the future. MCHP was built on the research creativity of Les and Noralou Roos when they arrived in Canada nearly 40 years ago (in the early 1970s). That's when they realized "there's gold in them thar hills" (although I'm sure they were much more articulate and grammatically correct). That phrase resonates with all of us. Gold has an enduring quality, and is looked upon as something of great value. But gold in the hills implies that there's work to do if we want to tap into the value. You have to dig for that gold, refine it and use it to purchase other valuable commodities.

In Manitoba, the "hills" could refer to government and the "gold" to the electronic administrative records upon which the government relied to run the basic universal healthcare system. Why focus on these data? Well, in the words of Jessie James, when asked why he robbed banks, "Because that's where the money is!" Those hills are where the data are, and not just any data, but population-based data, that is, data that has recorded healthcare transactions of virtually every person deemed a resident of Manitoba. Now that's gold, just waiting to be dug out. Once dug, the "gold" needs refining into great research, and the research needs to be translated into currency, that is, action that ultimately improves the health of the population.

According to our mission statement:

MCHP is a research centre of excellence that conducts world-class population-based *research* on health services, population and public health, and the social determinants of health. MCHP develops and maintains the comprehensive population-based data repository on behalf of the Province of Manitoba for use by the local, national and international research community. MCHP promotes *a collaborative environment to create, disseminate and apply its research*. The work of MCHP supports the development of policy, programs and services that maintain and improve the health of Manitobans.

So MCHP has three pillars – research, the Repository and knowledge translation (KT). Yet the more I think about it, the more I realize that we can't isolate the concept of knowledge translation – it is interwoven with everything else we do within MCHP. So to understand the KT pillar, we need to understand the research and Repository pillars, too.

## Research at MCHP

The birth of MCHP in 1990 was the birth of a sustainable research centre dedicated to digging out the gold by doing population-based research of international renown while maintaining its feet (or miner's boots?) on the ground. The novel idea of situating MCHP within the University of Manitoba's Department of Community Health Sciences in the Faculty of Medicine while obtaining ongoing, renewable core funding from the provincial government's department of health (Manitoba Health) combined the idea of academic freedom, intellectual curiosity and a high degree of research skills with the idea of grounded research that was relevant to the questions of top-level decision-makers. Government input continues to be integral to the process of deciding upon the five research projects funded through Manitoba Health annually.

This participatory model has been called "integrated KT" (Graham et al. 2007, 2009; CIHR 2010), in which users of the research are involved at the outset in a participatory model. If those people who are waiting for the answers are also involved in helping frame relevant questions together with (a) experienced researchers who know the limitations of the data, the scope of the research literature and what has already been done in the area and (b) the most valid and reliable way to analyze the data, it is no wonder that the research lends itself to KT. Not only does the research have its feet on the ground, but it begins to walk just by the very nature of the people involved. The findings are disseminated, through the natural interest of the decision-makers involved, to the various programs or policies. Although we are aware that research evidence is not the only influence on policy (often other pressures, such as economic or political realities, override the evidence), the research must be understood by policy makers and planners, and is one of the players sitting around the table during decision-making. MCHP's relationship with decision-makers reflects the model described by Lomas and Brown (2009) as a researcher-government interaction that enables evidence-informed policy development. Moreover, a high degree of involvement of users, combined with valid and appropriate research methodologies, may result in the greatest impact in the realm of policy, program or clinical research uptake (Martens and Roos 2005; Martens 2010).

Some people have questioned MCHP about the involvement of users in the research

process from start to finish. What if they bias the results? What if they ask the wrong questions? What if they don't like the results? What if...? (Insert your own worst nightmare!) I think such questions echoed our fears in the 1990s, but we have maintained a balance between a grant relationship with government vis-à-vis an embedded written guarantee of our academic freedom and our ability to take an idea and run with it. Through a combination of our research funded from government (which we call our "deliverables") and our external grant-funded research from granting agencies such as the Canadian Institutes of Health Research (CIHR), the Manitoba Health Research Council and others, we have learned over the past 20 years that the best questions come from an exchange of ideas, both among researchers and between researchers and users of the research. The Canadian Health Services Research Foundation (CHSRF) describes this integrated process as follows: "Knowledge Exchange occurs through 'linkage and exchange' – the interaction, collaboration and exchange of ideas. At every step in the research process – conception, investigation and dissemination of results – the Foundation encourages linkage and exchange between researchers and decision makers to get the best possible result for health services." (CHSRF 2010)

So, that pretty well says it all. "Going for gold" Olympic-style in the health services and population health research world takes a combination of individual and teamwork skills, and the individual may not (and probably would not) have all the skills, understanding, context, bird's-eye view or networking capability to get the questions right, to make the analysis meaningful, to contextualize the findings and to put the results into practice. Besides discussions between MCHP's director and the deputy minister of health to generate ideas for research, each deliverable also has expert input from advisory groups. These groups meet periodically with the research team to suggest ways to understand the data, provide insight into the clinical realities or give contextual wisdom that may lead to further analyses to untangle complex findings. Advisory groups on deliverables often include clinicians, healthcare or social services experts, provincial planners, policy makers, regional health authority representatives from urban and rural Manitoba, other researchers who are experts in the area of study and non-governmental groups with an interest in that particular topic. Many of our MCHP research scientists are themselves products of the experiential side of health services or public health, coming to research after a rich career of on-the-ground involvement in healthcare. And then there are scientists originally from the research world who now work in close collaboration with the experiential side, including clinicians, educators and planners in early child support programs or services for older adults.

But what about return on investment (ROI) in health research, golden music to the ears of any treasury department or granting agency? Do we turn our research gold into action, or hoard it away in a vault? Do we contribute towards a GDP of research use (GDPRU)? Steven Lewis, Louis Barré and I wrote a report in response to a request from the Treasury Board of Manitoba, and this report became the basis of a published paper on conceptualizing ROI from the perspective of a health services/population health research unit (Lewis et al. 2009). Since its inception, MCHP has demonstrated ROI in various facets, including cost savings to government (such as a reduction in use of a pharmaceutical), capital cost avoidance (such

as the decision not to build), improved cost effectiveness (such as showing anomalous rates in a region, thereby encouraging planners to look more carefully at the situation) and attraction of top research scientists, grants and salary awards to increase the capacity of the University of Manitoba. Moreover, as argued by Lewis and colleagues (2009), creating new awareness in decision-makers – including changing the anecdotally driven culture to evidence-informed decision-making – is an area in which MCHP has excelled, both at the provincial and regional planning levels (and sometimes at national and international levels, as well). The reader may well wish to read the full report for a more complete discussion of MCHP and its ROI.

## The Repository

In their book, *Connected: The Surprising Power of Our Social Networks*, Christakis and Fowler (2009) describe the beginning of the vital statistics office in Britain in 1836, originally intended to ensure proper transfer of property rights of the landed gentry. Dr. William Farr, appointed to oversee this office, used his knowledge and creativity to see “gold in them thar hills,” setting up not only the first national vital statistics system in the world, but using these data in unexpected ways to study mortality rates by occupation, by healthcare providers (insane asylums) and even by various social determinants of health (e.g., marital status). The authors state that “vital statistics were to Farr what the Galapagos finches were to Charles Darwin: an inspiration for a whole new science, and the key to a variety of seminal insights about the human condition” (Christakis and Fowler 2009: 81). Similarly, Noralou and Les Roos saw their own version of Galapagos finches in the electronic files of Manitoba’s universal healthcare system. They developed expertise in using linkages between administrative databases, which spawned the Population Health Research Data Repository (“the Repository”) housed at MCHP.

Going with golden analogies, let’s hearken back to the famous phrase “turning straw into gold” from the fairy tale “Rumpelstiltskin” (Grimm and Grimm 1812), in which the king demanded that the miller’s daughter spin straw into gold. The concept of turning straw into gold may be very apt in describing the Repository. People usually think of straw as being nearly useless – unless, of course, they come from a rural background. Straw is immensely practical on the farm. It’s used as bedding for animals, insulation for crops such as strawberries and when building houses or protecting wells from freezing over winter, mulching into the soil to add tilth and protecting soil by preventing erosion in the fall and spring prior to planting. Straw is not useless; it is, however, commonplace. Turning straw into gold, then, is turning something with daily, not particularly high value into something that is much more desirable, and much more valuable in the commodities market. That’s really what Noralou and Les did with the administrative databases they discovered in Manitoba – they turned the straw of daily government record keeping and bill paying into the gold of population-based health research.

MCHP continues to turn straw into gold as we become custodians of more and more de-identified (“anonymized”) but linkable databases housed in the Repository (see Martens 2010 for more detailed information). As of December 2010, there were over 97 annually updated data files, and many more are brought in on a one-time project basis. When you think about it, this is a form of KT; the knowledge that can be obtained through one data-

base alone is straw in comparison with the gold that can be obtained from linking both across other databases and across time, and more importantly, at the individual level (by linking to the health registry files for demographic information and geocoding). This Repository yields golden research opportunities to advance the understanding of complex relationships between population health and the use of health and social services. Current research projects that link existing Repository data with various clinical databases include ICU data (e.g., to study long-term outcomes beyond hospital walls), paediatric diabetes databases (e.g., to study long-term outcomes in childhood type 2 diabetes beyond what is normally studied within a paediatric practice), immunization databases (e.g., to study long-term outcomes of receiving childhood or adult immunizations, including H1N1). And on the social database front, we have the opportunity to study the effects of social programs and policies, such as the use of public housing by those living with mental illness, or the use of early child and family support programs funded through Healthy Child Manitoba, looking at subsequent health and social outcomes of the children and families involved. Definitely straw into gold.

Bogart fans may recall the 1948 classic movie, *The Treasure of the Sierra Madre*, and the famous line, “I know what gold does to men’s souls.” Fill in the blank: what do you think gold does to people’s souls? \_\_\_\_\_. Did you think – makes them greedy, mean, isolated, suspicious? So, what do you think having the Repository (i.e., the gold) housed at MCHP would do to the scientists associated with MCHP? The truth is... exactly the opposite of what you might expect. Les Roos is a prime example of someone who shows a great desire to share the gold. His work on MCHP’s Concept Dictionary and Glossary in the mid-1990s was (and continues to be) a renowned example of sharing the wealth. He has worked diligently to ensure that documentation was created and shared universally through MCHP’s website ([www.umanitoba.ca/faculties/medicine/units/mchp](http://www.umanitoba.ca/faculties/medicine/units/mchp)). Les Roos’s efforts are a prime example of a researcher-to-researcher KT initiative. Other researchers can read about, and even request, the statistical coding for various concepts that were derived using administrative data – such as how we define “continuity of care,” an “episode of care,” “comorbidity” or “completed high school” – and this accessibility continues to grow. Both Les Roos and the two most recent associate directors of the Repository – Lisa Lix and, currently, Mark Smith – have continued to expand the documentation through a grant from the Lupina Foundation. This has not only turned straw into gold; it is actually multiplying the potential of the gold by investing in the futures market (future research and future scientists).

Knowing now how MCHP’s research and Repository are integrated with KT itself, let’s explore other KT initiatives within MCHP.

## Knowledge Translation Models at MCHP

[K]nowledge translation is a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system. This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity,

complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user. (CIHR 2010)

CIHR's vision of KT involves both end-use KT (disseminating the message to the appropriate audience in a tailored way) and integrated KT (user involvement from start to finish).

At MCHP, do we make the users of our research dig or pan for gold, hoping that somehow, somewhere, the research is out there and applicable to their situation – if they can just find it? Or do we facilitate the digging and the panning, in settings and situations where we know the gold exists? There continues to be “push,” “pull” and “exchange” approaches, to use the terminology of Lavis (2006). MCHP scientists are eager to “push” the results of their research through typical dissemination modalities – reports, publications, briefings to government and other stakeholders, Web-based versions, four-page summaries in easily understood language, briefings, media interviews, abstracts and oral presentations at conferences. As well, through MCHP's use of one-day workshops with high-level planners and decision-makers to help them access and understand new research studies (described in greater detail below), there is constant “pull,” as MCHP scientists are often called upon to supply research summaries or studies when a question arises that needs immediate answers. This “pull” often comes in the form of questions from government, regions and media. Finally, there is “exchange” with policy makers and MCHP, in which certain topics of high policy relevance and great research interest can be explored through the negotiation of annual deliverables.

MCHP has established highly successful Rural and Northern Healthcare Days annually (with attendance of around 180–200 people), as well as annual Winnipeg RHA Days and Manitoba Health Days. These are one of the key “push” activities of MCHP. All three events are based upon an interactive model of roundtable discussions focusing on one or two major MCHP reports, with encouragement to look for the stories in the data. Top-level planners, policy makers, CEOs, VPs of planning, members of boards of directors for the RHAs, front-line workers, MCHP research scientists and data analysts, graduate students involved in health services research training from the Western Regional Training Centre, and other interested groups annually participate in these workshops. Key to these workshop days is the presence of MCHP scientists to explain how to read the reports (e.g., the meaning of statistical significance; the way in which indicators are defined and how this might relate to practical use by the RHAs). I recently read a book called *In Arabian Nights* by Tahir Shah (2008), in which the author tells about his father explaining the importance of stories to him as a child. “Stories are a way of melting the ice,’ [his father] said gently, ‘turning it into water. They are like repackaging something – changing its form – so that the design of the sponge can accept it” (Shah 2008: 298). This is a crucial concept when telling research stories. Until we turn our staid, clinically written research reports into stories by explaining how to read the graphs, how to look for connections or how to relate data to real-life settings, the research remains ice. Research needs to be repackaged to suit the audience (the sponge) and be understood and incorporated into the audience's way of thinking.

One of our key integrated KT strategies at MCHP is The Need to Know (NTK) Team.

It had its origins back in the “push” KT dissemination of our workshop days. In 1994, Charlyn Black held the first MCHP Rural and Northern Healthcare Day, a forum for “push” – sharing results of MCHP studies with top-level planners from government and the various (informal) regions of the province. Manitoba’s non-Winnipeg RHAs outside Winnipeg were established in 1997, and thus the Rural and Northern Healthcare Days became geared to CEOs and planners from each of the 11 (now 10) non-Winnipeg RHAs. In 1999, we abandoned the lecture format in favour of facilitated roundtable discussions. These featured the just-released RHA Indicators Atlas (Black et al. 1999). A brief session was held at the start of the day, explaining how to read the graphs (not what the results were), and then each RHA had a roundtable discussion facilitated by an MCHP research scientist, looking at the data from the perspective of that particular RHA. So this was a form of digging or panning for gold, looking for the golden nuggets that relate to the RHAs’ need for evidence, yet recognizing the importance of bringing the RHAs to research findings where there was a high probability of finding gold (evidence) for their regions. But the surprise for the MCHP scientists was how much they learned from the RHAs. Regional planners were able to critique the research, suggest better ways of doing it in the future and point out findings that had somewhat debatable face validity. Hence was born our desire for (what is now called) integrated KT models, in which we involve users (RHAs) from the start of the research projects rather than simply rely on end-of-research push mechanisms. This shift led directly to the writing of a grant through the CIHR Community Alliances for Health Research fund, resulting in The Need to Know Team in 2001.

The NTK Team, presently directed by myself and Randy Fransoo, comprises MCHP research scientists and graduate students, up to two top-level planners chosen by the RHA CEOs from each of the 11 Manitoba RHAs and planners from Manitoba Health. It has been described in various publications (Bowen et al. 2005; Martens and Roos 2005), featured as a Promising Practice of the Canadian Health Services Research Foundation (CHSRF) and awarded the CIHR 2005 KT Award for Regional Impact. The NTK Team meets for two-day workshops three times a year, together creating knowledge of relevance to regional planners, building capacity among the partners and devising dissemination and application strategies to ensure uptake of research at the planning level. There is ongoing opportunity for brainstorming new research questions of particular relevance, which is another instance of “digging for gold” or playing the role of the prospector to find that gold. When the NTK Team brainstorms new research ideas, sparks are jumping. It’s a viral experience – research ideas are highly contagious, and the infection of enthusiasm and creativity spreads like wildfire in the room as we formulate future research projects. Golden ideas for future prospecting are generated and then refined through the fire of friendly critique.

