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Services de santé, gestion et recherche de politique

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Data Matters • Discussion and Debate • Research Papers
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Health Services, Management and Policy Research
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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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Politiques de Santé/Healthcare Policy 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.

Bien que *Politiques de Santé/Healthcare Policy* encourage l'envoi d'articles ayant un solide fondement théorique et innovateurs sur le plan méthodologique, nous privilégions la recherche appliquée plutôt que les travaux théoriques et l'élaboration de méthodes. La revue veut maintenir une saveur distinctement canadienne en mettant l'accent sur les questions liées aux services et aux politiques de santé au Canada. Nous publions aussi des travaux de recherche et des analyses présentant des comparaisons internationales qui sont pertinentes pour le contexte canadien.

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EDITORIAL

The Importance and Power of Networks in Health Research, Practice and Policy

Movies and other forms of popular culture have propagated the notion that we are all joined by six degrees of separation. The conjecture dates back to at least the late 1920s and the writings of Hungarian Frigyes Karinthy (Boccara 2010). It continues to feature in games, television shows and social media today.

Formal research has proven this theory to be valid in some cases and has refined it in others. More importantly, studies have explored why people in networks sometimes do – and other times do not – invest time, energy and effort to connect and share knowledge with others. Factors such as the strength of ties between members of a network, its social cohesion and its range have been shown to influence this type of collaboration (Tortoriello et al. 2011). Likewise, while dense clusters of strong connections offer considerable value, new insights and information often come via weak ties with contacts who have access to non-redundant information (Granovetter 1973). This makes bridges between network clusters particularly helpful.

In producing *Healthcare Policy/Politiques de Santé* we depend on the power of networks and seek to connect and broaden them for the benefit of our community. For instance, networks are essential to eliciting high-quality manuscripts that fit the journal's mandate, to recruiting appropriate peer reviewers who are experts in a wide range of topics, and to serving the information needs of the journal's readers, both in domains that they are already familiar with and in those that are relevant to but beyond their usual focus.

This effort would not be possible without the many and varied contributions of the journal's editors, authors, peer reviewers and staff. We have strong ties with many experts in the topics that we cover and aim to build bridges across the community. We also take advantage of our collective networks to recruit suitable reviewers and to foster a rich discussion and debate through the articles that we publish.

Further, action on the results of the research and thinking published in the journal's pages depends on an even larger informal network that extends across the country and around the world. The breadth of articles in this issue of the journal illustrates the range and scope of possibilities involved. Authors focus on topics ranging from home care to hospitals, from broad public policy debates to specific questions related to coverage for orphan drugs.

As this is the final issue for this volume of the journal, I would like to extend my sincere thanks to everyone involved in the publication process over the last year. This thank you is due both on my own behalf and on behalf of all those who will benefit from the improved understanding, policy and health services that will come from the application of the learnings published throughout this volume of *Healthcare Policy/Politiques de santé*.

JENNIFER ZELMER, PHD
Editor-in-chief

References

Boccara, N. 2010. *Modeling Complex Systems*. 2nd edition. New York: Springer Science and Business Media.

Granovetter, M. 1973. "The Strength of Weak Ties." *American Journal of Sociology* 78(6): 1360–80. doi:10.1086/225469.

Tortoriello, M., R. Reagans and B. McEvily. 2011. "Bridging the Knowledge Gap: The Influence of Strong Ties, Network Cohesion, and Network Range on the Transfer of Knowledge between Organizational Units." *Organisation Science* 23(4): 1024–39. doi:10.1287/orsc.1110.0688.

ÉDITORIAL

Importance et force des réseaux pour les politiques, la pratique et la recherche en santé

Le cinéma et les autres formes de culture populaire ont propagé l'idée selon laquelle nous sommes tous reliés entre nous à six degrés de séparation. Ce principe date au moins des années 1920 avec les écrits du Hongrois Frigyes Karinthy (Boccara 2010). L'idée est encore et toujours à la mode dans des jeux, à la télévision et dans les médias sociaux.

La recherche a démontré la validité de cette théorie dans certains cas et l'a peaufiné dans d'autres. Mais il est particulièrement intéressant de voir que des études ont tenté de savoir pourquoi, dans les réseaux, les personnes investissent – ou non – du temps et de l'énergie pour communiquer et partager des renseignements avec les autres. Des facteurs tels que la force des liens, la cohésion sociale et la portée d'un réseau influencent le degré de participation (Tortoriello et al. 2011). Par ailleurs, bien que les agglomérations de fortes connections confèrent une valeur indéniable au réseau, les nouvelles pistes et les nouveaux renseignements se présentent souvent par les liens faibles où les contacts ont accès à une information non redondante (Granovetter 1973). Dans ce sens, les ponts entre les agglomérations de divers réseaux deviennent particulièrement utiles.

Dans la production de *Politiques de Santé/Healthcare Policy*, nous dépendons de la force des réseaux et nous cherchons à les étendre et les liens entre eux, pour le bien de la communauté. Par exemple, les réseaux sont essentiels pour obtenir des manuscrits de grande qualité qui répondent au mandat de la revue, pour recruter les pairs examinateurs adéquats dans une vaste gamme de domaines et pour présenter aux lecteurs les renseignements dont ils ont besoin, et ce, tant dans leurs domaines de prédilection que dans d'autres qui sont pertinents mais qu'ils n'ont pas toujours en tête.

Cet effort serait impossible sans la contribution des nombreux réviseurs, auteurs, pairs examinateurs et employés de la revue. Nous pouvons compter sur de forts liens avec plusieurs experts des sujets que nous couvrons et notre objectif est d'établir des ponts dans toute la communauté. Nous tirons aussi profit de nos réseaux collectifs pour recruter des pairs examinateurs adéquats et pour alimenter de riches débats grâce aux articles que nous publions.

De plus, les gestes concrets liés aux résultats et recherches de la revue dépendent d'un réseau officieux encore plus vaste, lequel s'étend d'un bout à l'autre du pays et parcourt le monde entier. L'étendue des articles du présent numéro illustre la portée des possibilités en cause. Dans ce numéro, les auteurs se penchent sur des sujets qui touchent aux soins à domicile ou aux établissements hospitaliers; ou encore, ils s'intéressent à de grands débats de politiques publiques ou à des enjeux précis liés aux remèdes orphelins.

Puisqu'il s'agit du dernier numéro pour ce volume de la revue, j'aimerais remercier toutes les personnes qui ont participé au processus de publication cette année. J'exprime ces remerciements en mon nom, mais aussi au nom de tous ceux qui tireront avantage d'une meilleure compréhension des enjeux, des politiques et des services de santé grâce aux connaissances véhiculées par ce volume de *Politiques de santé/Healthcare Policy*.

JENNIFER ZELMER, PHD
Rédactrice en chef

Références

Boccara, N. 2010. *Modeling Complex Systems*. Deuxième édition. New York: Springer Science and Business Media.