Not only has the NTK Team produced five extensive research studies using the Repository at MCHP, but we have also researched the integrated KT research process itself. To date, this work has produced three peer-reviewed publications on KT (Bowen and Martens 2006; Bowen et al. 2005, 2009) plus four Web-based reports (available at [www.rha.cpe.umani-toba.ca](http://www.rha.cpe.umani-toba.ca)). This research explores user involvement from start to finish, interactive forums with users and evidence-based story telling (which, hopefully, leads to evidence-informed decision-

making). It involves investment of time and money by the research community and the users, shared language, trust and relationship building. Researchers need to let go of their traditional roles as the only experts, and rather learn that they bring one type of expertise to the decision-making table. Decision-makers bring expertise in the arena of policy making, contextualization and political or economic realities. Creating a culture of evidence-informed decision-making also requires capacity building at the decision-makers' organizational level.

The strong sense of researcher–user collaboration of The Need to Know Team required time to grow from that first meeting in June 2001. The evaluation research found that it took about a year to a year and a half (three or four meetings) to develop trusting relationships and overcome distrust of academic researchers (Bowen et al. 2005). This finding reflects the Balti proverb upon which the title of the book, *Three Cups of Tea*, was based: “The first time you share tea, you are a stranger. The second time you take tea, you are an honored guest. The third time you share a cup of tea, you become family...” (Mortenson and Relin 2006: 150). KT happens best within an atmosphere of ongoing face-to-face relationship building, whether in the realm of policy, planning or clinical practice. This approach requires a great investment of time from the director of MCHP.

The director is the key link between the university research centre (MCHP) and the government of Manitoba. Every two weeks, a teleconference is held between the liaison in government (the executive director of the Health Information Management Branch) and the MCHP director, to share information about ongoing data acquisitions, progress of deliverables, privacy and confidentiality matters regarding data, and any other issues that may have arisen. Every six to eight weeks, the director meets directly with the deputy minister of health to ensure good communication about such matters as new research, upcoming research, ways to ensure KT within Manitoba Health and other government departments, or new databases for the Repository. Depending upon the topic of a deliverable, lead MCHP scientists will also brief Manitoba Health, the deputy minister and the minister of health, and sometimes the Healthy Child Committee of Cabinet just prior to public release of results. The director of MCHP also meets with groups of regional health authority CEOs, as well as the Office of the Ombudsman of Manitoba, at least once a year. Building and maintaining these relationships requires time, but the payoff is that research is understood and applied, ultimately benefiting the health of Manitobans.

MCHP's first decade was characterized by government–university push–pull models. Our second decade, through The Need to Know Team, extended our KT through integrated models with regional and provincial health planners. Thus, 20 years of experience and KT efforts have produced a made-in-Manitoba model, with ripple effects way beyond MCHP. Provincially, we created a more integrated approach to the whole process of community health assessments and five-year strategic planning efforts. It has now become the way of achieving evidence-informed decision-making throughout the province.

## Where To from Now? Future Vision of MCHP

We all want that proverbial pot of gold at the end of the rainbow. But in real life, it's rare to

achieve a final goal or result. In the life of a research centre especially, once you find one pot of gold, it just means you need to start pursuing another. So maybe it's really the rainbow that we should look for. Rainbows are bridges, visions. They are like the future, and one way we can "see" rainbows is to strategize, using the best of our knowledge to date and building upon that to create a rainbow of possibilities for the future.

After 20 years, MCHP has a strong understanding of its priorities of research, the Repository and KT. But we also know that we need to expand our abilities to help explain the complex relationships among health, social well-being and the use of services (whether health or social programs). The first Canadian Foundation for Innovation (CFI) funding in 1999 resulted in the building of MCHP's state-of-the-art data laboratory, and in the acquisition of the first "social" databases – social assistance and education. In June 2009, we obtained a second CFI grant in the Leading Edge competition (MCHP's LEADERS Initiative – Leading Edge Access and Data Enhancement Research Strategy). The objectives of this initiative include transforming the research potential of the Repository through further key database acquisitions in the health, social and clinical areas (including such acquisitions as justice data, provincial laboratory data and public housing data) and transforming scientists' access to the Repository by developing and piloting Remote Access Sites (RAS) using innovative, cost-effective, secure database management systems. Preliminary work in these areas has already begun with the attainment of public housing data and the piloting of our first RAS in the Faculty of Pharmacy. Knowing that the RAS model and the acquisition of key clinical and social databases continues to expand our footprint, we are venturing forth on a pathway to understand how to support, mentor and capacitate social scientists and clinician scientists to use MCHP's rich, complex and population-based Repository data.

MCHP has learned lessons on KT through its world-class research and Repository resources. Echoing our mission statement, MCHP's future research will continue to support the development of policy, programs and services that maintain and improve the health of people both provincially and around the world. And that's pure gold.

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# The Role of Administrative Record Linkage in Creating Trajectories of Early Human Development

## Le rôle du couplage des dossiers administratifs pour créer des trajectoires pour le développement de la petite enfance



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### Abstract

Early childhood development (ECD) is a significant social determinant of health. Monitoring ECD to reveal trends and patterns of development requires high-quality information on a population from infancy through adulthood. This study linked data from the Early Development Instrument (EDI), administered in senior kindergarten, with data from the Foundation Skills Assessment (FSA), graduation status and SES to show that Vancouver schools with poor FSA results also had high proportions of children with low EDI and SES scores. Linking EDI data to data on pregnancy, birth, medical history, hospital care and success in school would enable the creation of normative EDC trajectories for all children. A person-specific, anonymized, population-based record linkage system is an indispensable prerequisite for creating and monitoring developmental trajectories.

### Résumé

Le développement de la petite enfance (DPE) est un important déterminant social de la santé. Le suivi du DPE pour en dégager les tendances et les schémas requiert une informa-

tion de haute qualité sur la population, et ce, de la petite enfance à l'âge adulte. Cette étude fait le lien entre les données de l'Instrument de mesure du développement de la petite enfance (IMDPE), employé dans les classes maternelles, et les données relatives à l'Évaluation des habiletés de base (EHB), à l'obtention de diplômes et au statut socioéconomique. Les résultats révèlent que les écoles de Vancouver qui obtiennent un faible résultat selon l'IMDPE comptent également une forte proportion d'enfants dont le DPE et le statut socioéconomique sont faibles. Les liens entre les données de l'IMDPE et les données sur la grossesse, la natalité, les antécédents médicaux, les soins hospitaliers et le succès scolaire pourraient permettre la création de trajectoires normatives pour le DPE de tous les enfants. Un système de couplage des données personnalisé, anonyme et fondé sur la population constitue un préalable indispensable pour la création et le suivi de trajectoires pour le développement.

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**T**HE WORLD HEALTH ORGANIZATION (WHO) COMMISSION ON THE SOCIAL Determinants of Health has identified early child development as one of the world's most significant social determinants of health (Commission on Social Determinants of Health 2008). Unlike other factors, such as work and the urban environment, early child development (ECD) is actually an intermediate factor in social causation because it is strongly influenced by the environments where children grow up, live and learn; in turn, it goes on to influence health, well-being, learning and behaviour across the life course.

The social environments that influence early childhood range from the intimate (i.e., the nurturant qualities of the moment-to-moment interactions with mothers and other caregivers) to the global (the influences of the globalizing economy on family life). Between these extremes of social aggregation are the residential neighbourhood (neighbourhood safety and cohesion in relation to children) and the region and nation (the state of the economy and the child-/family-friendliness of laws, policies and programs) (Irwin et al. 2007). Cutting across geographies, the "relational community" and access to high-quality programs and services matter. While the latter is self-explanatory, the former requires comment. By relational community, we mean the group from which the family, and thus the child, gets its identity. This may be a religious or ethnic group, or it may be based upon the occupational status of one or more parent. In any case, relational communities are important because they influence parenting norms, gender roles and expectations, notions of a well-lived life and the status of the family as privileged or subject to discrimination within society (Irwin et al. 2007).

As a determining influence on outcomes across the balance of the life course, ECD is clearly important enough to warrant monitoring, and its multiple, overlapping social determinants create a powerful rationale for monitoring the state of ECD across the whole population. Children, by definition, integrate all the influences on them, which are then reflected in their state of development. No single environmental influence has overwhelming predictive power. For example, the literature on resilience shows that one-quarter to one-third of children from highly dysfunctional, economically challenged families nonetheless develop very successfully.

Directly monitoring the state of ECD may reveal trends and patterns of development that are not predicted by simply monitoring known determinants. Monitoring whole populations complements sample surveys in several important ways. It allows finer disaggregation (e.g., according to neighbourhood character and specific ethnic group) and makes it easy to factor out random variation when trying to identify and understand outlier groups (Kershaw et al. 2005).

In Canada, population-based assessments are done during the senior kindergarten year (the transition year to school at age five). ECD is measured using the Early Development Instrument (EDI), in which kindergarten teachers fill out a detailed checklist for each child in their class based on five scale measures of development: physical well-being, social competence, emotional maturity, language and cognitive development, and communication and general knowledge (Janus et al. 2007). The EDI allows each child to be scored as “vulnerable” or “not vulnerable” on each of these five scales. The individual EDI scores are not used to label the child but are aggregated to the school or neighbourhood level to identify population levels and trends of vulnerability, much as infant mortality rates allow us to understand levels and trends of child survival. The system is efficient and relatively inexpensive, requiring funding for approximately one day of kindergarten teacher buy-out to complete EDIs on a class.

By the end of the 2007/08 school year, EDIs had been completed on at least one kindergarten entry cohort, covering approximately 75% of the Canadian population. Through a pan-Canadian initiative, these data have been mapped according to the residential neighbourhood (defined as approximately 250 square blocks in an urban setting) where each child lives (Council for Early Child Development 2002). The principal summary measure used is the proportion of children who are vulnerable on one or more of the five scales of the EDI. The maps that follow in the next section reveal the following:

1. Across Canada, between 25% and 30% of children do not arrive at kindergarten meeting all the developmental benchmarks they need to thrive both now and into the future.
2. The range of vulnerability across neighbourhoods is 17-fold, from a low of approximately 4% to a high of approximately 68%.
3. Approximately 40%–45% of the variation in neighbourhood vulnerability can be “explained,” in a statistical sense, by socio-economic factors from census and tax filer data, leaving more than half the variation to be potentially explained by factors that are more likely to be under local influence, such as the quality of local leadership in ECD and parenting styles (Kershaw et al. 2005).
4. Vulnerability rates of less than 10% are possible and feasible in any Canadian neighbourhood, suggesting that over 60% of the vulnerability among Canadian children, by school age, is avoidable.<sup>1</sup>

## Developmental Trajectories

When EDI data are linked, on a person-specific but anonymous basis, to records regarding pregnancy, birth, medical history, hospital care and success from school entry to completion, normative developmental trajectories for early human development can be created for all chil-

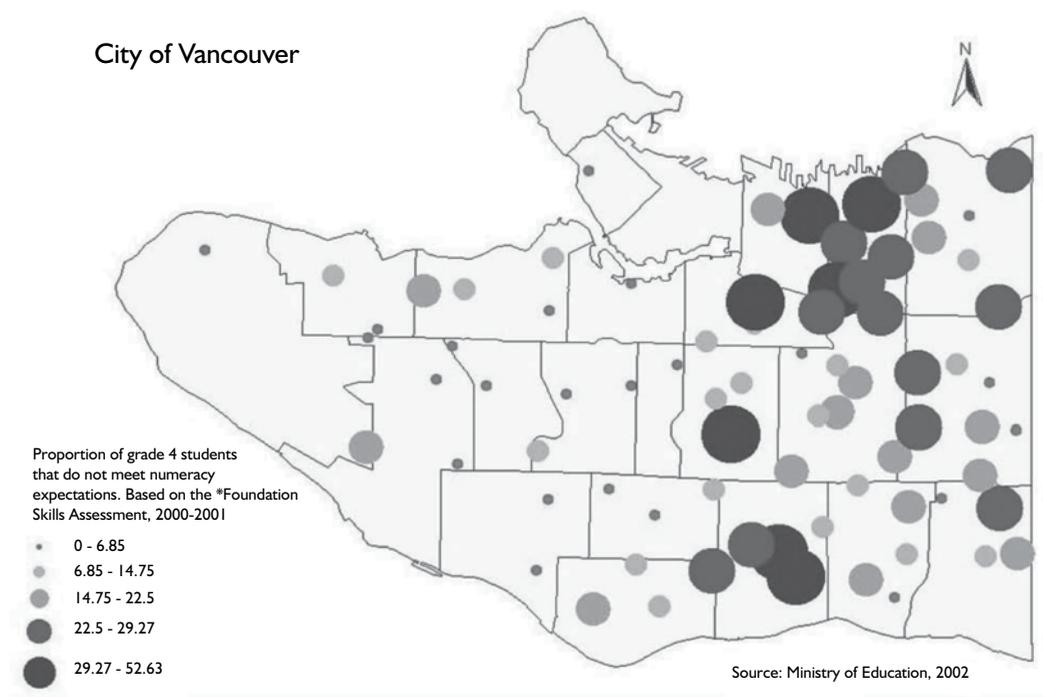
dren (Hertzman and Williams 2009). For a society that places a high priority on fostering human development, normative developmental trajectories are an indispensable indicator of progress. They allow a society to monitor success – what proportion of children have been born healthy and develop well until they reach adulthood; what proportion are developmentally challenged from birth but, nonetheless, do well thereafter; and what proportion reach school age vulnerable and yet overcome the challenges they face. Conversely, such data force society to confront the negative trajectories – those who are born healthy but become vulnerable and reach adulthood without the skills and competencies necessary for the modern world; those who are born developmentally challenged and do not do well thereafter; and those that reach school age developing well yet who do poorly thereafter. Societal progress means increasing the fraction of the former developmental trajectories at the expense of the latter.

Creating, analyzing and building policy on the basis of developmental trajectories is important because human development does not care about institutional boundaries. At present, we provide healthcare and social assistance to ensure basic survival and physical health; schools to develop competence in a range of cognitive skills; and social protection programs to provide children with a basic level of social and emotional support. We try to hold these institutions accountable as though they can function successfully in isolation from one another and from the facts of human development: if children fail at school, it is the fault of the schools; if children in care of the state do badly, it is the fault of that system, and so on. But an understanding of human development reveals that such narrow “stovepipe” judgments are perverse.

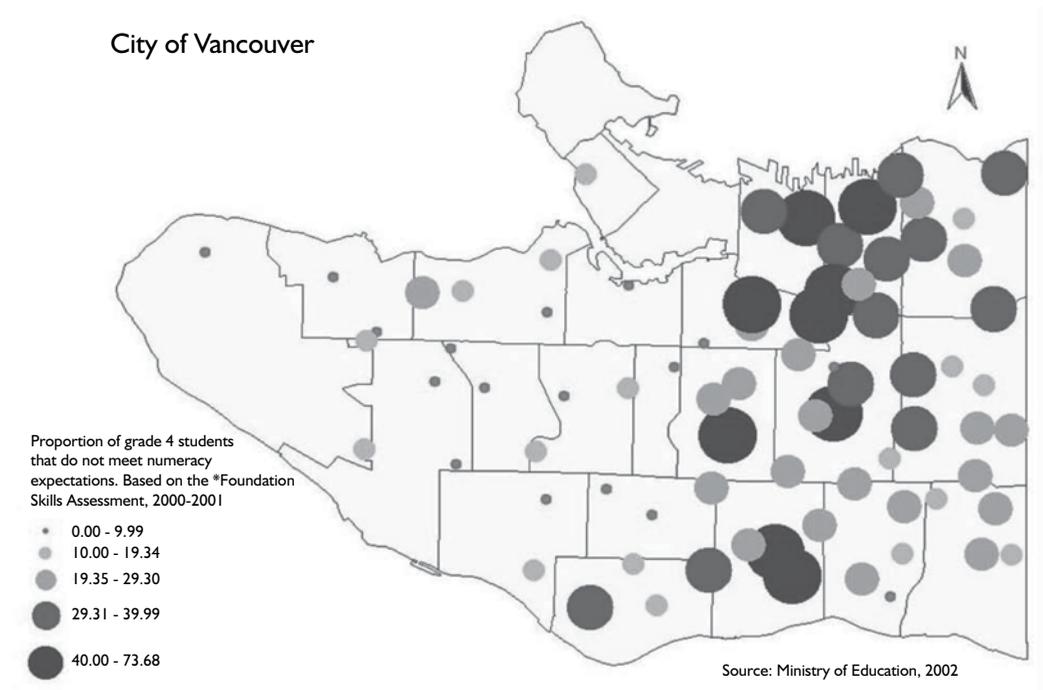
To illustrate this point, I present a before-and-after comparison of school success from the city of Vancouver (Hertzman et al. 2000). Maps 1 and 2 show the proportion of grade 4 students “failing to meet expectations” on standardized numeracy and reading tests (the Foundation Skills Assessments; hereafter, FSA) across 83 schools. Failure to meet expectations across the schools varies widely, from zero to more than 50% of students. The maps convey the impression that “school quality” can be easily judged using these raw scores, and doing so would follow the model of holding the schools accountable for human development in the school years, in isolation from all else. However, our EDI data by school showed us that, in general, schools with poor FSA results in grade 4 were also schools with high proportions of children vulnerable on the EDI in kindergarten. Similarly, schools in lower socio-economic status areas fared more poorly on the FSA than those in high socio-economic status areas.