Granovetter, M. 1973. "The Strength of Weak Ties." *American Journal of Sociology* 78(6): 1360–80. doi:10.1086/225469.

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Health, Wealth and the Price of Oil

Santé, richesse et prix du pétrole

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Abstract

The correlation between health and wealth is arguably a very solidly established relationship. Yet that relationship may be reversing. Falling oil prices have raised (average) per capita incomes, worldwide. But from a long-run perspective they are a public health disaster. The latter is easy to see: low oil reduces the incentive to develop alternative energy sources and "bend the curve" of global warming. Their principal impact on incomes has been redistributional – Alberta and Russia lose, Ontario and Germany gain, etc. Zero net gain. But the price has fallen because technical progress in extracting American shale oil has forced the Saudis' hand. These efficiencies have real benefits for (average) incomes, but costs for long-run health. A compensating carbon tax is an obvious response.

Résumé

La forte corrélation entre santé et richesse est clairement établie. Toutefois, cette relation pourrait s'inverser. La chute des prix du pétrole a fait monter (en moyenne) les revenus par habitant, dans le monde entier. Mais à plus long terme, cela représente un désastre en matière de santé publique. Cela est facile à voir : un pétrole abordable amenuise la volonté de développer d'autres sources d'énergie et fait « fléchir la courbe » du réchauffement climatique. Le principal impact des bas prix est une redistribution : l'Alberta et la Russie perdent, l'Ontario et l'Allemagne gagnent, etc. Le gain net est égal à zéro. En fait, les prix ont diminué à cause des progrès techniques de l'extraction du pétrole de schiste américain, ce qui a forcé la main de l'Arabie saoudite. Ces rendements opératoires sont avantageux pour les revenus (moyens), mais ils hypothèquent la santé à plus long terme. Le besoin d'une taxe carbone compensatoire semble évident.

Wealthier Is Healthier, Mostly

The correlation between health and wealth is arguably the most solidly established relationship we have in the study of the determinants of health. Countries with higher levels of gross domestic product (GDP) per capita tend to rank higher on various measures of health status, primarily life expectancy, but also (when available) morbidity and (with some interesting anomalies) self-reported health status. And within countries, people higher up on the socio-economic scale live longer, on average, and suffer less illness and disability while doing so. All long known and extensively documented. Richer is not only better, but also healthier.

Like all generalizations, this one is false-ish. Detailed examination yields all sorts of qualifications, exceptions and anomalies. There are diminishing health returns to wealth; when we look across countries, the relationship flattens out among high-income countries. On the other hand, within societies the relationship seems to hold all the way up the socio-economic spectrum. It also makes a difference how the aggregate national income is distributed, and how it is used. Recent US data, for example, show that over the long term there have been very large gains in life expectancy at the top end of the income distribution, but hardly any at the bottom. Health improvements, or at least gains in life years, are thus following the trends in income growth – big at the top, minimal at the bottom. Again, richer is better, even if a rising tide does not lift all boats. (In the US, at least, those on the bottom stay there.)

But This Time Is Different, Unless …

The details of the health–wealth relationship are endlessly fascinating and offer hours, years and even careers of harmless fun for health researchers. (Believe it!) Yet very recently – indeed, in little more than a year – a remarkable concatenation of technological and political forces has emerged that threatens to reverse this relationship on a very large scale. We are offered a significant short-term increase in average per capita world incomes, in return for an indeterminately large long-run reduction in health. Fortunately, there are well understood and readily available policy levers that could permit us to avert or at least mitigate the threat to health while capturing the economic gains. Unfortunately, a combination of conflicting economic interests and deep ideological convictions may place the obvious policies out of reach. At best, these forces are likely to delay implementation for a long time while health and other damages cumulate.

> The oil price plunge is unambiguously good news for the global economy. It transfers trillions of dollars of wealth from oil-exporting countries to oil-consuming countries. Since there are a lot more of the latter, the net effect is positive – even if it causes enormous pain to the likes of Saudi Arabia, Russia, Nigeria and Venezuela. When fuel prices fall, consumers' buying power increases, especially in regions that are clogged with cars, such as Europe and North America; a cheaper fill-up is the equivalent of a tax cut (Reguly 2016a).

Reguly has it right, of course, about the redistribution of wealth. As the price falls, oil producers lose – Alberta, Newfoundland – and consumers gain – Ontario, Quebec. The massive transfer of wealth from west to east is the exact reverse of that which occurred after the OPEC "oil shocks" of 1974 and 1979. At the first shock, the Liberal government of Pierre Trudeau introduced the much reviled National Energy Program (NEP) in a perfectly reasonable attempt to protect Eastern consumers against the rapacity of the oil companies and their Western provincial backers. But the NEP was greeted by a storm of political protest and propaganda from corporate Canada. The NEP threatened the huge windfall profits that OPEC was handing them on a platter: "landlords, like all other men, love to reap where they never sowed" (Adam Smith 1776). Even today the NEP is a dirty phrase in Western Canada, among the many who have no idea what it was all about. But everybody knows that it was *really bad*. (Its chief architect, Ed Clark, left government for a highly successful career as CEO of Canada Trust Financial Services and, later, of TD Canada Trust. (If you can't beat 'em, join 'em.))

These interprovincial or inter-country swings of wealth when oil prices fluctuate simply rob Peter to pay Paul. How do they, on average, benefit or harm the world as a whole? Reguly counts heads. There are many, many more people in consuming countries, so more winners than losers when the price goes down. Falling oil prices are on balance a *good thing*, no matter what they think in Calgary or Venezuela, Texas or Russia.

Not so fast.

Balancing Benefits. Where's the Net Gain?

First, head-counting ignores the severity of the impacts on winners and losers. Prices at the pump may fall in Ontario and Quebec; in Alberta, people lose jobs and houses. Worse, in countries where oil revenues are used to pacify unhappy populations, there may be blood in the streets. Counting heads may be a reasonable start to judging net benefits in a stable society with various forms of interpersonal and inter-regional transfers; elsewhere, matters become more complicated.

But secondly, wealth redistribution, within and across countries, is only part of the story. There is also a net global wealth gain that tends to be obscured by the loud and very real distress of the losers and the mysterious disappearance of trillions of dollars from world financial markets. (Where did they go?)

Technology Matters

Behind the drama, the real cost of obtaining oil has fallen, and fallen a lot. That cost, the notorious opportunity cost (op cost) of the economics classrooms, is the collection of other good things that could have been produced with the enormous amount of human time, energy and skills, and the huge physical and intellectual capital that has to be devoted to the discovery, extraction, transportation, processing and distribution of petroleum products. Insofar as the fall in oil prices corresponds to a significant decline in that op cost, it follows that the world's people are, on average, better off – wealthier. We do not have to work as hard,

collectively, to get the oil we are using, and we have resources to spare to produce other things – or even just more oil. And the op cost has fallen a lot, as a result of major technological advances in the extraction of "unconventional" oil. As always, technological advances are the fundamental basis for increasing wealth.

The oil locked up in American shale has been well known for at least a century, but was not previously economically feasible to extract. Now it is.

"Peak oil" – the point at which the maximum rate of extraction of petroleum is reached (predicted, not so long ago, for 2005) – would otherwise have been reached. Indeed, we may be reaching it for "conventional" sources. With falling global production, and extraction costs rising, the result would have been a global reduction in economic productivity – more time and effort required to get the same output. This didn't happen.

But the Effects Are Indirect

The simple picture of technological progress, lower op cost and increased wealth (on average) is, however, obscured by the large differences in extraction costs in different parts of the industry. In Saudi Arabia and the Persian Gulf, one needs do little more than stick a pipe into the ground. Drilling from platforms in the North Atlantic is vastly more expensive – as is mining and processing bitumen in Alberta. (There is no oil in the deliberately mislabelled "oil sands." Bitumen must be mined and processed, at relatively high economic and environmental cost.) The current world glut of oil is the indirect result of dramatically expanded American production of shale oil cutting into Saudi Arabian world market share (Reguly 2016b). The Saudis reacted, in November 2014, by maintaining their production levels and allowing the price of oil to collapse. The intent was to force out the American shale oil, which, while much cheaper to produce than previously, is still higher in cost than oil from the big Middle Eastern producers.

The Alberta Economy? Collateral Damage

In the process, the Alberta economy has been crushed and investment in new tar sands development has almost ground to a halt. The Harper strategy of betting all of Canada's economic chips on oil has (predictably) collapsed, leaving the new Trudeau government with a very big mess (while the remaining Harperites jeer from the sidelines). "Tighten your belts, Canadians."

But these are merely local concerns. From a global perspective, driving out the high-cost producers (Canada, for example) has both economic and environmental benefits – lower op cost and less greenhouse gas emissions. From a health standpoint, double happiness. Too bad about the distributional effects, but those will all work out – in the long run. (Actually, they won't. The winners and losers do not even out. Let us, like good economists, look this difficulty squarely in the face and move on. That worked for Alberta in 1974.)

So that is all good. The Saudis turn out to be the environmentalists with real muscle. When they say, "Leave the tar in the ground," it is going to stay in the ground, unless and until the price of oil comes up a long way. But there is a catch.

Is It Getting Hotter In Here, Or Is It Just Me?

The planet is still warming up.

Though the timing may be unclear, we know that the era of fossil fuels is going to come to an end, either by their replacement with other energy sources, or by the "radical restructuring" of the human species. Not this August, perhaps, nor this September, but it will happen. And in the meantime, while we or at least the winners are enjoying their increased wealth every time they fill up at the pump, there is an increasing amount of environmental damage that is not being priced.

The real cost of low oil prices is the thus-reduced incentive to develop alternatives. High oil prices were a double-edged sword. While they stimulated the development of high-cost, high-polluting sources of supply, such as the tar sands and deep-water drilling, they also provided a powerful stimulus to the technological advances that we really need for the collection, distribution and storage of alternative energy sources.

Low-cost oil is thus a short-run benefit, but a long-run disaster for human health, a disaster no less real for unfolding very slowly. Whatever gains may flow in the near term from increased wealth, they will eventually be offset by the costs of planetary warming. (How do you measure the health of an extinct species?)

Make Canadian Tax Policy in Canada, Not in Saudi Arabia

But as noted above, there is a solution ready to hand. Reguly (2016a) points to it: "When fuel prices fall … a cheaper fill-up is the equivalent of a tax cut." So reverse the cut.

In effect, the Saudis have brought about a highly selective tax reduction, one that most rewards the heaviest users of oil. This also creates a powerful incentive to increase consumption.

Consumers are responding already. Cheney (2015) points out that regulatory measures forcing vehicle manufacturers to improve fuel efficiency have had considerable success. Just like a fall in fuel prices, this lowers the cost per mile driven. But drivers are responding by buying bigger, more gas-guzzling vehicles:

> The only obstacles that have stood in the way of the SUV's quest for global domination are fuel prices and government legislation. … The consumer preference for ever-larger vehicles is driven by psychology and enabled by clever engineering that lets them drive a vehicle such as the [large, powerful, luxurious] SVR while burning the same amount of fuel that a mid-size car did in the 1990s. "They use the fuel savings to get more car," says industry analyst Dennis DesRosiers. "That's how it works" (Cheney 2015).

Now the Saudi tax cut has dramatically lowered the first obstacle.

Yet surely no government in its right mind would enact such a selective tax cut as deliberate fiscal policy. It does not become any better by virtue of being introduced by Saudi Arabia. The obvious response is to reverse the ill effects by imposing a countervailing

national carbon tax. The revenues could then be used both to support the development of alternative energy sources, and to build a less energy-intensive public (and private) infrastructure. Why not?

You could even sweeten the politics by knocking a bit off the GST or HST.

The need for a carbon tax is so obvious, and the present opportunity is so golden. But years of ideological anti-tax rhetoric stoked by the representatives of the wealthy have clouded the public discourse. To that is added the fierce opposition of the fossil fuel industries and their political representatives. So we are offered ludicrous proposals to continue extracting and burning oil, and then paying to put the carbon back into the ground – "sequestering" CO_2. Seriously?

Professor Pigou to the Rescue?

The carbon tax is in fact an example of a "Pigouvian tax," named for the Cambridge economist Arthur Cecil Pigou. Pigou was a contemporary, colleague and friend of John Maynard Keynes, whose ideas are also undergoing a revival at present. Canada in particular has a new federal government that is struggling with the legacy of a decade of "pre-Keynesian" fiscal policy. But Pigou was arguably even more influential in his own day, at least prior to the Great Depression.

Pigouvian taxes (or subsidies) are rooted in the presumption that a market-based, price-guided system for determining what to produce, how and for whom, had at least the potential to yield the greatest sum of human happiness, given the inherent scarcity of resources and limitations of technology. That story is laid out in every conventional course in intermediate microeconomics. Consumer sovereignty, free markets, competitive private for-profit production – a beautiful, self-regulating system. No Marxists here, though maybe some echoes of Deism and still earlier influences (see, for example, Becker 1932).

Pigou was well aware that price systems in the real world are both incomplete and distorted. In particular, when human activities absorb resources and yield commodities, both of which can carry prices and trade in well-ordered markets, they may also generate externalities or external effects, negative and positive consequences, that are not priced or traded. The result, in a free-market system, is that activities generating negative (positive) externalities will be oversupplied (undersupplied). Pigouvian taxes and subsidies would correct the system of price signals, taxing activities or commodities that generate non-priced costs to others, such as air or water pollution, and subsidizing those that generate non-priced benefits to others, such as having one's children immunized.

Negative externalities do not come much bigger than global warming.