In order to take early development and socio-economic context into account, we regressed FSA scores for reading and numeracy over two school years (a total of four analyses) against EDI and socio-economic status (SES) of the school catchment area. Together, EDI and SES explained approximately 50% of the variation, by school, in the proportion of children failing to meet expectations, leaving the residual 50% to be potentially attributable to school quality. Accordingly, we were able to reclassify schools into five groups: those that consistently did better than would be predicted based upon EDI and SES across at least three of four analyses; those that did better than predicted on one or two analyses; those that tended to do as predicted; those that did worse than predicted on one or two analyses; and those that did worse than predicted on at least three of four analyses. Map 3 illustrates the schools that fell into each of these categories.

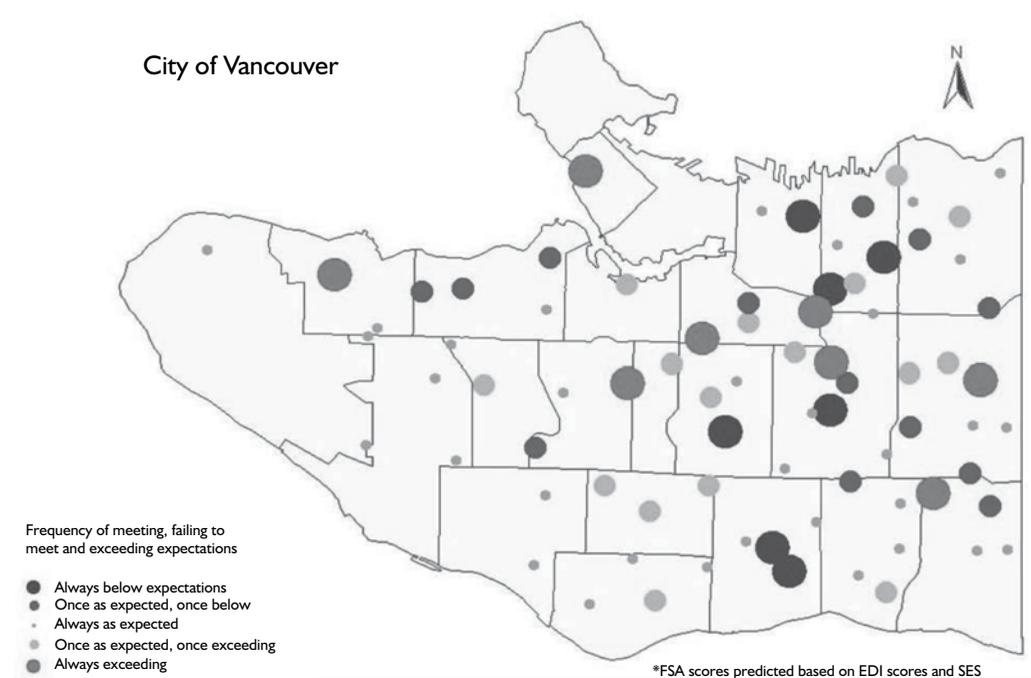
MAP 1. Proportion of grade 4 students scoring below FSA\* numeracy expectations, 2000–2001



MAP 2. Proportion of grade 4 students scoring below FSA\* reading expectations, 2000–2001



**MAP 3.** Frequency of meeting, failing to meet and exceeding predicted\* values of the FSA, 1999–2000 and 2000–2001



Comparing Map 3 with Maps 1 and 2 shows that there is simply no relationship between the schools that are doing well or poorly after EDI and SES are taken into account and those that seem to do well or poorly on raw scores. This set of maps demonstrates how trying to hold institutions (i.e., schools) accountable for outcomes without taking the principles of human development into account is a form of public policy malpractice.

In contrast, placing developmental trajectories at the centre of an accountability framework should help guide us in public policy and institutional reform. For example, we used population-based, person-specific, anonymous data linkage to create developmental trajectories in order to study the economic costs of early vulnerability (Kershaw et al. 2009). Our study examined EDI data across time within British Columbia since 2001. We linked the BC EDI data to FSA achievement data in grade 4. Next, FSA data from grades 4 and 7 were linked to graduation status (i.e., graduation at a level that would allow the student to go on to university); graduation status, in turn, was linked to data showing its contribution to subsequent economic growth. The result was a synthetic cohort that linked EDI to school graduation to economic participation, allowing us to simulate the impact on economic growth of reducing early vulnerability in British Columbia from its current rate of 29% to 10%, a threshold above which child vulnerability is biologically avoidable. Economic analyses revealed that this 19% surplus vulnerability will cause British Columbia to forgo GDP growth that will cumulate in a 20% higher GDP over the following 60 years (Kershaw et al. 2009). For

Canada, each percentage of reduction in EDI vulnerability should add a percentage of GDP growth over the following 60 years. The benefits to society would outweigh the costs by more than 6 to 1, a phenomenal return on investment by any standard.

In order to guide these investments, developmental trajectories need to be understood and monitored not only from birth, but also from the parents' earlier circumstances and experiences (e.g., quality of the relationship that produces the child; pre-natal nutrition, smoking, alcohol consumption and stress), such that modifiable factors and opportunities for intervention can be identified and interventions tracked. Such a data system requires a high level of inter-ministerial/researcher collaboration. At present, Canada has two emerging systems: the Healthy Child Manitoba/Manitoba Centre for Healthy Policy collaboration and Population Data BC/Human Early Learning Partnership.

## Conclusion

Supporting the early stages of human development is a smart policy option for any society. Doing so requires high-quality information in the form of developmental trajectories from the earliest stages of life through adulthood. A person-specific, population-based record linkage system, where linked records are used anonymously, in a secure and privacy-sensitive manner, is an indispensable prerequisite for creating and monitoring developmental trajectories. The technical, methodological and ethical barriers to creating such systems in Canada have all been solved. The current challenge is to find the political will to implement them.

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## NOTE

<sup>1</sup> The estimate that vulnerability rates of less than 10% are feasible and possible comes directly from the pan-Canadian EDI data. It shows that approximately 7% of neighbourhoods, regardless of region, urban/rural status, ethnic mix or SES, have rates of vulnerability below 10%. In regions of the country where EDI data have been collected multiple times, these data show that it is possible to maintain vulnerability below 10% over time.

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# Can Joined-Up Data Lead to Joined-Up Thinking? The Western Australian Developmental Pathways Project

La mise en commun des données mène-t-elle à la mise en commun des idées? Le projet Western Australian Developmental Pathways



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## Abstract

Modern societies are challenged by “wicked problems” – by definition, those that are difficult to define, multi-causal and hard to treat. Problems such as low birth weight, obesity, mental ill health, teenage pregnancy, educational difficulties and juvenile crime fit this category. Given the complex nature of these problems, they require the best data in order to measure them, guide policy frameworks and evaluate whether the steps taken to address them are actually making a difference. What such problems really require are joined-up approaches to enable effective solutions. In this paper, we describe a unique initiative to encourage a more preventive, whole-of-government approach to these problems – the Developmental Pathways Project, which has enabled the linkage of a large number of de-identified administrative databases in order to explore the pathways into and out of the negative outcomes affecting our children and youth. This project has not only enabled the linkage of agency data, but also of agency personnel, in order to improve and promote cross-agency research, policy and preventive solutions. Through the use of these linkages we are attempting to shift the paradigm to encourage agencies to appreciate that these “wicked problems” demand a preventive approach, as well as the provision of effective services for those already affected.

## Résumé

Les sociétés modernes font face à d’« épineux problèmes », soit ceux qui sont difficiles à définir, qui résultent de multiples causes et dont le traitement est complexe. Des problèmes tels que l’insuffisance de poids à la naissance, l’obésité, la maladie mentale, la grossesse chez les adolescentes, les difficultés d’apprentissage et la criminalité juvénile font partie de cette catégorie. Étant donné leur nature complexe, il est nécessaire d’obtenir les meilleures données pour les mesurer, orienter les politiques et évaluer l’impact réel des mesures prises pour y remédier. En réalité, ce qu’il faut pour traiter ces problèmes est l’adoption de démarches communes pour mettre au point des solutions efficaces. Dans cet article, nous décrivons une initiative originale qui vise à favoriser une démarche plus préventive et pangouvernementale, soit le projet Developmental Pathways qui a permis de mettre en lien un grand nombre de données administratives anonymes afin d’examiner le parcours en matière de résultats négatifs chez les enfants et les jeunes. Ce projet a permis de mettre en lien non seulement les données des organismes, mais aussi celles de leur personnel, de sorte à promouvoir et améliorer la recherche, les politiques et les solutions préventives au niveau transorganisationnel. Ces liens visent à modifier le paradigme, et ce, en vue d’inciter les organismes à comprendre que ces « problèmes épineux » nécessitent l’adoption d’une démarche préventive de même que la prestation de services efficaces pour ceux qui en souffrent.

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**M**ODERN SOCIETIES ARE CHALLENGED BY “WICKED PROBLEMS” (SEE BOX 1) THAT demand the best data in order to measure them, guide policy frameworks and evaluate whether the steps taken to address them are actually making a difference. A list of “wicked problems” challenging Australia (and many other developed countries) appears in Box 2.

## Can Joined-Up Data Lead to Joined-Up Thinking?

### BOX 1. Wicked problems

- Are socially complex with multiple layers of stakeholders
- Are difficult to define clearly, and there is often disagreement about the cause
- Are interdependent and often multi-causal
- Have no clear or “correct” solution
- Defy conventional approaches to problem-solving
- Are cross-cutting, i.e., do not fit into organizational silos

The list includes a range of child and youth problems (Stanley et al. 2005) that are the focus of population research at the Telethon Institute for Child Health Research in Western Australia ([www.ichr.uwa.edu.au](http://www.ichr.uwa.edu.au)) and in a national alliance we have established to encourage effective policies and implementation (Australian Research Alliance for Children and Youth; [www.aracy.org.au](http://www.aracy.org.au)). By “wicked” we mean that these problems are complex in causation, have few effective treatments, and cross multiple agencies and professional groups in terms of the responses needed to address them. Their impacts are also extremely costly (Collins and Lapsley 2008).

Primary prevention of many of these problems will result only when attention is paid to the very fabric of our societies, such as how our economies are managed for social equality and participation across the whole population, and whether there is a culture of valuing children, young people and those who care for them. The variability in measures of child well-being (e.g., health, safety, income, education) observed across wealthy OECD nations (UNICEF 2007) raises questions as to whether such problems can be explained by policy differences across these nations. If we can identify the relative importance of policies, then we can attempt to change them in those countries where there is obvious room for improvement (such as Canada and Australia). A vital policy question for both Canada and Australia is why we continue to fail in effectively delivering most services in health, mental health, education, child protection and justice to our most vulnerable, including Aboriginal and socially disadvantaged people.

On the whole, the response of health and welfare agencies to these very challenging issues has been to focus on the ends of pathways when most of these problems are harder to manage or treat and success in avoiding harm or damage is less likely. In spite of these difficulties, agencies attempt to measure their massive investments in these areas by analyzing trends in the problems’ occurrence. We need a paradigm shift to get agencies to appreciate that these problems demand a preventive approach *as well as* the provision of effective services for those already affected. Most pathways to juvenile crime commence in early childhood or even in utero, or via intergenerational environments. An example of such a pathway would be that involving foetal alcohol exposure and its consequences.

Solutions, particularly those aimed at successful prevention, are more likely to come from multiple agencies working together (e.g., our definition of “joined-up thinking” and what others may define as cross-agency or whole-of-government strategies). Agencies responsible for intervening earlier are often different and remote from the role and expertise of the agency responsible for the end-stage outcomes. An example from our own work is health workers’ reducing the risk of potential child abuse and neglect through identifying children born with neonatal withdrawal syndrome and providing support and referral to substance-using mothers (O’Donnell et al. 2009).

Hence, in this paper we want to address the question of whether joined-up data (i.e., de-identified data that have been linked at the individual level) can lead to joined-up thinking by describing the experience of a novel capacity developed in Western Australia (WA). The Developmental Pathways Project is a unique collaboration between our institute and 11 government agencies. We are using de-identified individual records, linked across several government agencies that collect data for a range of administrative purposes. This collaboration brings together researchers, policy makers and community members to quantify the extent to which the main pathways into child and youth problems traverse these agencies, demonstrating their joined-up nature and answering policy-relevant questions.

**BOX 2.** Wicked problems challenging Australia

Poor Health and Well-being
• Low birth weight
• Complex diseases (asthma, diabetes, obesity)
• Mental ill health
• Substance abuse (foetal alcohol syndrome)
• Teenage pregnancy
• Disabilities
Social Disease
• Child abuse/domestic violence
• Behavioural problems/disengaged youth
• Educational problems
• Juvenile crime
• Workplace stress
• Reduction in human capital
Environment
• Climate change
• Environmental degradation
• Water resources
• New and emerging infections

## The WA Population Health Data Linkage System

We have used population health data, including registers, for more than 30 years in WA (Stanley et al. 1994), with linkages done regularly between all births, midwives' notifications, hospitalizations, deaths, mental health services and our total population registers (birth defects, cerebral palsies, intellectual disabilities, autism, cancers).

These data are either statutory collections (e.g., births, deaths, midwives' notifications), agency data (hospital morbidity, child protection) or special population registration of cases of diseases or problems (often research funded, e.g., birth defects). All are collected without consent under national and state-based guidelines pursuant to privacy legislation to enable secondary use of data for monitoring and research in public health and health services (NHMRC 2000).

These linked data sets enable a large number of epidemiological and health services research projects to investigate causes, suggest preventive and other strategies, evaluate medical care and inform policy frameworks (Brook et al. 2005; Hillman et al. 2000; Jablensky et al. 2005; Hansen et al. 2002).

### Advantages and Limitations of Population Data Record Linkage

The linking of population data at the individual level offers a number of important advantages compared with other research designs: (a) it is relatively cheap, using existing and available data; (b) it captures the total population, including those at highest risk or with other characteristics that make them least likely to participate in, or to be included in, surveys, cohort studies and randomized controlled trials (resulting in biased participation and loss to follow-up); (c) it includes the total population, an approach that usually ensures adequate statistical power for robust analyses; (d) it includes all birth cohorts, allowing investigation of the effects of changes over time in family, societal and environmental factors (compared with single birth cohort studies); (e) it provides the basis for research and policy evaluation across all groups in the population; and (f) it allows analyses of sensitive information that is hard to collect via survey methods (e.g., mental health, child maltreatment, criminal behaviour, drug use, termination of pregnancy).

Of course, agency data are limited to what is collected by each agency, and many variables relevant to child development (e.g., developmental milestones, parenting style) are not collected. Therefore, in addition to these population data, our institute engages in a range of other epidemiological studies such as population surveys, case control and cohort studies, and randomized controlled trials. All studies are conducted with full consent, and for all studies conducted since the late 1990s, we have sought permission (and received it in well over 95% of cases) to link these data with the population data. So although we have limited but still useful data on all individuals, the additional complementary studies allow us to obtain a more complete picture.