Keynes launched a fundamental challenge to the idea of a self-regulating economic system – a challenge with major, indeed revolutionary, political implications. Pigou by contrast was proposing a comprehensive repair of the price system to reflect more accurately the full costs and benefits of carrying on different economic activities – in principle, a profoundly conservative agenda (until *your* ox is being gored).

The Pigouvian agenda, though not so labelled, actually played an important role in the early efforts by health economists to fit the observed realities of healthcare systems into the received framework of "mainstream" economic theory. Their (our) indifferent success may suggest some limitations of the Pigouvian approach.

But If Improving Market Efficiency Is Not the Real Objective …

Consider, first, tobacco. Smokers generate various forms of negative externalities of stink, butts and other forms of environmental contamination, fire hazard and, notoriously, various forms of cancer risk. There is thus a good Pigouvian case for heavy taxation. But the objectives of tobacco policy go beyond correcting externalities. Tobacco is a toxic, highly addictive substance that is marketed to children. Many, if not most, adult smokers wish they could quit, and many try. Heavy taxation is part of a three-pronged strategy that includes regulation and education, to suppress or at least minimize a noxious activity. Ideally, the industry would be wiped out. The "consumer sovereignty" basis for the Pigouvian tax could hardly be more irrelevant.

A similar confusion of objectives underlay early efforts to interpret public financing for healthcare as a form of Pigouvian subsidy. The public finance literature referred to it as a "merit good," whose private consumption generated benefits for the wider community, although the nature of those benefits tended to be quite fuzzy. The negative externalities associated with communicable disease are easily identified, but one does not respond to an Ebola epidemic with taxes and subsidies. Moreover, communicable disease is fortunately now a minimal part of healthcare activity. How to offer a Pigouvian explanation for public support of the rest?

Moreover, healthcare is not in itself a uniform "good," but is valued for its putative beneficial effects on the user's health. The right care for the present circumstances of a particular patient can be of enormous value, but the wrong care can be at best useless and at worst seriously harmful. This is the justification for the extensive web of professional and public regulation that surrounds modern healthcare systems. A Pigouvian interpretation of a general public subsidy to undifferentiated "healthcare" amounts to staging *Hamlet* without the Prince of Denmark.

Economists (including this one) responded by extending the concept of externalities to include interactions among individual utility functions, interactions that might depend upon the perceived efficacy of the care provided, not just the amounts. But this approach, although it works (I think) in a formal sense, has a distinct whiff of Claudius Ptolemy – too many epicycles. Why not just accept that the objective of public policy in this sector is not to remedy the imperfections of the private market, but to try to provide people with the healthcare they need, to ensure that it proceeds efficiently, and to discourage useless and harmful care. Seems reasonable.

Please, Granddad, Tax the Carbon!

None of which is to argue against carbon taxation. But Cheney's observations above suggest that we are dealing here with something similar to the tobacco case. We are not just trying

to make the private market work more smoothly; we are trying to reduce the production of greenhouse gases. We have to learn, sooner or later, to live without the industry, or else we die with it. The faster we can develop the necessary technology, the better. This will probably require the multipronged approach – taxation, regulation and education – combined with serious stimulus to technological advances. No industry welcomes its own euthanasia – see above under tobacco. But our grandchildren, and certainly our great-grandchildren, will not thank us for spending the Saudi tax cut on bigger and more powerful vehicles. (But hey, what did they ever do for us?)

References

Becker, C. 1932. *The Heavenly City of the Eighteenth Century Philosophers*. New Haven: Yale University Press.

Cheney, P. 2015 (December 10). "Oil Hog Nation: How We Squandered Fuel Economy Advances on Bigger Vehicles." *The Globe and Mail*. Retrieved March 24, 2016. <http://www.theglobeandmail.com/globe-drive/adventure/red-line/oil-hog-nation-how-we-squandered-fuel-economy-advances-on-bigger-vehicles/article27660738/>.

Reguly, E. 2016a (January 21). "Yes, $15-Trillion Lost from Stocks, but Take a Deep Breath. The End Is Not Nigh." *The Globe and Mail*. Retrieved March 24, 2016. <http://www.theglobeandmail.com/report-on-business/15-trillion-lost-from-stocks-but-take-a-deep-breath-the-end-is-not-nigh/article28304794/>.

Reguly, E. 2016b (February 14). "Saudi Arabia's Oil Strategy Could Turn Ugly for All Participants." *The Globe and Mail*. Retrieved March 24, 2016. <http://www.theglobeandmail.com/report-on-business/economy/economic-insight/saudi-arabias-oil-supply-strategy-could-turn-ugly-for-all-producers/article28756025/>.

Smith, A. 1776. *The Wealth of Nations* (Book 1, Chapter 6, para. 8). Retrieved March 24, 2016. <http://geolib.com/smith.adam/won1-06.html>.

Accountability for Community Benefit: A Reasonable Expectation for Canadian Hospitals

L'obligation redditionnelle au service de la communauté : attentes raisonnables envers les hôpitaux canadiens

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Abstract

North American hospitals have historically struggled to engage in prevention and health promotion activities because they have not been incentivized or held accountable for doing so. However, in order to be exempt from federal taxes, 3,000 non-profit hospitals in the US must now regularly assess the health status of the communities they serve, and take action to address identified health needs. This is called "accountability for community benefit," and it is required under the *Patient Protection and Affordable Care Act* (commonly known as Obamacare). A modified version of accountability for community benefit warrants exploration in the Canadian context, as it may support Canadian hospitals to direct resources towards prevention and health promotion activities – something many Canadian hospitals want to do, but struggle with in the current accountability environment. This is an important health policy topic because even a small shift in focus by hospitals towards prevention and health promotion has the potential to improve population health and reduce healthcare demand.

Résumé

Les hôpitaux nord-américains doivent habituellement lutter pour pouvoir mettre en place des activités de prévention et de promotion de la santé, car ils n'y sont pas incités ou n'en sont pas tenus responsables. Cependant, afin de pouvoir bénéficier d'une exemption d'impôt fédéral,

3 000 hôpitaux à but non lucratif aux États-Unis doivent désormais évaluer, sur une base régulière, l'état de santé des communautés qu'ils desservent et prendre des mesures pour répondre aux besoins en matière de santé qui ont été repérés. Il s'agit de l'« obligation redditionnelle au service de la communauté » exigée en vertu de la loi sur la protection des patients et des soins abordables (surnommée Obamacare). Une version modifiée du principe d'obligation redditionnelle au service de la communauté vise le contexte canadien et pourrait aider les hôpitaux canadiens à affecter leurs ressources à des activités de prévention et de promotion de la santé – ce que plusieurs souhaiteraient faire, sans toutefois y arriver facilement en raison du contexte redditionnel actuel. C'est là un important sujet de politique de santé, puisqu'un petit changement dans les efforts déployés par les hôpitaux pour la promotion de la santé peut donner lieu à une amélioration appréciable de la santé de la population et à une réduction de la demande de soins.

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> What good does it do to treat people's illnesses, to then send them back to the conditions that made them sick? (Bégin 2010: 5).

The notion that hospitals should strive to promote health and to prevent (not just treat) illness and injury was popularized in Canada 30 years ago (WHO 1986). However, while many Canadian hospital leaders agreed with the idea (and still do), progress towards this goal has been limited because few hospitals have been supported, incentivized or held accountable for engaging in prevention and health promotion activities (Graham et al. 2014; Huynh 2014). Instead, health systems across Canada typically only hold hospitals accountable for financial and clinical performance, which is important, but limited, as these areas "have only tenuous or very indirect linkage" with population health improvement (Denis 2014: 8). Similarly, the Canadian Institute for Health Information's health system performance framework does not report indicators in its "improve health status of Canadians" category by hospital (Veillard et al. 2015: 37). This scenario perpetuates the belief that prevention and health promotion are the sole responsibility of public health and primary care (Hancock 2011). Even when public health and hospitals are "integrated" within regional health authorities (RHAs), the result is often that the responsibility for population health improvement remains with public health (Moloughney 2016). Similarly, others have found that public health and hospitals can be siloed within RHAs, limiting the degree to which hospital resources can be leveraged to influence upstream determinants of health (Cohen et al. 2014; Huynh and Cohen 2012).

This is an important health policy issue because hospitals are well-positioned to improve population health using primary prevention, secondary prevention and health promotion strategies (Pelikan et al. 2013). Hospitals represent the main concentration of health system resources, skills and technology. Hospitals also have significant social capital, meaning they often represent "health" to their community (presenting opportunities for advocacy and partnerships). Hospital staff are respected and seen as credible sources of advice on health issues beyond medical treatment.

Hospitals are also large employers (presenting opportunities for workplace health promotion), and hospital visits often occur at key moments in our lives (presenting opportunities for behaviour change). This means even a small shift in focus by hospitals towards prevention and health promotion could, in time, improve population health (Johnson and Baum 2001).

Acknowledging the important role for hospitals in population health improvement, US hospitals have faced "growing pressures to move beyond caring for individual patients to taking broader responsibility for the health of the populations they serve" (Rubin et al. 2015: 554). Part of this pressure is from a new requirement in the *Patient Protection and Affordable Care Act* (ACA) that ~3,000 non-profit hospitals must (1) conduct regular community health needs assessments (CHNAs) and (2) demonstrate community benefit (CB) by taking action to address identified health needs, to be exempt from federal taxes. Although this approach has been controversial, its current iteration has "far-reaching implications for population health improvement, health system transformation, and health equity" (Somerville et al. 2013: 2). This article provides a brief history and description of the ACA's CHNA and CB requirements, followed by a discussion of their transferability to the Canadian context.

Background

A major distinction between private hospitals and non-profit hospitals in the US is that the later are considered charities and are expected to provide free or low-cost medical care for marginalized individuals. This "charity care" is clearly beneficial for a large number of uninsured Americans and in exchange, non-profit hospitals have long been exempt from nearly all federal, state and municipal taxes (Rubin et al. 2015). However, expansion of public health insurance in the US has made the tax-exemption of non-profit hospitals controversial. As more Americans have health insurance, there are fewer instances where hospital services are uncompensated (Burke et al. 2014). Private hospital leaders and health policy makers have also suggested that modern non-profit hospitals in the US, with highly paid executives, sophisticated operations and aggressive collection practices, barely resemble the charities that once warranted tax-exemption (Rubin et al. 2015).

In response to this criticism, the definition of CB and eligibility for tax exemption has changed over time (see below). In 2010, the ACA introduced the requirement that non-profit hospitals could remain tax-exempt, but would have to provide CB activities based on the results of regular CHNAs (Singh et al. 2015). Where the initial accountability for CB aimed to improve access to care, the ACA reform signalled "recognition among health policy makers that the prevailing medical model of focusing on treatment and cure at the expense of prevention and health promotion is ineffective and unsustainable" (Rubin et al. 2015: 554).

Community benefit

The definition of CB has changed over time (Table 1). Since 1969, CB was defined and reported at the state level, with most states using the Internal Revenue Service (IRS) definition (Rubin et al. 2015). This definition aimed to improve access, with the addition of maintaining a "community-controlled board" as a strategy to ensure unique community health needs were addressed.

However, this definition was found to be limited and ineffective (Rubin et al. 2015). In response, the IRS broadened its definition in 2007 to include "community health improvement" activities, research, education of health professionals and contributions to community groups that engage in CB activities (Young et al. 2013). See Table 1 for a description of these items.

TABLE 1. IRS definitions of hospital community benefit

1969 Definition (Rubin et al. 2015: 547)	2007 Definition (Young et al. 2013: 1521)
1. Operate a 24-hour emergency room 2. Provide charity care to the extent of the hospital's financial ability 3. Extend medical staff privileges to all qualified physicians in the area, consistent with the size and nature of the facility 4. Accept payment from Medicare and Medicaid programs on a non-discriminatory basis 5. Maintain a community-controlled board (i.e., a governing board with membership, by appointment, primarily from the local community)	1. Charity care (i.e., subsidized care for persons who meet the criteria for charity care established by the hospital) 2. Unreimbursed costs for means-tested government programs (e.g., Medicare and Medicaid) 3. Subsidized health services (i.e., clinical services provided at a financial loss) 4. Community health improvement services and community-benefit operations (i.e., activities carried out or supported for the express purpose of improving community health, such as conducting or otherwise supporting childhood immunization efforts) 5. Research 6. Health professions education 7. Financial and in-kind contributions to community groups (i.e., contributions to carry out any of the activities that are classified as community benefits)

Despite its expansion, an examination of hospitals' initial reporting using the 2007 definition found that (1) access to care represented >86% of hospital CB activities, and (2) hospitals engaged in limited community health improvement activities (Young et al. 2013). Other research demonstrated wide variation in CB spending across states, ranging from $30 to $335 per capita (Bakken and Kindig 2015). Because the expanded definition also did not produce the desired result, the ACA added the requirement that non-profit hospitals must conduct regular CHNAs as a condition of their federal tax-exempt status (Singh et al. 2015).

Community Health Needs Assessment

Non-profit hospitals in the US must now conduct CHNAs at least every three years to remain exempt from federal taxes. Each assessment must include consultations with community stakeholders and public health officials, and multi-hospital networks must conduct an assessment for each facility (Singh et al. 2015). Following the assessment, each hospital must develop and publish an action plan regarding how identified needs will be addressed according to the CB categories in the 2007 definition (Somerville et al. 2013). Although it is too early to tell, many report the CHNA requirement as a positive reform that will support hospitals to better contribute to population health improvement (Burke et al. 2014; Singh et al. 2015). In fact, Casalino et al. (2015: 819) report everyone in healthcare in the US is now "working to improve population health these days. Or will be very soon. Or feel that they ought to be."