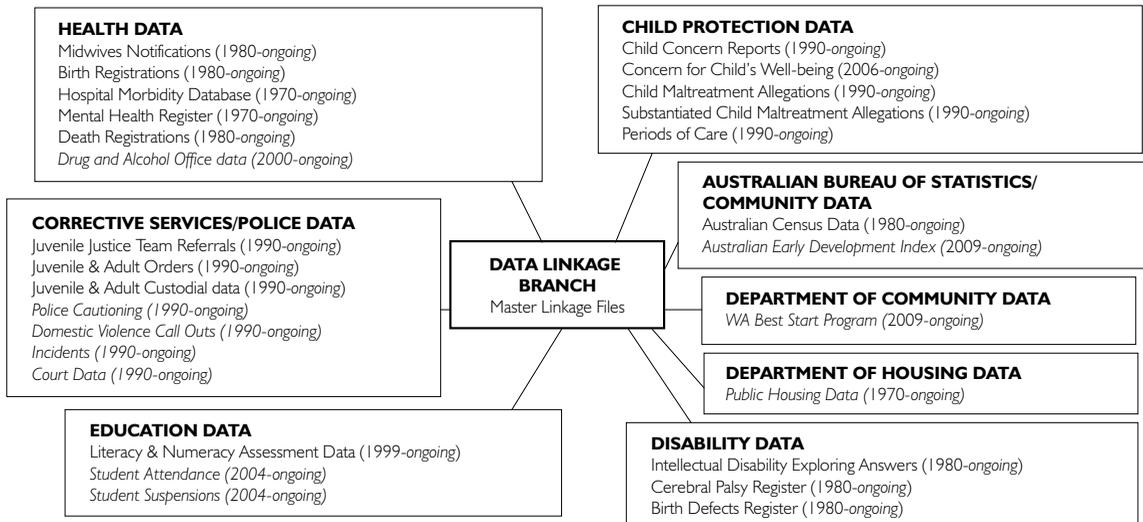
These other studies and their linkages also enable us to imbed them in a total population sample, thereby testing their generalizability and participation bias. They also provide multiple opportunities to validate a range of variables in the population data, such as diagnostic, demographic and ethnic information. The population data linkage expands the capacity of the sample surveys and cohort studies, converting the former into quasi-longitudinal studies and, in the case of the latter, enabling some information on those lost to follow-up. Because the information available in the total population agency data is limited, these linkages to in-depth studies enable better interpretation and analysis of the developmental pathways of interest.

#### *Extending health data linkage to educational and welfare agency data: The Western Australian Developmental Pathways Project*

Our institute, in collaboration with government agencies, recently succeeded in winning two research grants to extend further our population health data to enable linkage across agencies for a range of developmental and behavioural problems. The overall aim was to enable more “joined-up,” “integrated” or “whole-of-government” thinking in relation to the costly and distressing issues that affect children and youth in WA. The Developmental Pathways Project

(DPP) has been in place for five years. Figure 1 lists agencies involved, the data currently linked and the data planned for linkage (shown in italics).<sup>1</sup> Other collaborators include the departments of Indigenous Affairs, Attorney General and Treasury and Finance.

**FIGURE 1.** Agencies involved in the Developmental Pathways Project



This unique project has had remarkable success. We have managed to obtain and link data from a large number of agencies, with more becoming involved. We have engaged with the agencies to ensure that the projects serve their policy needs, and we have developed a system of governance that enables excellent interactions among the agencies and data custodians, agency heads, the head of Treasury, the researchers, the data linkage unit and the doctoral students who do much of the work.

A novel aspect is that the doctoral students are co-supervised by both academic and policy experts. This means that in addition to the various committees set up to connect the researchers and the agencies, each project has dedicated policy input guiding them throughout. Hence, not only do the students produce publications for scholarly journals; they also write policy briefs, present to agency staff and conduct additional analyses specifically to serve a policy agenda. Examples of some of the work that has been achieved through the project include our work on prior hospital morbidity of children in contact with the child protection system (O'Donnell et al. 2010); birth outcomes and educational achievement (Malacova et al. 2008); and the impact of baby bonus payments on birth rates (Langridge et al. 2010).

### *The role of community participation and governance structure*

In 2002, the Telethon Institute for Child Health Research, with support from the state's peak consumer organization, the Health Consumers' Council, commenced a long-term strategy to

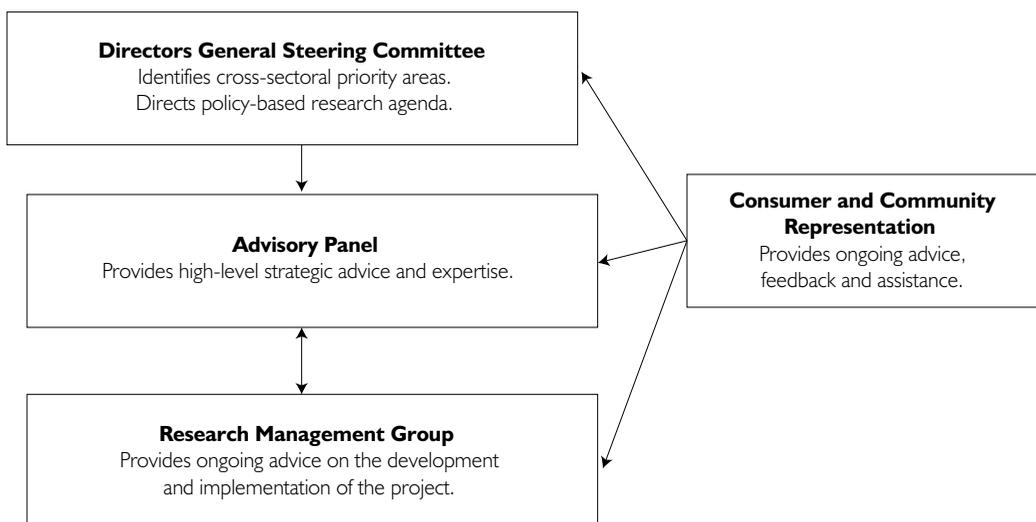
## Can Joined-Up Data Lead to Joined-Up Thinking?

enhance and increase consumer and community participation in its research activities. This strategy has resulted in a strong, sustained consumer and community engagement program that includes the following components:

- a dedicated consumer advocate on staff;
- a well-developed governance and policy framework for participation, including the establishment of a Consumer and Community Advisory Council;
- budgeted participation activities for consumers and community representatives in research grant applications;
- the development of a range of models for consumer and community participation;
- training events relevant to participation for researchers and consumer and community representatives; and
- integrative forums known as “community conversations,” which bring researchers, other professions and consumer representatives together.

Participation and engagement from consumers and community members is being sought in this project to ensure that (a) knowledge and experience are shared, to assist in guiding the research process; (b) the research is consistent with community values and aspirations; (c) advice and feedback are incorporated into the research process; (d) the interpretation of results and the drafting of recommendations are accurate, valid and culturally appropriate for translation of the findings into policy development; and (e) research findings are communicated and disseminated to key stakeholder groups and community organizations. Consumer and community representation will be sought at every level of the DPP’s governance structure (Figure 2).

FIGURE 2. Project governance structure



Senior DPP staff used a “community conversation” process to include the consumer and the community voice in the development of the 2009 DPP grant application. Researchers, members of the Consumer and Community Advisory Council, and Aboriginal and non-Aboriginal community members met to learn about the current research and to discuss community priorities for future research projects. The feedback from this meeting had a twofold positive outcome, i.e., the inclusion of community suggestions – for example, the inclusion in the grant application of questions about appropriateness of services and service use – and the addition of the WA Department of Housing to the government agencies involved in the project.

Consumer and community representation has been greatly facilitated by the consumer research liaison officer and the manager for the Kulunga Research Network (a partnership with the WA Aboriginal community) at the Institute. Their help has enabled collaboration with the Institute’s Consumer and Community Advisory Council and the Aboriginal Collaborative Council Advising Research and Evaluation (ACCARE), community groups and organizations.

The project’s governance structure encourages maximum involvement by all members of the project team, ownership, clear lines of communication, transparency and translation of the research, all of which are vital to the success of the project.

## Privacy protection

The protocols and procedures employed by the Data Linkage Branch at the WA Department of Health to link data are now accepted as international best practice (Kelman et al. 2002). The protocols were developed to minimize the risk to privacy while maximizing link efficiency. Individual identifying information is restricted to a specialized team who create the linkage keys. Under memoranda of understanding (MOUs) between the Department of Health and each of the agencies providing data, strict processes are outlined, identifying the methods of linkage, extraction and hand-over for data. These MOUs also enable ownership of data to be maintained by each agency.

This process has reduced the use of identified data supplied by the Health Department for research purposes (Trutwein et al. 2006), and has enabled the research of sensitive issues (e.g., mental health problems, child abuse and juvenile delinquency) while protecting the privacy of participants.

To maintain the privacy and confidentiality of the data entrusted to researchers on this project, the researchers are governed by confidentiality policies and the National Privacy Principles.

### *Has the DPP encouraged joined-up thinking? Has this process informed policy?*

We anticipated that the joined-up data would mostly influence policy frameworks rather than specific policies. We aimed to (a) shift thinking towards prevention and early intervention strategies; (b) increase interest in whether the data could guide policy approaches that targeted high-risk groups or were universal across the whole population; (c) identify those subgroups of the population for whom services work best and those for whom they fail; and (d) identify “paradoxical” groups that did well in spite of poorer circumstances and more risk factors.

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Although the process is still young, we believe that there is evidence that this project has resulted in joined-up thinking across bureaucracies, not just as a result of the data, but also because of the governance structures set up around the project. A shift has begun from academics deciding on linked projects to the agencies requesting their agendas. The heads of all agencies involved attend two meetings a year to decide on priorities. The list of research questions generated by the directors general of departments (Box 3) demonstrates that they are now thinking across departmental silos with projects that benefit from the cross-agency data linkages, the developmental aspects of pathways, and the high priority placed on prevention in their agendas. The leadership from the head of the Treasury was key to engaging all the heads of the other agencies. They are starting to view this cross-agency data and capacity as a vehicle for whole-of-government, joined-up thinking.

**BOX 3.** Examples of research questions developed in consultation with the Directors' General Steering Committee and Community Advisory Group

1. What are the early childhood characteristics of those who develop mental illness?
2. What are the characteristics of Aboriginal children and youth not in contact with the justice system?
3. What proportion of people in juvenile detention have pre-existing mental health problems?
4. What are the characteristics and precursors of those who enter the juvenile justice system, and how and when can we attenuate these particular risk factors?
5. What are the characteristic pathways of children with a disability who enter care and protection?
6. What are the health and social problems contributing to poor educational performance?
7. What are the outcomes for children who have a substantiated child maltreatment allegation who enter care?
8. Identify poor geographical areas with good educational outcomes and examine their characteristics.

An example of policy developments and practice changes as a result of our research is our work on neonatal withdrawal syndrome (O'Donnell et al. 2009). Our government briefing paper led to an invitation to present our results and recommendations to the Impact of Parental Drug and Alcohol Use on Pregnancy, Newborns and Infants Working Party, an interagency group responsible for prevention and intervention in this area. Meetings were also held at WA's primary maternity hospital on the needs of these women and long-term follow-up. This collaboration has resulted in the strengthening of the pre-birth interagency protocols among the departments of Child Protection and Health, as well as a review of follow-up and secondary services for these women.

Challenges in this project relate to the capacity and time of bureaucrats to participate, rapid turnover of staff and changes in government departments, the need to collect more qualitative information to inform policy questions, adequate descriptions of policy and practice to enable evaluation, and development of appropriate communications strategies to inform our community about the public good that arises from using data in this way and how we protect privacy.

## Summary and Conclusions

Pathways into major adverse outcomes for children and youth start very early, as they did even in the previous generation. This fact poses huge challenges for both prevention and the future plan-

ning of crisis services, such as disability, health and education services for the increasing proportions of surviving very preterm infants or of children exposed in utero to alcohol. Many of the early risk and protective factors (e.g., growth in utero; harmful antenatal exposures; social disadvantage; parental, particularly maternal, educational level; maternal pregnancy factors; geographic location) are seen in a range of outcomes, currently handled in silos by separate bureaucracies.

The early promise of this WA data linkage project – which encourages agencies to use their own data in novel ways, bridging jurisdictions to understand these problems – shows promise in generating a more appropriate policy framework, leading to more balanced and humane solutions.

#### ACKNOWLEDGEMENTS

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#### NOTE

<sup>1</sup> ABS data are not unit record data.

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# How Has Health Services Research Made a Difference?

## Comment la recherche sur les services de santé a-t-elle donné lieu à des changements?



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### Abstract

Health services research (HSR) is commonly conceived as an applied discipline whose success is defined by its tangible impact on policy, practice or both. In Canada there has been a concerted effort to engage decision-makers in informing the research agenda. While it is admirable to aspire to practical utility, the HSR community has no control over the ultimate disposition of its work. Furthermore, the conditions for change must be present if the pathway from relevant, high-quality research to application is to be relatively smooth and immediate. In such cases, the changes may have occurred regardless of whether the research to support them took place. An examination of some widely renowned HSR reveals that timely and significant impact is relatively rare. Moreover, research that fundamentally changes how we view the world plays out over decades; it would be impossible to act on it in the short term, and in some cases it is not clear what ought to be done. The implications are that the first duty of HSR is to seek truth, and that funding and decision-making communities should define “useful” broadly, from a longer-term perspective. Taking the wide and the long view will in the end generate a greater return on investment in HSR than focusing too narrowly on contemporary preoccupations.

### Résumé

On conçoit habituellement la recherche sur les services de santé (RSS) comme une discipline de recherche appliquée dont le succès se mesure par son impact concret sur les politiques et

la pratique. Au Canada, il y a eu des efforts concertés visant à engager les décideurs à éclairer le programme de recherche. Bien qu'il soit admirable d'aspirer à une telle utilité pratique, le milieu de la RSS n'a aucun contrôle sur l'utilisation finale de son travail. De plus, les conditions nécessaires au changement doivent être présentes si on souhaite que le parcours entre une recherche pertinente de haute qualité et son application soit relativement souple et immédiat. Dans ce cas, les changements peuvent avoir eu lieu indépendamment de la recherche visant à les appuyer. L'examen de certains projets de RSS de grande renommée révèle qu'il est plutôt rare d'observer un impact significatif et opportun. De plus, l'effet des recherches qui transforment fondamentalement les choses s'étale sur plusieurs décennies; il est donc impossible d'agir à court terme et, dans certains cas, on ne sait pas clairement ce qu'il faut faire. En conséquent, le principal devoir de la RSS est de rechercher la vérité alors que les milieux de financement et de prise de décisions doivent adopter une définition plus large de la notion d'« utilité », et ce, dans une perspective à plus long terme. Cette approche élargie permettra de générer un rendement sur l'investissement dans la RSS plus important qu'une vision étroite centrée sur les préoccupations quotidiennes.

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**H**EALTH SERVICES RESEARCH (HSR),<sup>1</sup> LIKE ALL RESEARCH, IS SUPPOSED TO improve the human condition. Cultures that support and produce research tend to be more prosperous and free than those that don't. That research in general makes a difference is rarely disputed; in fact, the question is rarely asked. But it is asked of HSR for two main reasons. First, the discipline is only a few decades old, but there is already good evidence that the insights of comparative effectiveness studies and thousands of clinical practice guidelines are widely ignored. Second, HSR has come to advertise itself as a practical discipline that aims for tangible and fairly immediate impact (the very name of the Manitoba Centre for Health Policy implies that its primary activity – research – is instrumental). The public and governments tend to support basic science research as an intrinsic good that will pay off somewhere, some day, in unanticipated ways. They rarely cut HSR such slack: here, it's show me the impact.

Impact is not so easy to define. If only studies that result in a tangible change in the way health services are delivered, or the outcomes they achieve, can claim to have made a difference, HSR has almost always fallen short. But the definition is far too narrow. HSR can influence thinking, culture, policy, behaviour and practice. It takes place in an economic, social and political context, not in a linear, rationalist world where systematically acquired evidence explains all choices and results. Power, tradition, interests and uncertainty all affect what is done and what is achieved. Furthermore, health systems are riddled with perverse incentives and are principally organized for the convenience and profit of the supply side rather than the public or patients. Long-standing problems remain unresolved despite the efforts of managers, leaders and politicians, some of whom are genuinely interested in a more evidence-informed world.

The question is thus less whether HSR has made a difference, but what HSR should aspire to achieve. The argument here is that HSR should seek truth. It should shed light on

phenomena inaccessible to common sense or intuition – the counterfactuals that confound simplistic analyses and glib prescriptions, and force a re-examination of the status quo. It should attempt to answer questions that are both broad and deep, mirroring the experience of people and organizations in complex adaptive systems. To be actionable, it should ask how and why things are as they are in addition to describing what they are. Producers of HSR are rarely decision-makers in the health system, but they can and should be attuned to how decisions are made and the vagaries of the political arts. The case here is not to exempt the choice of HSR topics or the design of studies from all considerations of relevance or potential use. It is to define “useful” and “important” in a more nuanced way.