Accountability Leads to Action

As reported in a special issue of this journal, Ontario hospitals are currently held accountable for financial performance, service volumes, quality and patient safety (Kromm et al. 2014). These accountabilities appear to be similar for hospitals across Canada, including those within RHAs

(Marchildon 2013). While important, these accountabilities will have little effect on the upstream determinants of health (Alley et al. 2016; Denis 2014). Given the pressing need to prevent and manage chronic diseases, as well as reduce healthcare demand in Canada, numerous authors have proposed strategies for how Canadian hospitals can better address community health needs (e.g., Cohen et al. 2014; Neudorf 2012). These include increased public health service delivery (for hospitals within RHAs), use of a "population health lens" in decision-making, and increased collaboration with non-health sector stakeholders to address upstream health determinants. These approaches are valuable, but they rely on hospitals voluntarily directing scarce resources towards activities for which they are not held accountable and receive no compensation. Although Canadian hospitals have long seen health promotion as part of their role, hospital funding has lagged behind treatment costs and demand. This makes it challenging for hospitals to dedicate resources towards prevention and health promotion activities (Graham et al. 2014). In contrast, evidence indicates that external accountabilities drive internal accountabilities and activities within Canadian hospitals (Kraetschmer et al. 2014). In other words, accountability leads to action (Deber 2014).

I suggest the CHNA requirement and accountability for CB warrant exploration in the Canadian context. Not only is hospital accountability for CB a highly studied policy intervention, it has been refined over the past half-decade in the US. In its current iteration, accountability for CB has also generated considerable new research and guidance that would be valuable for Canadian hospitals (e.g., Burke et al. 2014). There are even new online "hubs" where hospitals can exchange learnings and best practices (e.g., http://www.communitybenefitconnect.org and http://www.cdc.gov/chinav/index.html).

Modifications and Challenges

With five modifications, CHNA and CB requirements could be valuable in the Canadian context. First, since all Canadians have some healthcare insurance, the definition of CB should be revised to focus on specific, evidence-based prevention and health promotion activities that have the highest probability of improving community health (Rubin et al. 2015). Second, the role of population health in CB should be clarified, since CB is rarely discussed in the Canadian context. This includes clarifying that "population" refers to hospitals' responsibility for improving the health of those within their *geographic* population, not just their *client* populations (see Casalino et al. 2015 for a fulsome description of the distinction between these terms). Third, since nearly all Canadian hospitals are non-profit, CHNA and CB requirements should be included in existing accountability frameworks rather than being requirements for tax-exemption. Fourth, transparency should be central to this work to support accountability and knowledge-exchange (which would be critical given the novelty of these requirements) (Rubin et al. 2015). Fifth, as most Canadian hospitals are part of RHAs, it should be made explicit that (1) CHNA and CB requirements are for hospitals – not RHAs, and that (2) these requirements are an opportunity to foster collaboration between hospital leaders and public health leaders. These are important clarifications because if RHAs are held accountable, but not hospitals, experience tells us that hospitals will resume their focus on illness care, and the responsibility for CHNAs and CB will likely fall to public health (Moloughney 2016). That said, hospitals held accountable for CB would be wise to collaborate with their local public health colleagues. Public health

epidemiologists have expertise in population health assessment and likely already conduct CHNAs that could inform hospital planning. Similarly, public health staff can assist their hospital colleagues determine where health promotion and prevention strategies could be both effective and practical.

The ultimate goal is to have CHNA results inform hospital planning and resource decision-making. Holding hospitals accountable for CB solidifies the importance of CHNAs in hospital planning, and provides justification for hospitals to allocate resources towards activities that prevent (not just treat) illness and injury, and reduce health inequities – something that is desired, but challenging for many Canadian hospital leaders in the current accountability environment. While some Canadian hospitals would embrace these requirements (and some already have), clearly others would find them challenging given the resource constraints. Some hospital leaders might even echo the attitude expressed when the notion of "health-promoting hospitals" was first introduced: "let somebody else do it; we already have too much to do" (Lalonde 1989: 40). Hospitals should utilize existing CHNA results and collaborate with other hospitals that serve the same geographic populations. However, where no CHNA has been conducted, hospital leaders should collaborate with their public health colleagues to undertake this work. Learning from the experience of 3,000 non-profit hospitals in the US, as well as related initiatives, such as the over 1,000 member hospitals of the International Health-Promoting Hospitals Network (Pelikan et al. 2013) would also be critical. Furthermore, early and active collaboration with researchers would be wise to ensure the CHNA and resultant activities produce desired outcomes.

Conclusion

Nearly 3,000 hospitals in the US are now required to conduct CHNAs and are held accountable for demonstrating CB by taking action to address identified local health needs. This is an exciting step towards improving the impact that hospitals can have on community health – an idea originated in Canada 30 years ago. Canadian health policy makers would be wise to examine and test a modified version of this approach. While there would be initial challenges for some hospitals, the health of the Canadian population and the sustainability of our health system demand we take bold action and utilize best practices from other jurisdictions.

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References

Alley, D.E., C.N. Asomugha, P.H. Conway, D.M. Sanghavi. 2016. "Accountable Health Communities-Addressing Social Needs through Medicare and Medicaid." *New England Journal of Medicine* 374(1): 8–11.

Bakken, E. and D. Kindig. 2015. "Does Nonprofit Hospital Community Benefit Vary by State?" *Journal of Public Health Management and Practice* 21(1): 18–22.

Bégin, M. 2010. "Foreward." In J. Mikkonen and D. Raphael, eds. *Social Determinants of Health: The Canadian Facts*. Toronto, ON: York University School of Health Policy and Management.

Burke, J.G., S. Truong, S. Albert, J. Steenrod, C. Gibert, B. Folb, A. Saleh and E. James. 2014. "What can be Learned from the Types of Community Benefit Programs that Hospitals already have in Place?" *Journal of Health Care for the Poor and Underserved* 25(1): 165–93.

Casalino, L.P., N. Erb, M.S. Joshi and S.M. Shortell. 2015. "Accountable Care Organizations and Population Health Organizations." *Journal of Health Politics, Policy and Law* 40(4): 819–35.

Cohen, D., T. Huynh, A. Sebold, J. Harvey, C. Neudorf and A. Brown. 2014. "The Population Health Approach: A Qualitative Study of Conceptual and Operational Definitions for Leaders in Canadian Healthcare." *SAGE Open Medicine* 2. doi:10.1177/2050312114522618.

Deber, R.B. 2014. "What have we Learned from the Substudies?" *Healthcare Policy* 10(SP): 163.

Denis, J.L. 2014. "Accountability in Healthcare Organizations and Systems." *Healthcare Policy* 10(SP): 8–11.

Graham, R., J.A. Boyko and S.L. Sibbald. 2014. "Health Promoting Hospitals in Canada: A Proud Past, an Uncertain Future." *Clinical Health Promotion* 4(2): 70–75.