A short paper cannot fully articulate the argument, but it can be illustrated by an examination of the impact of what are widely regarded as blockbuster HSR studies. Table 1 identifies examples of groundbreaking studies, their findings and, in very general terms, their impact.

Are there any patterns in this small sample of renowned research findings? It would appear that those with the greatest apparent impact – the Hormone Replacement Therapy and hospital utilization studies – deal with discrete phenomena where behavioural change is relatively straightforward; where (in the case of HRT) users of services can act unilaterally; where findings evoke embarrassment, fear, hope, shame or other strong emotional response; and where the environment is more manageable (hospitals). Those with the least apparent concrete and tangible impact deal with complex phenomena; require concerted and multi-pronged initiatives to address; threaten traditional cultures, elites, egos and interests; and do not suggest an obvious blueprint for action.

Nothing, of course, is that simple, and experiences and research suggest further possible explanations for the presence or absence of a tangible and attributable response to research. People generally discount future, anonymous health benefits quite steeply in comparison to potential here-and-now health benefits that would accrue to identifiable people. (It is easier to raise money to send Alice Wilson to Loma Linda Hospital for a double-organ transplant than for programs that would help those under-achieving kids in poor Winnipeg neighbourhoods.) Hence population health studies are, other things being equal, less likely to engender a rapid, tangible response than some clinical studies (complexity is, of course, another major barrier to change).

But let’s frame the question differently. Aside from natural disasters, intellectual insights and ideas have been responsible for all the great changes in human systems. The biggest ideas had no immediate and quantifiable impact. The Copernican and Newtonian revolutions did not change manufacturing, inspire armies or rearrange the means of production in any observable way. Yet, they changed the world and spawned an explosion of ingenuity in untold ways to enormous and irreversible effect. The new knowledge changed everything – but not in a mechanical, causal, transparently traceable fashion. Analogously, it is no longer possible to think that healthcare alone (or even mainly) determines health status; that need alone drives spending; or that regulation and licensure are sufficient to guarantee quality.

The health and healthcare conversation is vastly different today than it was 30 years ago, precisely because of the contributions of HSR writ large. Atul Gawande’s (2009) compelling account of the Dartmouth studies in *The New Yorker* became required reading in the White

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**TABLE 1.** Selected groundbreaking HSR studies

Body of Research	Main Findings	Impact
UK studies on gradients in health and the impact of inequality on health status	<ul style="list-style-type: none"> <li>• Health status differs all along the SES gradient (Marmot et al. 1991)</li> <li>• The level of societal inequality is associated with both aggregate and group health status (Wilkinson and Pickett 2009)</li> </ul>	<ul style="list-style-type: none"> <li>• Shifted focus to non-medical determinants of health</li> <li>• Revived interest in class as an analytic construct in health</li> <li>• Broadened the nature of high-level reports on health</li> <li>• Led to major focus on inequalities in health in Europe, WHO</li> <li>• <i>No reduction in health disparities in past three decades in almost all countries</i></li> </ul>
Dartmouth studies on variations in healthcare use and costs	<ul style="list-style-type: none"> <li>• Up to threefold variations in use controlled for health status, satisfaction and outcome (Wennberg and Gittelsohn 1982; Welch et al. 1993)</li> <li>• Explained by variations in supply-side behaviour (Gawande 2009)</li> </ul>	<ul style="list-style-type: none"> <li>• Broad recognition that healthcare use and results are poorly correlated</li> <li>• High-performing subsystems in US deliver better quality and lower cost</li> <li>• Work replicated in many jurisdictions</li> <li>• <i>No reduction of variations in the US after 30 years of documentation</i></li> </ul>
Women's Health Initiative Hormone Therapy Study	<ul style="list-style-type: none"> <li>• Documented widespread use of HRT over decades (Rossouw et al. 2002)</li> <li>• Revealed major health risk factors that increase with duration of HRT</li> </ul>	<ul style="list-style-type: none"> <li>• Enormous publicity of findings immediately after publication</li> <li>• <i>Virtually instantaneous reduction in HRT utilization</i></li> </ul>
Acute care utilization studies in Canadian provinces in 1990s (BC, SK, MB, ON)	<ul style="list-style-type: none"> <li>• Widespread use of hospitals for alternative levels of care (ALC) ("bedblockers"; up to 40% in urban hospitals and 80% of small rural hospitals) (Health Services Utilization and Research Commission 1994)</li> <li>• ALC needs ranged from none to nursing home beds</li> </ul>	<ul style="list-style-type: none"> <li>• Major, widespread focus on length of stay, discharge planning, utilization management</li> <li>• Changed conversation on rural healthcare in at least one province (SK)</li> <li>• <i>Methods and tools that formed basis for earlier studies no longer widely used</i></li> </ul>
Institute of Medicine <i>To Err Is Human</i> (Kohn et al. 2000) and related international studies	<ul style="list-style-type: none"> <li>• Major iatrogenic death toll in hospitals in US, Canada, UK, Australia</li> </ul>	<ul style="list-style-type: none"> <li>• Sparked and accelerated the patient safety movement</li> <li>• Foundation of campaigns such as Safer Healthcare Now!</li> <li>• <i>Symposium held five years after IOM publication lamented lack of progress in saving lives</i></li> </ul>
RAND studies of primary care quality in US (McGlynn et al. 2003)	<ul style="list-style-type: none"> <li>• Quality of care varies substantially from evidence-based guidelines</li> <li>• People commonly receive recommended care 50%–60% of time</li> </ul>	<ul style="list-style-type: none"> <li>• Did not spawn major replications</li> <li>• Confirmed earlier findings about lack of impact of clinical practice guidelines</li> <li>• <i>No discernible acceleration of primary care reform or accountability</i></li> </ul>
MCHP study of high school graduation trends (Brownell et al. 2004)	<ul style="list-style-type: none"> <li>• Huge neighbourhood-level variations in percentage of youth completing high school on time</li> <li>• Effect size exceeded intuitive estimates</li> </ul>	<ul style="list-style-type: none"> <li>• Major self-reported transformation in education policy makers' perspectives</li> <li>• A foundation of greater focus on intersectoral initiatives</li> <li>• <i>No claim of major impact on extent of disparities in performance</i></li> </ul>

House. As Clyde Hertzman has noted, some people are able to ignore convincing evidence in reaching their own conclusions about school performance but most, eventually, do not. In a world where there is a touted new cure, drug and technology every week, and where the media have an insatiable appetite for healthcare gadgetry and magic, there is nonetheless broad awareness that healthcare and health are conceptually distinct, and that the former explains rather little of the variance in the latter. HSR findings created this awareness, and the implications are potentially enormous.

All this suggests a paradox: the more concrete and obvious the relevance and impact of HSR, the less likely it is to be paradigm-altering. Typically, change happens because the antecedent conditions are already in place; research findings may be little more than confirmatory, or may provide a small additional tailwind to journeys already underway. Conversely, truly game-changing research is unlikely to change the game any time soon because it bumps up against the powerful forces of tradition, hierarchy, inertia, vested interests and complexity. Thus, the HSR that may make the biggest difference in the long run is highly unlikely to make any concrete difference in the short run because genuinely original and creative research is so difficult to absorb, let alone apply.

As a result, HSR would do well to resist selling itself as a purely responsive, relevant and useful service industry, its ear attuned to “Listening for Direction” and driven by the preoccupations of decision-makers faced with daily and vexing dilemmas. It has been clear for millennia that you cannot derive the ought from the is, and HSR is about the is. Often, decision-makers and other actors find the low-hanging fruit inedible, for whatever reason: there is a lesson in the widespread failure of healthcare workers to wash their hands in hospitals 160 years after Semmelweis’s elegant and definitive research. There are no algorithms for estimating “knowledge demand,” and not all wisdom lies in crowds (even crowds of talented decision-makers). You never know when that long-neglected research will emerge from the dusty shelf when the decision-making context changes.

Finally, this perspective suggests some reflection on another contemporary truism: you can’t manage what you can’t measure. That may be true in healthcare, but it is less true in estimating the worth of research. In my own efforts to assess the impact of HSR, it became clear that there are no reliable measures of the real or potential impact of the most interesting and relevant studies. It is easier (though not always easy) to recognize an important and original idea than to divine its likely impact in the foreseeable future. Researchers cannot control anything beyond the conception, design and execution of their research, and we do not live in a particularly evidence-seeking health culture. Before judging HSR on its utility, it would be helpful to learn how decision-makers perceive their role in leaving so much ostensibly useful research on the shelf. And before the wider community decides that putting itself in charge of the HSR agenda will yield a greater return on investment, it might profit from its own accounting of how it has used the research it has commissioned in the past. This would be a valuable complement to the work the Canadian research community has already done to advance the science of measuring return on investment (Panel on Return on Investment in Health Research 2009).

Lest this argument be misconstrued, I should add that I have spent my own HSR career in an applied health research agency and as a consultant whose livelihood derives from doing oth-

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ers' bidding. It is my instinct to want to do things that will make a difference, but that presumes that those able to make a difference have the intention and the will to do so. There are infinitely more false negatives (not "using" research that should inform policy and practice) than false positives or true positives. That is the way of the world, and in such a world, it is ultimately more useful to attempt to enlighten than to steer. That is what the best HSR has always done, and when insights and ideas take hold, the world changes, and the return on the initial investment is immense, albeit unquantifiable – for now at least, and possibly for a very long time.

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### NOTE

<sup>1</sup> HSR is defined here broadly, to include population health research as well as studies of the organization, financing and delivery of health services.

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# Panning for Population Gold: 20 Years of Research at MCHP

## À la recherche de l'or de la population : 20 ans de recherche au Centre des politiques de santé du Manitoba

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**T**HIS SESSION STARTED WITH DR. MARCHESSAULT PRESENTING HIGHLIGHTS from her research project, “The Manitoba Centre for Health Policy: A Case Study” (see pages 29–43 of this Special Issue). Semi-structured interviews with 28 participants revealed that a multitude of factors were involved in establishing MCHP. Donald Orchard, then Minister of Health for Manitoba, and Deputy Minister Frank Maynard initiated discussions about creating a research centre. They were motivated by a need for information to guide decisions they faced in an era of financial pressure, by influential presentations from figures including Dr. Fraser Mustard and by the international reputation of

Drs. Noralou Roos and Leslie Roos. They saw the benefit of having information come from a reliable source outside of government and wanted to “put some science behind some of the decisions we were making.” Mr. Orchard was willing to take the political risk in order to advance healthcare in Manitoba. Fortunately, Manitoba had excellent electronic records of the population and their health services use – data that the Rooses had been working with for 15 years, achieving exemplary scholarship. Manitoba was small enough that the entire data system was manageable given the computing power of the day. Small size also facilitated cooperation among managers of different sectors. Leadership from Dr. Brian Postl, head of the University of Manitoba’s Department of Community Health Sciences, Dr. John Wade, dean of the Faculty of Medicine, and Dr. Arnold Naimark, president of the University of Manitoba, helped establish an appropriate budget and agenda for research projects, as well as systems to protect academic freedom to publish without government interference. The structure of the MCHP advisory board balances university and government interests, and the process of negotiating research topics ensures that questions of relevance to the government are addressed while taking advantage of the strengths of the data system.

Dr. Black then spoke about the excitement and challenge of assembling a comprehensive data system, building on early research conducted with data from Manitoba Health. This initiative required learning how to transform program-specific data into richer information. These efforts were aimed at informing important and enduring policy and program questions about population health status and its distribution. Based on emerging models of population health (Evans and Stoddart 1990) and an understanding of the strengths and limitations of the data, a conceptual model was developed to guide this work. It quickly became apparent that population-based approaches, together with a broader perspective on health (rather than a focus on specific disease states) would provide remarkably powerful insights and perspectives about health and healthcare. While administrative data often lack depth, the breadth of the Manitoba data, both in terms of population coverage and the range of services included, makes conducting rich analyses possible. The process of creating a health information system required extensive effort to acquire and organize the data and also to develop approaches to conduct both population-based (i.e., based on where people lived, not just where they used services) and more traditional provider- and organization-based (i.e., based on where services are delivered) approaches. It also required the development of measurement tools for a large number of key concepts – for example, to report on “health status” and “need” for healthcare across populations, as well as measures for key concepts such as access to care, effectiveness and cost of services provided, and performance in delivering services. The combination of these measures and approaches has provided a powerful foundation for developing more focused information in response to specific policy questions.

Dr. DeCoster discussed some of MCHP’s communications successes, including her role in creating the first short summary of a research report, which became the universally popular “four-pagers.” These plain-language summaries remain a central part of MCHP’s dissemination strategy, appealing to a broad range of readers. Dr. DeCoster also talked about her research on waiting times, and how that early work at MCHP has grown into a key focus of

her ongoing research interests and partnerships. Key findings from analyses of wait times for cataract surgery include the revelation that having a parallel private system did not reduce wait times for cataract surgery in the public sector in Manitoba, and that rates of injury increase with duration of wait time. This avenue of research connected Dr. DeCoster to a network of researchers and the Western Canada Wait List Project, which now involves a large group of researchers from across the country who currently investigate issues of appropriateness and outcomes. She concluded by noting that knowledge translation at MCHP historically involved communications, collaboration and documentation, and that these three facets remain centrally important in her work today.

All three speakers noted the importance of teamwork in the MCHP environment, including reaching out to stakeholders in policy and program areas to ensure validity of research techniques and appropriate context for interpreting the results.

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# The Whole Is Greater Than the Sum of the Parts: Using Data Linkage and Cohort Designs to Create Data Synergy at MCHP

Le tout est plus important que la somme de ses parties :  
utilisation du couplage de données et des modèles  
de cohortes pour créer des synergies au Centre des  
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**T**HE MANITOBA CENTRE FOR HEALTH POLICY (MCHP) HAS BEEN CALLED A “data-rich environment” (Roos et al. 2004). Indeed, the depth and breadth of the data justify this description – there are currently nearly 100 databases held in the Population Health Data Repository (“the Repository”) at MCHP, with some containing data back to 1970. And the number of databases continues to grow. However, it is not merely the volume of data that is important – rather, it is the synergy that is created when these databases are linked. Every data set at MCHP can be linked to others through a longitudinal registry of

virtually every resident of Manitoba. This comprehensiveness presents unique research opportunities that would not be possible otherwise. All personal identifiers are removed, and the Personal Health Identifier Number (PHIN) that is used to link all databases is scrambled to protect individual privacy. In addition, strict access control and approval processes are in place.

The administrative data at MCHP currently cover four distinct domains of provincial government services: healthcare, education, social services and justice. Within each of these groups are anonymized records of contacts Manitobans have with the particular service. For example, the healthcare database includes virtually all contacts individuals have with physicians, every in-patient hospitalization and every prescription drug that is dispensed. The education databases contain records of class grades, school enrolments and performance on standardized tests. Social services databases include, among others, data on social service recipients, public housing and the Early Development Instrument (EDI). Having the capacity to link these databases and follow individuals over time, with appropriate privacy controls, enables researchers to consider important policy questions. In this brief report, we will review some examples of the types of research that have been possible using these data.

It is important to be able to identify individuals who have certain health conditions, and particularly chronic conditions, for many purposes. Examples include examining the prevalence of these conditions in the population, examining trends in chronic disease and comparing the cost of healthcare for people who have these conditions to those who do not. Through linking the Canadian Community Health Survey with health administrative data, Lix and colleagues (2006b) have developed and validated algorithms that have made this possible. Another highly useful kind of analysis involves linking the health administrative data with clinical data contained in the provincial bone mineral density database. This linkage has allowed Leslie and colleagues (2008) to use these two data sets to develop models to predict fracture risk.

In addition to the linkage capability, these data may be used longitudinally. For example, Lix and colleagues (2006a) followed three cohorts over a three-year period to describe differences in residential mobility patterns for people with diagnosed schizophrenia, a matched cohort with no diagnosed mental disorders and people with diagnosed inflammatory bowel disease. The implications of the findings are important for housing and health policy analysts because mobility may result in discontinuities in health services delivery.

The administrative data housed in the Repository may also be used for multi-level modelling, for example, looking at the factors affecting educational achievement of children given their individual characteristics, the characteristics of their family and those of the neighbourhood in which they live. For example, being able to group individuals into their family units is a tremendous benefit for a variety of research projects: suicide and its effect on family members, and sibling research on the effects of childhood health and socio-economic status on educational achievement and labour force participation are but two examples. Such “nesting” of data has a number of benefits: it avoids the dilemma of the unit of analysis, it handles the lack of independence among observations (e.g., children in the same family) and it can be used to clarify confounding variables at both the within- and between-group levels.