Hancock, T. 2011. "Health Promotion in Canada: 25 Years of Unfulfilled Promise." *Health Promotion International* 26(Suppl 2): ii263–67.

Huynh, T.M. 2014. "Population Health and Health Care: Exploring a Population Health Approach in Health System Planning and Decision-Making." Canadian Institute for Health Information: Ottawa, ON.

Huynh, T.M. and D. Cohen. 2012. "Innovators and Early Adopters of Population Health in Healthcare: Real and Present Opportunities for Healthcare – Public Health Collaboration." *Healthcare Papers* 13(3): 53–57.

Johnson, A. and F. Baum. 2001. "Health Promoting Hospitals: A Typology of Different Organizational Approaches to Health Promotion." *Health Promotion International* 16(3): 281–87.

Kraetschmer, N., J. Jass, C. Woodman, I. Koo, S.K. Kromm and R.B. Deber. 2014. "Hospitals' Internal Accountability." *Healthcare Policy* 10(SP): 36–44.

Kromm, S.K., B.G. Ross, W.P. Wodchis and R.B. Deber. 2014. "Acute Care Hospitals' Accountability to Provincial Funders." *Healthcare Policy* 10(SP): 25–35.

Lalonde, M. 1989. "Hospitals Must Become True Health Centres." *Dimensions in Health Service* 66(8): 39–41.

Marchildon, G.P. 2013. *Canada: Health System Review: Health Systems in Transition*. London, UK: European Observatory on Health Systems and Policies.

Moloughney, B. 2016. "The Impacts on the Public Health Function with Integration with Regionalized Healthcare Systems." Prepared for Toronto Public Health: Toronto, ON. Retrieved March 31, 2016. <http://www.toronto.ca/legdocs/mmis/2016/hl/bgrd/backgroundfile-88527.pdf>.

Neudorf, C. 2012. "Integrating a Population Health Approach into Healthcare Service Delivery and Decision Making." *Healthcare Management Forum* 25(3): 155–59.

Pelikan, J.M., C. Dietscher and H. Schmied. 2013. "Health Promotion for NCDs in and by Hospitals: A Health Promoting Hospital Perspective." In *Global Handbook on Noncommunicable Diseases and Health Promotion* (pp. 441–60). New York, NY: Springer.

Rubin, D.B., S.R. Singh and G.J. Young. 2015. "Tax-Exempt Hospitals and Community Benefit: New Directions in Policy and Practice." *Annual Review of Public Health* 36(1): 545–57.

Singh, S.R., G.J. Young, S.Y.D. Lee, P.H. Song and J.A. Alexander. 2015. "Analysis of Hospital Community Benefit Expenditures' Alignment with Community Health Needs: Evidence from a National Investigation of Tax-Exempt Hospitals." *American Journal of Public Health* 105(5): 914–21.

Somerville, M.H., G.D. Nelson, C.H. Mueller and C.L. Boddie-Willis. 2013. *Hospital Community Benefits after the ACA: Present Posture, Future Challenges*. Baltimore, MD: The Hilltop Institute: University of Maryland, Baltimore County.

Veillard, J., B. Tipper and S. Allin. 2015. "Health System Performance Reporting in Canada: Bridging Theory and Practice at Pan-Canadian Level." *Canadian Public Administration* 58(1): 15–38.

World Health Organization (WHO). 1986. *Ottawa Charter for Health Promotion*. Ottawa, ON: WHO. Retrieved April 11, 2016. <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/>.

Young, G.J., C.H. Chou, J. Alexander, S.Y.D. Lee and E. Raver. 2013. "Provision of Community Benefits by Tax-Exempt US Hospitals." *New England Journal of Medicine* 368(16): 1519–27.

The Council of Academic Hospitals of Ontario (CAHO) Adopting Research to Improve Care (ARTIC) Program: Reach, Sustainability, Spread and Lessons Learned from an Implementation Funding Model

L'initiative d'adoption de la recherche pour l'amélioration des soins (ARTIC) du Conseil des centres hospitaliers universitaires de l'Ontario (CAHO) : communication, durabilité, diffusion et leçons apprises d'un modèle de mise en œuvre du financement

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Abstract
Despite evidence on what works in healthcare, there is a significant gap in the time it takes to bring research into practice. The Council of Academic Hospitals of Ontario's Adopting Research to Improve Care program addresses this research-to-practice gap by incorporating the following components into its funding program: strategic selection of evidence for implementation, education and training for implementation, implementation supports, executive champions and governance, and evaluation. Funded projects have been sustained (76% reported full sustainability) and spread to over 200 new sites. Lessons learned include the following: assess readiness, develop tailored implementation materials, consider characteristics of implementation supports, protect champion time and consider evaluation feasibility.

Résumé
Malgré les données disponibles sur ce qui fonctionne bien dans les soins de santé, il y a un fossé important dans le temps nécessaire pour transposer la recherche en pratique concrète. L'initiative d'adoption de la recherche pour l'amélioration des soins du Conseil des centres hospitaliers universitaires de l'Ontario se penche sur ce fossé entre la recherche et la pratique en incorporant les éléments suivants à son programme de financement : choix stratégique des données pour la mise en œuvre, éducation et formation en matière de mise en œuvre, appui à la mise en œuvre, champions-cadres, gouvernance et évaluation. Les projets financés ont été soutenus (76 % de soutien entier déclaré) et diffusés à plus de 200 nouveaux sites. Les leçons apprises comprennent les points suivants : évaluer l'état de préparation, développer du matériel sur mesure pour la mise en œuvre, envisager les caractéristiques du soutien pour la mise en œuvre, réserver du temps pour les champions et envisager la faisabilité de l'évaluation.

Background
Despite a growing body of evidence on what works in healthcare, there is a significant delay in the time it takes to bring research into practice (Brownson et al. 2006); without infrastructure in place to support research implementation, it may take up to 17 years for research to be implemented in practice (Balas and Boren 2000). Because health systems are not maximizing research uptake, there are large inefficiencies in these systems that result in reduced quantity and quality

of life (Davis et al. 2003; Kennedy et al. 2004; Madon et al. 2007; McGlynn et al. 2003; Pimlott et al. 2003; Shah et al. 2004). For example, an estimated $240 billion is invested annually in health and biomedical research, but approximately 85% does not result in evidence implemented into practice (Chalmers et al. 2014); even when evidence is implemented, it often results in little to no meaningful practice change (Davidoff et al. 2015). Knowledge translation (KT) science is the field of study that was developed to address this research-to-practice gap. KT is the "dynamic and iterative process (including the 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 healthcare 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 and the needs of the particular knowledge user" (Graham 2000).