These are but a few examples of work done at MCHP using linked and longitudinal

data. Of the approximately 92 major research projects taken on since 1991 for the provincial Ministry of Health, 79 would have been entirely impossible without the capacity to link databases – and all but eight used the registry of the provincial population. During this same time period, 491 papers using linked data have been published by MCHP and external investigators, all while maintaining privacy and access controls. The “atlases” produced at MCHP (Fransoo et al. 2009; Martens et al. 2003) always compare changes in rates between two points in time, and many other projects describe events over time. MCHP reports are used to inform policy, to monitor health and the healthcare system and to develop the requisite tools for researchers who need linked data to answer important research questions.

MCHP has been funded to expand the number of databases and to develop secure “remote access arms” that will make these data more accessible to others, while maintaining stringent protection of personal information through anonymization of databases, physical controls, and review and approval processes. These enhancements will further increase the opportunities for researchers to investigate policy-relevant questions.

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# Taking It to the Streets: Figuring Out and Communicating What's Really Important in Children's Health and Well-being Research

Sortir au grand jour : compréhension et communication de ce qui compte vraiment en matière de recherche sur la santé et le bien-être des enfants

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**H**OW DO ACADEMICS ENSURE THAT THE ANALYSES THEY PRODUCE CAN BE accessed and understood by those in a position to use evidence to “make a difference”? This question became a concern as early findings from analyses of education data began to emerge.

In this session, Dr. Noralou Roos showed what the schools see when they review the performance of students taking grade 12 tests: 76% of those children in families receiving income assistance passed the test, compared with 96% of the students who lived in the affluent areas of the city. These results, however, report only on those who are in school, in grade 12 and writing the tests. A second graph showed the results for those who should be writing the test. We identified all children born in Manitoba who remained in Manitoba until they were 17. Then, we determined where they were in the school system at that time (that is, during what should have been their final year in school) and identified those who had withdrawn from school. These

data demonstrated a very different reality: only 14% of the children whose families had at some point received income assistance passed the grade 12 test on time, compared with 80% of the students living in the high SES areas who passed. Over 20% of kids from the poorest families had already withdrawn from school, and many of them had not yet made it to grade 12.

Gerald Farthing, Deputy Minister of Manitoba Education, said that when government representatives saw the evidence on how far behind disadvantaged children were, they were startled. Although those in the ministry knew there was a relationship between low income and educational achievement, they were surprised by the strength of the relationship in their own community. Their first reaction was, "It can't be this bad," but they also understood the quality of the research. Farthing reported that the research had an impact in part because researchers had taken the time to develop a working relationship with the ministry. He emphasized that developing a relationship of trust and mutual respect between researchers and policy makers was critical. He also found it helpful that Manitoba Centre for Health Policy (MCHP) researchers made over 50 presentations to school boards, superintendents, ministry staff and others explaining the approach taken and what was found. Farthing noted that the ministry has developed policy and allocated resources, to a large degree, in directions motivated by the research.

Jim Carr, CEO of the Business Council of Manitoba, described how seeing the statistics relating educational achievement to socio-economic status led the Business Council to a social policy agenda. Understanding the evidence on school outcomes motivated Carr to accept the responsibility of becoming co-chair of the Winnipeg Poverty Reduction Council. He described how the council went to inner city schools and asked, "What are your priorities?" Council members were told the top priorities were adequate food (kids can't learn if they are hungry) and mentors. The council is now looking for a business partner to provide students with food for a full year. They have also contacted potential mentors, who responded, "When can we start?" Carr concluded that to engage others and create something people want to be part of, you must have data on the situation in reality as opposed to abstractions.

Jane Freemantle, Principal Research Fellow at the University of Melbourne, described a similar process in Australia to support targeted interventions for Aboriginal people and those living on Torres Strait Island. She demonstrated a clear example of how the analysis of linked population data could be used to engage government and community to redress inequalities in infant health among Indigenous populations. She reviewed how the Western Australian Data Linkage System was used to describe infant mortality trends, the causes of death and the context in which these deaths occurred. In particular, the data were disaggregated to identify the patterns and trends of mortality among Aboriginal compared to non-Aboriginal infants. The data were further analyzed to observe the mortality trends in deaths attributed to sudden infant death syndrome (SIDS) following a well-resourced universal intervention. While deaths attributed to SIDS declined sharply in the overall population, Aboriginal mortality rates remained significantly high, with a ninefold relative risk of death observed. These data were then used to attract substantial funding to address the persistently high rates of SIDS among Aboriginal infants. The funds were used to support targeted and culturally specific interventions in consultation with members of the Aboriginal community, NGOs and government.

# Clinical Research at MCHP Over the Next 20 Years

## La recherche clinique au Centre des politiques de santé du Manitoba pour les 20 prochaines années

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**T**HE POPULATION HEALTH DATA REPOSITORY (“THE REPOSITORY”) HOUSED AT THE Manitoba Centre for Health Policy (MCHP) has been used for many different types of research. Despite the fact that both investigator-driven research and deliverables conducted by MCHP research scientists as part of the centre’s contract with Manitoba Health have included clinical research, this area has not been MCHP’s strength. Over the past 20 years, some clinicians have used the Repository to study a variety of topics; however, this work has constituted only a small percentage of the research done at the Centre, and relatively few clinicians have seen the Repository’s potential to answer their research questions. The purpose

of this session was to share the experiences of two clinicians actively engaged in research using the Repository and to explore barriers and facilitators to clinician engagement in research using the Repository's data.

The first speaker, Dr. Allan Garland, shared his experience in being given the opportunity to lead a deliverable at the Centre soon after joining the University of Manitoba's Faculty of Medicine. Dr. Garland is an intensive care specialist and a researcher with extensive experience in database research. The potential of working with the Repository was one of the factors that drew him to Winnipeg. In addition to his skills and interest, there was the untapped potential of linking an extensive and detailed intensive care unit clinical database covering all ICU admissions in Winnipeg to the population-based Repository data in order to understand what happened to patients before and after their ICU admission.

Dr. Garland first identified many challenges in using the Repository data, and then shared some preliminary results from his ICU study. Challenges facing clinicians seeking to use the Repository include lack of understanding of the potential uses of administrative data, the power and limitations of such data, lack of knowledge about the data housed in the Repository and the need to rely on MCHP staff to address these challenges. If researchers wish to link their clinical database to the Repository data, there is a process to follow to comply with the privacy and confidentiality requirements mandated by Manitoba Health. In addition, the study needs to be approved by both the local university research ethics board and the Health Information Privacy Committee at Manitoba Health before the research can begin. The data can be analyzed only using SAS, and data analysis can currently be performed only within MCHP's secure environment. Preparation of data and use of analysts' time are billed to the researcher at an hourly rate based on cost recovery.

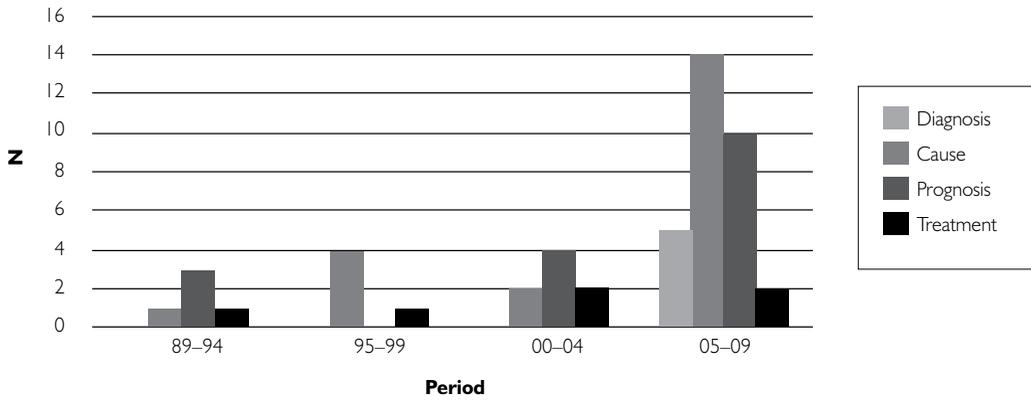
The second speaker, Dr. Bill Leslie, described the development of his research program on bone health. He has gained international recognition based on his use of a bone mineral density (BMD) measurement database he developed and subsequently linked to the Repository. His research has addressed many of the cutting-edge questions about BMD testing, the impact on clinicians' prescribing practices of osteoporosis medications and the appropriate treatment for osteoporosis, all using the linked data.

The third speaker, Dr. Mike Moffat, presented an overview of clinical research involving the Repository. He reviewed the list of publications from MCHP from 1989 through 2009 and tagged the research according to a number of criteria: research that was directed at one of four areas of clinical knowledge (diagnosis, etiology, prognosis and treatment or prevention) (Figure 1); research that was applied to individuals; and finally, research that was not exclusively about the effect of poverty or socio-economic status. Studies about the healthcare system, costs, efficiencies and resources were also excluded from his review. He concluded that although clinical research using the MCHP Repository is accelerating exponentially, the research covers limited clinical areas. Dr. Moffat highlighted similar challenges to those raised by Dr. Garland.

This session presented several suggestions to support the growth of future clinical research at MCHP. There are needs for better training for clinician-researchers in general and for academic support for time to undertake clinical research, possibly with an alternative

funding plan for academic physicians. There is always a need for increased research funds, but a special competition for clinical research using the Repository was specifically suggested. MCHP needs to work at making data more easily accessible, and a short training course for clinicians to learn how to use the Repository would be helpful. Facilitating partnerships between clinicians and MCHP research scientists as well as outreach to clinical departments were also thought to be potentially useful future directions. Regular rounds for clinicians presenting research using the Repository were proposed as a way to further engage clinicians.

FIGURE 1. Clinical research at MCHP, 1989–2009



# Using Administrative Data to Study Child Health

## Utilisation des données administratives pour étudier l'état de santé des enfants

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**T**HE MANITOBA CENTRE FOR HEALTH POLICY (MCHP) IS SUPPORTED BY THREE pillars: the Repository, the research and knowledge translation. The importance of each of these pillars was illustrated in our discussion of the usefulness of linked administrative databases for studying child health and development.

## The Repository

The collection of population-based administrative databases held at MCHP, which are referred to as the Population Health Research Data Repository (“the Repository”), offers an ideal resource for studying health and social outcomes from the prenatal period through to adolescence and young adulthood. The population research registry provides a census of all children resident in Manitoba, and the common scrambled identifier allows linkages across data sets and over time, making it possible to study the influences of predictors on later outcomes, for example: maternal prenatal smoking and infant health at birth on cognitive development at kindergarten; developmental readiness at school entry on numeracy skills in grade 3 and school engagement in grade 8; and involvement with child welfare in childhood on high school completion.

## The Research

Linkages across clinical and administrative data sets have been used to build on insights into the origins of childhood asthma that have come from survey research.

The Study of Asthma, Genes and the Environment (SAGE) is a novel, retrospective cohort study of Manitoba children born in 1995, which was created from the MCHP population research registry and uses the Repository’s longitudinal healthcare records of these children (Kozyrskyj et al. 2009). Nested within the birth cohort is a case-control study of children recruited at age 8–10 to perform clinical and home assessments and obtain biologic specimens. These children are being followed prospectively to collect data on overweight, insulin resistance and neuro-endocrine hormones (Mai et al. 2007). Among its strengths, the SAGE is a population-based cohort with detailed database records on early-life exposure to antibiotics and vaccinations. Such exposure can be linked to measurements of house dust allergens as well as immune system function and asthma gene polymorphisms in children. The SAGE has found several risk factors for childhood asthma, including antibiotic use during infancy (Kozyrskyj et al. 2007) and maternal postnatal distress (Kozyrskyj et al. 2008). Linkage with child cortisol levels has provided evidence on pathways for maternal distress (Dreger et al. 2010).

A second example of research using the Repository involves an exploratory, descriptive study focusing on the economic impact of children in care with Foetal Alcohol Spectrum Disorder (FASD) (Fuchs et al. 2009). FASD, a preventable condition resulting from prenatal alcohol exposure, is a serious social and health issue for the child welfare, healthcare and education sectors owing to its significant social and economic costs. Data from the Child and Family Services administrative database and the MCHP Repository allowed identification of five groups of children, categorized according to whether they were in or not in the care of a child welfare agency, and whether they had or did not have a diagnosis of FASD. The findings revealed that both the children diagnosed with FASD and those affected by parental alcohol misuse account for significantly higher utilization and costs in the health, education and child care sectors, compared to the general population. This study is a starting point, providing a more accurate picture of resource utilization; previous research established no meaningful link between parental alcohol misuse and the costly health and educational resources consumed each year by those children affected. This study suggests that placing greater emphasis on pri-

mary prevention would effectively expand the public policy approach to FASD in Canada, as well as create efficiencies in the allocation of scarce resources.

## Knowledge Translation

Even the highest-quality research does not automatically get translated into policy. Information has to be presented to policy makers in ways that are not only useful, but usable. Policy makers ask such questions as: How prevalent is this problem? What predicts it? What policies/programs work to improve it? What price is paid?

Manitoba's Healthy Child Committee of Cabinet provides cross-sectoral knowledge translation (KT) structures at the highest levels of government, and has commissioned MCHP deliverables regarding epidemiology, explanation and evaluation, thereby informing expenditures. MCHP adapts knowledge to the Manitoba context (via the power of local population-based data) and addresses political, structural and technical barriers using effective products (e.g., presentations) and tools (e.g., government-to-MCHP cross-appointments).

What makes MCHP KT work for children's policy in Manitoba? Relationships (respect, responsiveness, reciprocity), reputation (on both sides) and the Repository (new questions and data sets drive new KT cycles). Longitudinal linked studies and large-scale evaluations await, as we ask: Can we change the social gradient, level the playing field and raise the bar for children's developmental outcomes across the life course and across generations?

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# International Health Data Linkage Network

## Réseau international de couplage des données sur la santé

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**T**HE INTERNATIONAL HEALTH DATA LINKAGE NETWORK (IHDLN) ([www.ihdln.org](http://www.ihdln.org)), inaugurated in London, UK, in December 2008, facilitates communication among linkage centres and users committed to the systematic application of data linkage to produce community benefit in the health and health-related domains. One of the

purposes of the IHDLN is to foster collaborative projects that show the value of international comparative data applications, data quality and methods assessments, and concept dictionaries. The IHDLN aims to demonstrate the benefits of international collaboration, with ambitions to work creatively together to pool international aggregated de-identified health data to increase the power of knowledge for population-based research. There are currently over 120 members from Australia, Canada, England, New Zealand, Singapore, Scotland and the United States. The network is seeking wider international representation, and membership is open to any group or individual that supports the network's purpose.

The following three presentations were included in a breakout session highlighting some of the work of our members.

*Using International Population Health Data to Explore an Alarming Increase in Excessive Bleeding Post-Childbirth*

*Dr. Jane Ford, Senior Research Fellow, Clinical and Population Perinatal Health Research, University of Sydney*

Comparable hospital discharge data from three countries (Canada, Australia, US) have identified increases in excessive bleeding post-childbirth (postpartum haemorrhage) over the period 1994–2005. Associated information suggests this finding may represent an increase in severe haemorrhage. Analysis of these data indicates that demographic and obstetric factors, such as increasing maternal age and rising caesarean section rates, do not explain this increase. An international collaboration has been formed (International Working Group on Postpartum Hemorrhage), which has made recommendations regarding future data collection, research and management of postpartum haemorrhage, with the aim of identifying reasons for the increase in rates. Potential risk factors warranting further research include duration of labour, obesity and changes in management practice around the second and third stages of labour.

*Population Health Research Network*

*Dr. Merran Smith, Chief Executive, Population Health Research Network*

*Dr. James Semmens, Chair of Population Health Research, Curtin University of Technology*

*Ms. Diana Rosman, Manager, Data Linkage Branch, WA Department of Health*

The Population Health Research Network (PHRN) is developing data linkage infrastructure for health research, policy and planning in Australia. Data linkage units (nodes) are being established for all states/territories and will link together health-related information within their jurisdictions. A separate dedicated linkage unit will facilitate linkages across jurisdictions, and a national data access and delivery regime is being developed to streamline provision of information to support research, monitoring and policy evaluation. Key elements of the national initiative presented include the following.

- The PHRN Program Office is leading implementation of the new data linkage infrastructure throughout Australia. This includes establishment and ongoing management of PHRN governance and contractual, policy and client services processes.

- The PHRN Centre for Data Linkage (CDL) has been established to build a secure data linkage facility to facilitate linkage between jurisdictional data sets, and between these data sets and research data sets, using demographic data. The centre will not hold these data sets but will link the demographic data that have been separated from the remainder of each data set to create “linkage keys.”
- A Proof of Concept Collaboration has also been created to test the ability of the new linkage infrastructure to perform cross-jurisdictional linkages and provide linked de-identified data for research studies. “In-hospital and 30-day post-discharge mortality: Learning about quality of care using national data linkages” has been chosen as the first topic to investigate.

*Using Linked Health Survey and Hospital Data to Examine the Risk Factors Associated with Alcohol-Related Morbidity and Mortality*

*Ms. Catherine Storey, Information Analyst, National Health Services, Scotland*

Through the Information Services Division of the National Health Service in Scotland, linked Scottish Health Survey hospital and death records were used to create a prospective cohort to gain an idea of the risk factors associated with an alcohol-related hospital admission. A second, prospective cohort was identified, of individuals who died from alcohol-related causes from 2000 to 2006. Hospital admission patterns and such factors as age, sex and deprivation were analyzed to identify characteristics among those who die of alcohol-related causes.

Of the prospective cohort, it was found that those at highest risk for an alcohol-related death included males, current or former smokers, people in receipt of income-related benefits and those with a marital status of divorced, separated or widowed.

The retrospective study revealed that 25% of those dying from alcohol-related causes died within one year of their first alcohol-related hospital admission, and that admission patterns and diagnoses varied significantly between the most and least deprived quintiles in Scotland.

# Dancing with the Media – Be Careful Not to Step on Your Partner’s Toes: The Challenge of Working with the Media to Share Research Findings with the Public

Danser avec les médias – attention de ne pas fouler le pied de votre partenaire : le défi de travailler avec les médias pour partager les conclusions de recherche avec le public

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**W**HILE IT IS VITAL THAT HEALTH SERVICES RESEARCH BE SHARED WITH decision-makers, in some instances it is equally important for this research to be shared with the population at large, because public opinion has the power to persuade those in public office who make the decisions and form policy.

This session discussed the challenges that researchers face when presenting their find-

ings to journalists. Dr. Malcolm Doupe, senior research scientist at the Manitoba Centre for Health Policy (MCHP), shared examples from past experience; Richard Cloutier, journalist and host of *Richard Cloutier Reports on CJOB* – a long-standing news and talk radio station in Winnipeg – gave media perspectives; and Mary Agnes Welch, public policy reporter with the *Winnipeg Free Press* and president of the Canadian Association of Journalists, provided insights from a journalist’s point of view. Jack Rach, MCHP’s communications officer, chaired the panel session and provided perspectives from his role as an intermediary between researchers at MCHP and the media.

Dr. Doupe began the session with a pair of anecdotes that essentially highlighted the strengths of plain language in combination with the necessity for preparation when communicating with journalists. Mr. Cloutier and Ms. Welch agreed, indicating that most journalists’ backgrounds are not based in science; they further concurred that ultimately it is a journalist’s job to be able to tell a story using the research presented. In ideal situations, a communications person will also act as a translator, interpreting scientific information found in research data into language that most people will be able to grasp and understand. For the most part, this means researchers and their communications staff need to eliminate jargon and simplify statistics and numbers by explaining the issue as if it were done at a coffee shop among friends.

Fundamentally, the interaction between researchers and journalists is a form of knowledge translation. Considering the fact that most journalists lack a science background, it can be difficult for them to find news in highly statistical data. Researchers must therefore be able to answer one simple question: “So what?” One way of tackling this question is to identify how the research has the potential to affect people. Journalists look for stories about real people – those who have first-hand experience with the issue in question at hand.

Another major component of the researcher–journalist interaction is building and maintaining relationships. Mr. Cloutier suggested giving exclusives, confirming the popular conception that media outlets are always trying to get the “scoop” by publishing or broadcasting a story before anyone else. Because this scenario is not always possible, one way Mr. Rach builds relationships between MCHP and journalists is to send embargoed copies of reports in advance of their publication date. This approach allows reporters to do their homework and perform their own investigation into the issue at hand – especially considering the long timelines of some of the research at MCHP. This method also enables television and radio news outlets to plan their schedules in advance. To do this successfully, however, journalists, their editors and producers must understand the reason behind such embargos and agree not to publish or broadcast any findings from the research prematurely.

Ms. Welch suggested the power of “stories with legs” – that is, stories that last days with coverage from multiple angles. Not all stories have this capacity. Furthermore, the dynamic state of the news media means that research often takes a backseat to other headlines, including natural disasters and the latest celebrity scandals. Both Mr. Cloutier and Ms. Welch indicated that they don’t mind receiving notices more than once, given their busy schedules and workloads. This is also true when researchers claim they have been misquoted or misinterpreted. The panel suggested that such miscommunications happen but most of the time they are not inten-

tional. Reporters want to be known for their accuracy, just as researchers do. So the best way to correct a story that has been broadcast or published is for the researcher or communications person to contact the journalist directly and explain what was wrong. If this approach doesn’t work, researchers can go up the ladder to the reporter’s editor or senior producer.

Although not all research is good news for everyone, journalists aren’t typically out to get researchers. At the same time, unless they are working in a commercial-free medium such as CBC Radio, part of journalists’ job is to sell the public something. The saying that “a story that bleeds, often leads” is true – but this shouldn’t deter researchers from sharing their findings, especially if the data in their research show evidence that can eventually improve the health of a population.

# Seeking the Balance between Harm and Benefit: The Role of Pharmacosurveillance in Choosing the Drugs We Should Take

## Trouver l'équilibre entre les torts et les bénéfiques : le rôle de la pharmacosurveillance dans le choix des médicaments qu'il convient de prendre

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**P**HARMACOSURVEILLANCE IS THE REGULAR MONITORING OF MEDICATIONS IN REAL clinical practice for benefits and harms. This paper outlines the advancements of the Manitoba Centre for Health Policy (MCHP) and others to date in participating in pharmacosurveillance research. It proffers what we could do in the future to produce information that informs the balance between benefit and harm of the use of pharmaceuticals.

A research framework for looking at questions of pharmacosurveillance was posed at the beginning of this workshop (Metge et al. 2005a). According to Health Canada, safety, efficacy (whether a drug works) and quality are the attributes of a drug that are evaluated when its

manufacturer is seeking a licence for its use in Canada (Metge et al. 2005b). Drawing a parallel with Donabedian's structure/process/outcome quality paradigm (Donabedian 1982), Dr. Metge outlined the work that MCHP has done regarding the attributes of quality:

- Utilization of quantitative data on the access, extent, variability and cost of the use of pharmaceuticals corresponds to Donabedian's focus on structure.
- Appropriateness, or determination of whether the right drug was prescribed to the right person at the right time and in the right dose, aligns with assessment of process.
- Outcome, or the net of benefit and harm when a pharmaceutical is prescribed, dispensed and taken under real-life circumstances, is similar to Donabedian's third step in the model of quality.

At MCHP, several studies have developed methods to look at these attributes of quality. Early work concentrated on "quantifiability" and in developing the Drug Programs Information Network (DPIN) database for research purposes, which included linking to other data sets (e.g., physician visits, hospitalizations, vital statistics). DPIN data include persons' use of pharmaceuticals from birth to death for most of the population.<sup>1</sup>

Several government initiatives and individual researchers have taken advantage of the DPIN's linkages. For example, from a drug utilization perspective we know that elderly residents of Manitoba, on average, cost more per year than other Manitoba residents, yet the amount paid per dose differs significantly (Metge et al. 2005a). Elderly persons' (65+ years) total costs for pharmaceuticals are more per year than persons less than 65 years.

We have also found, by applying an appropriateness lens, that physicians appear not to be using a "step-up"<sup>2</sup> approach to prescribing for new, uncomplicated hypertensive patients. When doctors were given a choice of entities for the first prescription to newly diagnosed persons with hypertension, 64% of these prescriptions specified the top-end, or most expensive, option (Metge et al. 2003).

A study of utilization and costs of antipsychotic agents in Manitoba was undertaken using data housed at MCHP, and showcased by Dr. Silvia Alessi-Severini. The time series perspective of this study provides an overview of what has changed in the use of antipsychotic agents in Manitoba over time (Alessi-Severini et al. 2008). For example, second-generation antipsychotic agents (SGAs) rapidly overtook first-generation agents (FGAs) in 2001. Over a 10-year span (1996–2006), the market share of FGAs fell from 90% to 20%, while SGAs' market share rose from 10% to 80%.

Costs per dose of SGAs are far greater than costs of FGAs. A recent master's thesis completed at the University of Manitoba (Vasilyeva 2009) considered the difference in adverse events in the elderly population treated with both FGAs and SGAs. SGAs were significantly associated with a lower risk of all-cause mortality but a significantly higher risk of myocardial infarction compared to FGAs. No significant difference was found between the two kinds of agents for cerebrovascular events, cardiac arrhythmia and congestive heart failure. The entire data source for these findings was the MCHP Repository (years 2000–2007).<sup>3</sup>

Dr. Ingrid Sketris discussed two examples of the use of administrative data in the area of pharmaco-surveillance, one of them involving Manitoba data. Case 1 compared antibiotic use in three Canadian provinces – Nova Scotia, Saskatchewan and Manitoba (Sketris et al. 2004). A rich panel of other data (patient, provider and system factors; industry marketing strategies) offered explanations for the findings that the use of antimicrobials differed markedly among the three provinces. No appropriateness analysis was done; however, the finding that the use of different agents was very different among the three provinces was interesting. Pharmaco-surveillance data (on appropriateness) was not largely considered as the purpose of the study was to see if comparative studies of drug utilization across provinces was possible (Health Transition Funding from the late 1990s).

Case 2 looked at the effectiveness of disease-modifying drugs (DMDs) in delaying the progression of multiple sclerosis. This project has built on the use of registries, examining the development of policies on prescription drug coverage based on evidence culled from research (Brown et al. 2007). Specifically, by combining clinical registry data and administrative data, Nova Scotia has been able to estimate the treatment effect size of DMDs in the context of real-world clinical practice (Fisk et al. 2005). These estimates were similar to the efficacy estimates from the pivotal licensing trials.

The implications for Manitoba are that the synthesis of administrative and clinical data can be powerful in answering questions about both safety and effectiveness. Nova Scotia has a MS registry; Manitoba has a bone mineral density (BMD) registry, and similar studies have used Manitoba Health and other clinical data. Pivotal licensing trials are the clinical trials required for a pharmaceutical company to receive its licence to market the drug in Canada. The value added from the Nova Scotia study was the importance of obtaining permission to link administrative data with clinical data and the increased knowledge that can be gained from doing so.

At the conclusion of the formal presentations, questions were posed to the participants for discussion. These focused on the knowledge translation aspect of pharmaco-surveillance research. For example: “We may have done a good job at providing knowledge support to decisions about the effectiveness of prescription drugs and their use, but do we perceive that the knowledge has been used?” “Will the evolution of the Drug Safety and Effectiveness Network (CIHR/Health Canada) help us to improve the translation of pharmaco-surveillance knowledge?”

Discussion of these points concluded that the answer to the first question was most likely no, for now – many decision-makers appear to continue to question the validity of the observational data used to report on drug safety and effectiveness (Metge et al. 2005b). Discussion of the second question was inconclusive, since the new Drug Safety and Effectiveness Network was just beginning the process of being established. However, several participants expressed hope that because DSEN has been given sufficient funding and a sufficiently strong mandate that it will help the evidence produced by it to be used in informing both individual and population-based decisions about the use of pharmaceuticals.

#### NOTE

<sup>1</sup> DPIN data do not include drugs dispensed through First Nations Inuit Health nursing stations and some federal programs (prisons and the RCMP). Less than 5% of data were missing, although for nursing stations in at least

## Seeking the Balance between Harm and Benefit

one northern region, upwards of 20% of data may have been missing. A recent analysis of this missing data has not been done.

<sup>2</sup> The act of applying (or prescribing) the minimum pharmacological force necessary to achieve a stated therapeutic objective when initiating therapy.

<sup>3</sup> The master's thesis had not been completed when this session was offered.

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# Expanding the Data Repository: New Technology and Resources for the 21st Century

## Accroître le registre de données : nouvelles technologies et ressources pour le XXI<sup>e</sup> siècle

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THESE ARE EXCITING TIMES TO BE AT THE MANITOBA CENTRE FOR HEALTH POLICY (MCHP). The size and diversity of databases at MCHP provide an unprecedented opportunity to conduct population health and health services research and research into the determinants of health. Current holdings now represent over 90 databases of health, education, social services, survey and clinical data, as well as instruments such as the Early Development Indicator (EDI) now routinely administered to all primary school children in Manitoba. In the near future we expect to add public housing, infectious disease reporting and justice. Individual records in all these data sets can be linked, as approvals from research ethics boards, health information privacy committees and individual data trustees permit, through the use of an encrypted individual identifier.

Because of previous requirements, only individuals who were physically on-site could analyze data. For off-site investigators wanting to do their own data analysis, this meant that working with MCHP data was cumbersome. To address this limitation, several new and emerging technologies have been combined and will be piloted at MCHP over the next four

years using funds provided by a recent Canadian Foundation for Innovation (CFI) award. Chief among these are: two-level authentication, the SASTM Scalable Performance Data Server (SPDS) and thin clients running virtual desktops. (A thin client is one that relies on the server to do most of its processing.) SPDS provides finer control over data access (to the row and column level in data sets) and better user tracking than previous implementations. The final requirement is that all thin clients be available only in controlled-access areas (using swipe card technology) and that users log use of all thin clients. These requirements are part of a planned auditing process that will occur both routinely as well as randomly on short notice. By using these technologies and meeting these requirements researchers and analysts will be able to analyze MCHP data from remote locations. Users who breach confidentiality agreements are subject to penalties imposed by their respective institutions, as well as losing rights of access to the Repository.

We also undertook a review of other policies and procedures and noted that the better our online documentation is, the fewer are the demands placed on MCHP staff. As a consequence, a major reorganization of documentation and its accessibility is currently taking place, some of which will be available only on internal portal sites (for confidentiality reasons). This reorganization will include integrated access, for every data set, to trustee-provided documents, data schemas, data dictionaries, codebooks, history and file revisions, common problems and data quality reports.

Perhaps one of the largest undertakings was the development of an accreditation process, a half-day workshop that must be completed by all investigators who sign a data access agreement. This workshop introduces researchers to MCHP policies and procedures concerning access to confidential information, the expectations we have of them and those that they can have of us, and the wide range of supports (many online) for learning about and using administrative data. The entire accreditation process is available online at [www.umanitoba.ca/medicine/units/mchp/](http://www.umanitoba.ca/medicine/units/mchp/).

Combining data from new and different domains does not come without analytical and statistical pitfalls. First, individual household-level data are available for only a subset of the population (based on information from the Manitoba prescription drug insurance plans); families receiving income assistance can also be specified. For everyone else, only ecological data on income are available. Second, scores on standardized tests provide information on student achievement, but many children in the appropriate age groups will not have scores recorded. Other files on enrolment, school grades, year in school and residency in the province without school attendance must be combined to provide a fuller picture for a given birth cohort. Techniques pioneered by Mosteller and Tukey (1977) have proven to be particularly useful in showing how messy data from multiple files can be put together to generate “normalized” distributions relevant for an entire population. For index creation, a standardized score for each individual can be computed by assuming an underlying logit distribution, divided into pieces according to the percentage of cohort members in each category (Roos et al. 2008; Willms 1986). Such distributions facilitate the use of powerful statistics.

MCHP research has highlighted the development of several kinds of family information

(Strohschein et al. 2009). Particularly useful may be the construction of family histories to assess the effects of critical life events – e.g., parental divorce or death – at different stages of childhood on educational achievement, health status and labour force participation. Second, longitudinal information on place of residence should permit the study of residential mobility as both a correlate and a predictor of health and achievement (Lix et al. 2006). Third, sibling–parent designs that link parental histories to child histories can be used to assess the contribution of such conditions as maternal depression to a child’s mental health and subsequent outcomes. Multi-level modelling is a particularly useful statistical tool that allows the comparison of individual, family and neighbourhood factors within a single analysis (Gelman and Hill 2007).

Finally, the socio-economic gradient can be studied from a variety of perspectives over a rich array of outcomes. Preliminary analysis using educational achievement shows that siblings living in lower-income families have lower, but more highly correlated, scores than their higher-income counterparts. This finding ties in with research in behavioural genetics suggesting that a more restricted environment leads to higher within-family correlations in IQ and achievement scores (Loehlin et al. 2007). The possibilities for interdisciplinary collaboration are many.

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# Beyond Administrative Data: A Vision for Health Information Systems for Canada

## Au-delà des données administratives : vision pour les systèmes canadiens d'information sur la santé

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**T**HE MANITOBA CENTRE FOR HEALTH POLICY HAS ACHIEVED MUCH SUCCESS over the past 20 years in building an administrative claims data repository, using that data for innovative, policy-relevant research, and developing effective knowledge translation mechanisms. Researchers have long recognized the limitations of administrative data while working creatively to minimize these limitations using linkages and cutting-edge analytical techniques. We are, however, on the verge of a new era of data use in Canada. The Canadian Institute for Health Information (CIHI), Canada Health Infoway and federal, provincial and territorial ministries of health are collaborating on an initiative to inform the planning and development of health information systems across Canada to support a full spectrum of uses of data, including health research.

Previously called “secondary use,” the utilization of clinical electronic data (including admin-

istrative data, “electronic health records” and “electronic medical records” – EHRs and EMRs) for system evaluation, planning, policy development and management has now been recognized as a critical legitimate use of that data. The significant investment in the electronic health record by the federal government (\$1.6 billion, to date) through Infoway has spurred the development of data sources across the country, with the potential for a sea of change in the information potentially available for system management, policy development and research. However, it should not be assumed that these data, intended to streamline, simplify and improve the quality of clinical services delivery, will be available and valuable for health system use.

Louis Barré, Vice-President of Strategy, Planning and Outreach for CIHI, presented the current national vision for the utilization of clinical data and the collaborative strategies underway to achieve this vision.

An early step has been the acceptance of a change in the language used when referring to data use. *Health system use* (HSU) is the use of health information for purposes beyond direct patient care, including clinical program management, health system management, population health surveillance and research, all of which lead to improved patient care and health outcomes. This new term has been endorsed by the Conference of Deputy Ministers of Health. The categories of use are outlined in Figure 1.

The technical strategy includes defining the business requirements, seizing existing investment opportunities, supporting jurisdictions in current and future efforts, developing the required standards and getting the technical architecture right. Each of these aims brings its own significant challenges and barriers when considered within the context of the complex federal–provincial/territorial relationships governing healthcare in Canada. For example, the ultimate cost of the required health information infrastructure has been estimated to be as high as five times the current level of investment!

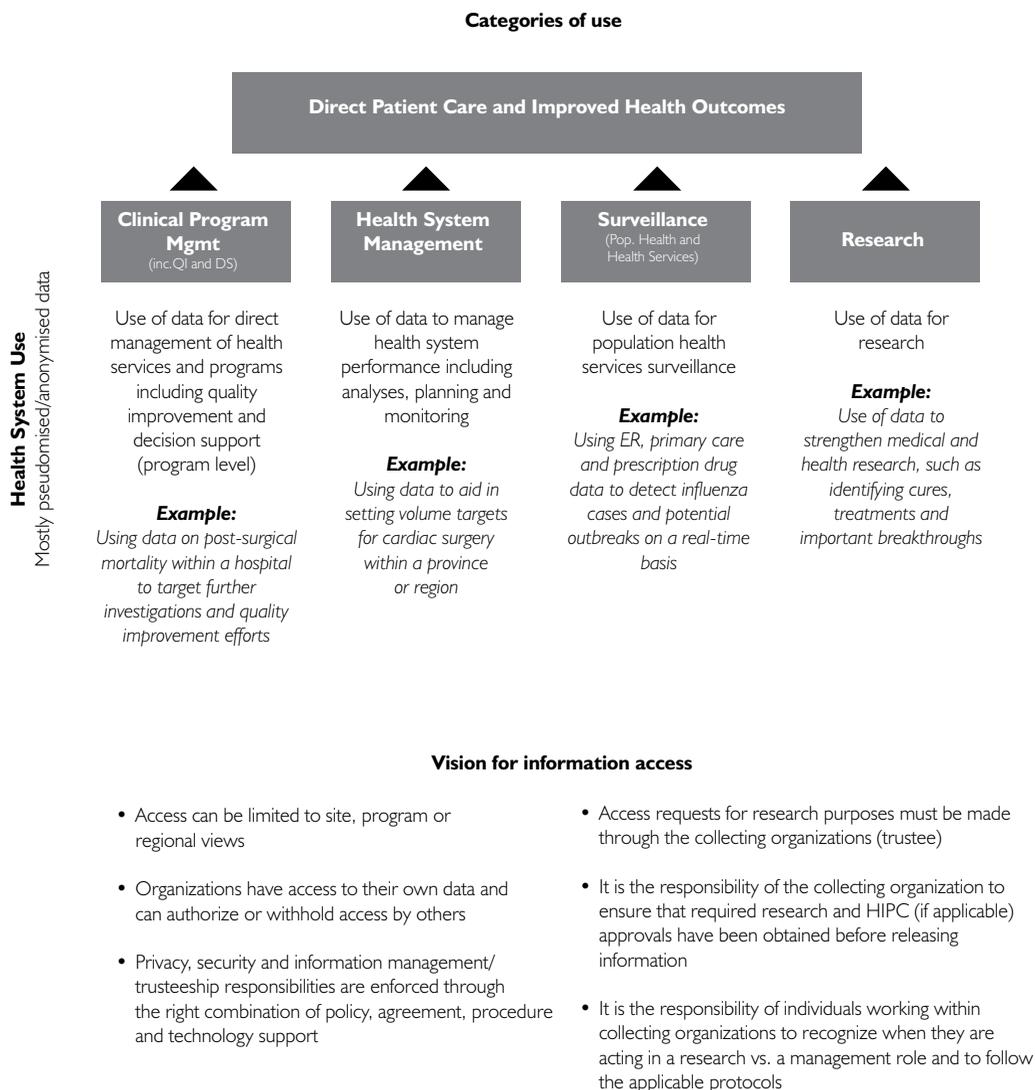
The ultimate goal of securing access to usable EHR and EMR data in an efficient and acceptable way will need to build on point-of-care systems and minimize duplication. The data and the related database software will need to be coded or structured with the ability to link, query and extract information at the record level. We will need to develop standardized concepts, data models, data definitions and minimum data sets that are acceptable across all jurisdictions, and all this needs to be done within a framework of privacy and security that garners the support of Canadians.

Tom Fogg, Director of Strategy and Planning, Manitoba eHealth, presented the Manitoba perspective. He described Manitoba eHealth’s mandate under three major aims: to integrate healthcare systems across regions and care sectors; to improve and expand healthcare services by managing information and communication technology (ICT) to achieve economies of scale provincially; and to improve the efficiency and effectiveness of ICT services.

Manitoba’s overall approach to eHealth strategy is driven by the three key goals of (1) access/client service, (2) quality and safety and (3) efficiency/sustainability of the health system. These goals are applied by examining opportunities in each of several health sectors as well as across sectors. The two cross-sector foci are coordination of care for individual patients and information integration to facilitate health system management.

## Beyond Administrative Data

FIGURE 1. Categories of health system use and vision for information access



Manitoba eHealth believes that the strategy to make information valuable to health system decision-makers will also benefit the research community. Information that becomes available as new operational systems are implemented and “harvested” to support the analytical needs of decision-makers should be more comprehensive, better structured and standardized, higher in quality and more timely than much of the information used for research today. The organizations that collect this information originally and act as trustees will determine how and when it is made available for research, pursuant to Manitoba’s privacy legislation and research ethics policies. As an information manager on their behalf, Manitoba eHealth will take direction from these trustees.

As with the vision presented by Louis Barré, the Manitoba eHealth vision faces challenges in moving from the current situation to the target state. These include:

- Lack of an integrated health system management environment and toolset;
- Limited human resources capacity;
- Confusion about policies and procedures; and
- Uncertainty about the level of buy-in to the value of investment in health system management.

Despite these challenges there was a sense of optimism from the session that reflected a common national and provincial vision and recognition of the increasing amount of energy being directed to this issue.

# The Inside Story: Knowledge Translation Lessons from the Need to Know Team

## Le fond de l'histoire : leçons en matière de transfert de connaissances de la part de l'équipe Need to Know

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THIS SESSION BEGAN WITH DR. MARTENS OBSERVING THE IMPORTANCE OF HAVING different perspectives on the same information, much as different-shaped lenses provide different perspectives on the same image, an idea from art called anamorphosis. She described how the idea for *The Need To Know* (NTK) Team grew out of MCHP's Rural and Northern Healthcare Days, which began in 1994. Five years later, she transformed the event into an interactive workshop. That workshop quickly led to a desire on the part of research scientists at MCHP to extend the partnership so that work on issues of importance to regional and provincial planners could incorporate research users from the start of the process rather than at the end. This change reflects the NTK Team's approach to integrated knowledge translation.

Dr. Martens also described the nature and membership of the NTK Team, which includes MCHP research scientists and graduate students, top-level planning representatives from each regional health authority (RHA) chosen by the CEOs, and representatives from Manitoba Health. Through this approach, the NTK Team incorporates people from a variety of roles and backgrounds: medical officers of health, VPs/directors of planning, managers of quality assurance and public health, among others. This variety is key to the NTK Team's success, as it means that a number of perspectives are included in all discussions. To date, the NTK Team has completed five major MCHP research reports, four evaluation reports and several peer-reviewed publications.

Dr. Fransoo discussed a number of findings that would not have been revealed by researchers working in isolation, because both the research topics and the methods used have been heavily influenced by NTK Team members. The impetus behind MCHP's mental illness report (Martens et al. 2004) was RHA members' insistence on its importance. It has been one of the NTK Team's more influential reports, in particular the finding of the substantial burden of physical illness among those with mental illness. In the sex differences report (Fransoo et al. 2005), the NTK Team insisted on producing age-specific rates by sex for all indicators. Among other findings, this detailed analysis showed the confounding of age and sex in cardiac care after heart attacks, revealing that there is no sex bias in cardiac care after heart attack.

Suzanne Dick explained the responsibilities of NTK Team members and spoke about how the team's activities have affected the North Eastman Health Association. Among other things, NTK Team activities led to the formation of an Evidence Informed Practice Team (EIPT), a group of staff from the region who work together to ensure that evidence is used to inform practice, and to provide input and feedback on other issues. The EIPT is also integral in completing the region's regular comprehensive Community Health Assessment Report.

Tannis Erickson spoke about the numerous benefits of NTK Team membership to RHAs and provided an example of how evidence from a team report was used to launch a more detailed study of adolescent health involving the Teen Clinic in Selkirk. Data from the MCHP report were triangulated with results from local Youth Health Surveys, which revealed the characteristics of clinic visitors, and connected with other health-related issues faced by local teens.

Deborah Malazdrewicz spoke about how the NTK Team has affected a number of aspects within Manitoba Health, including providing data and information on initiatives, enhancing linkage and integration with RHAs, capacity building, research partnerships, analy-

sis methods, networking, improved understanding of the context and realities of rural health issues and their management, and of course encouraging evidence-informed practice within Manitoba Health. Interestingly, most of these items affect MCHP researchers as well, reflecting how the NTK Team has been a remarkable “win–win–win” experience.

Elaine Burland then spoke about her experience participating on the NTK Team as a graduate student. She explained how it provided her a more practical understanding of her studies as well as a chance to learn about issues of relevance for RHAs and to observe integrated knowledge translation in action. It also gave her opportunities to assist in the preparation of reports and to make numerous presentations at scientific conferences, as well as contribute as a co-author of academic publications. Finally, it helped her establish connections with key contact people for her doctoral research, which involves a program evaluation of fall management practices in personal care homes in two RHAs.

Pearl Soltys wrapped up the session by outlining the multi-stage evaluation process used by the NTK Team, and how the results inform ongoing team practices. This evaluation process also led to the creation of the project called From Evidence to Action (Bowen and Erickson 2007), a separately funded study that examined organizational factors associated with the use of evidence in the real world, and tools to enhance the use of evidence to inform decision-making.

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# Healthcare Services for an Aging Population: Using Administrative Data to Help Prepare for the Future

## Services de santé pour une population vieillissante : utilisation des données administratives pour aider à préparer l'avenir

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**T**HREE CONCURRENT DEVELOPMENTS IN THE 1970s HAS LED TO MANITOBA becoming a leader in the field of research into aging. First, the provincial government launched the Continuing Care Program, to provide home care and nursing home placement if needed – the first such program in Canada. Second, the province hired the late Dr. Betty Havens to initiate a study on the needs of Manitoba elders, which became known as the Longitudinal Study on Aging (LOS). Third, Drs. Noralou Roos, Betty Havens, the late Evelyn Shapiro and others decided to link the LOS data with healthcare use data housed at the University of Manitoba Medical School, to conduct studies that have developed critical knowledge on the use, delivery and quality of care delivered to its elders. Many of the ques-

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\* Dr. Shapiro passed away on November 10, 2010.

tions addressed were developed in consultation with provincial stakeholders, providing key evidence to support planning decisions (Doupe et al. 2006; Menec et al 2002; Roos et al. 2001). This team-based approach has also fostered strong partnerships that still exist today and, in some respects, are unique in Canada.

With the knowledge we have gained from the past, today is an especially exciting time to conduct research into older adult health services. In many respects, the most pertinent questions from the past still remain today. Largely due to our aging “baby boomer” population, the number of older adults in Manitoba is expected to almost double by the year 2036. This population aging trend, while prolonged, will also be transient, and collectively our challenge is to develop more effective healthcare alternatives during this interim time. In response to this challenge, Manitoba decision-makers have expanded their current continuum of care to include supportive housing services as an alternate choice for some personal care home (PCH) residents. Much research is required to guide this process, and essential questions include: How much and when will population aging affect the demand for PCH use? Who are the main users of supportive housing services, and what is the potential for this program to reduce PCH demands? How much, if any, will supportive housing services impact healthcare costs, and what are the additional out-of-pocket expenses for older adults? How can we measure the quality of care in these alternative healthcare services, and what policies are needed to improve care further? What additional options are needed to help support continued community living, and what types of partnerships (e.g., housing and healthcare) are required to leverage this change? The Manitoba Centre for Health Policy (MCHP) is well positioned to conduct research on these and other pertinent questions, to help guide the development of alternative older adult healthcare services.

Research is but one type of evidence, however. Decision-makers must also respond to clients, family members and political and media perspectives when planning for change. Understanding these different perspectives is important when redesigning the healthcare system, and to help ensure support for these changes. This being said, older adult healthcare research has been used extensively in Manitoba to guide policy development in such areas as quality of care and PCH wait times. Leaders from the Winnipeg Regional Health Authority (WRHA) have incorporated MCHP evidence into their long-term care planning strategies, in particular, to guide discussions about PCH bed needs and alternative approaches to long-term care. This use of data has led to new PCH developments, the creation of additional supportive housing spaces and the development of senior group-living models and other specialty services, such as PRIME (Program for the Integrated and Managed Care of the Elderly, a health centre for seniors that provides comprehensive primary care using a case management model).

What’s next for older adult health services research in Manitoba? Data from the home care and PCH interRAI tools, gathered in the WRHA, can now be linked to the healthcare use files housed at MCHP. This new linkage provides unique research opportunities in Manitoba, as extensive clinical, demographic, and social information is now available. In addition to addressing the aforementioned research, these data will allow us to revisit previously conducted analyses, to understand when and why older adults use healthcare services and to

better measure the quality of care, especially across nursing home ownership types. In an era of integration and the need for cost containment, research is also required to better understand strategies for integrating the primary and long-term healthcare sectors. Research on transitions in care is also important, for example, to assess the reasons for and consequences of PCH resident transfers to emergency departments.

Manitoba is a leader in developing both community and long-term care services for older adults. As in most other Canadian jurisdictions, baby boomer aging presents a major challenge to the province. Research and experience provide an excellent base for meeting this challenge, and interprovincial collaborations are essential for helping us all to prepare for the future.

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