The amount of funding set aside for KT is a fraction of the money dedicated to research; it is, therefore, sometimes considered "decimal dust" despite KT's integral role in changing population-level outcomes (Kerner 2006; Tetroe et al. 2008). In an environmental scan of KT funding opportunities worldwide (24% from Canada), approximately 20% of the *KT funding* supported implementation activities (as opposed to dissemination or synthesis activities; Timmings et al. 2015). In recent years, there has been a push to fund more KT activities, including efforts from the Canadian Institutes of Health Research (CIHR), the National Institute of Health Research in the UK, the Health Research Council of New Zealand and the Michael Smith Foundation for Health Research in British Columbia (Holmes et al. 2012, 2014; Timmings et al. 2015). For example, CIHR funds several KT initiatives, which have been found to perform well against traditional funding mechanisms in terms of producing KT and academic outputs, providing training opportunities, improving the health of Canadians, strengthening the healthcare system and creating more effective health services and products (Graham et al. 2014; McLean and Tucker 2013). Simply funding more KT projects, however, is not enough to move research into practice, and there is a move to incorporate more implementation supports from funders, as "greater involvement of funding agencies in all forms of KT … is essential for the maintenance of the health research enterprise in the face of many competing and compelling demands on the tax base" (Kitson and Bisby 2008). As the number of implementation funding opportunities increases, there is a need to understand the impact of these funding mechanisms, particularly those using less traditional approaches to funding that incorporate implementation supports (Tetroe et al. 2008). Based on the Council of Academic Hospitals of Ontario (CAHO) Adopting Research to Improve Care (ARTIC) program's experiences through three rounds of funding and an evaluation, ARTIC has identified several lessons learned that could inform future funding opportunities/agencies interested in supporting the uptake of evidence-based practices using effective implementation strategies. The aim of this paper is to describe an implementation funding model; evaluate reach, sustainability and spread of this model; and share lessons learned.

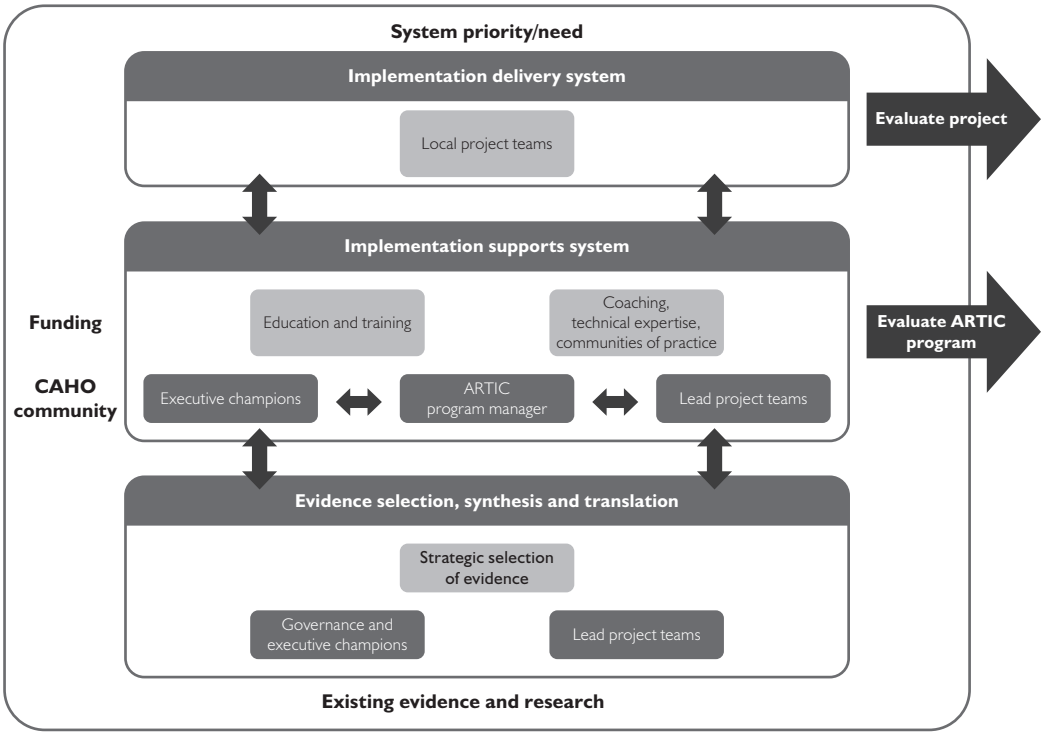
Implementation Funding Initiative

The CAHO ARTIC program is a model for accelerating and supporting the implementation of research evidence into practice across the healthcare system to drive improvements in the quality of care. CAHO is the non-profit association of Ontario's 24 research hospitals and provides a focal point for strategic initiatives for these hospitals. CAHO developed ARTIC to accelerate the adoption of research evidence within hospital settings; this funding model was CAHO's first attempt to implement and evaluate an implementation funding mechanism. It aims to transform the healthcare system by using evidence to drive quality and therefore make the best use of resources, enabling a culture of continuous quality improvement and creating a jurisdiction where implementation strategies to support clinical interventions are sustained and spread across the province.

The ARTIC model is based on the Knowledge-to-Action (KTA) model for moving research into practice, a model that is based on a review of over 30 theories of planned action (Graham et al. 2006). The funding mechanism of change is drawn from work by the CIHR KT funding program and associated logic model, which hypothesizes that funding KT projects will produce meaningful researcher and knowledge user partnerships, facilitate the dissemination and application of knowledge and advance the science of KT, which, in the long-term, will improve services to and the health of Canadians (McLean et al. 2012). The partners (i.e., funder, implementers and supports) and their relationships to each other are presented in Figure 1, an adapted version of the Interactive Systems Framework (ISF; Wandersman et al. 2008). Driven by the KTA and CIHR's KT funding model, the implementation infrastructure includes five implementation enablers: (1) strategic selection of evidence; (2) implementation supports (e.g., coaching, technical expertise and communities of practice); (3) education and training for implementation; (4) executive champions and governance; and (5) evaluation.

As a funder, ARTIC provides $800,000 to $1.7 million for the implementation of interventions across multiple sites over a two-year period. However, an integral component of this structure is ARTIC's role not only as a funder but also as an implementation support, knowledge broker and partner, which is different from the roles of most funding agencies. As a partner, ARTIC is involved in engaging senior leadership and fostering the idea of working and thinking as a community of academic hospitals rather than as individual institutions. This partnership model aligns with the integrated KT approach, in which there is a partnership between researchers and knowledge users who actively contribute to the research agenda and implementation activities and make research findings directly relevant to the knowledge user (Graham et al. 2014). ARTIC enhances the typical integrated KT approach by also incorporating senior leadership who can serve as a facilitator of project implementation (Aarons and Sommerfeld 2012) and central ARTIC Program staff who are accountable to support the Communities of Practice and facilitate implementation on a wide range of projects.

FIGURE 1. ARTIC program and project structure



Strategic selection of evidence for implementation strategy and clinical intervention

The program uses a systematic process to identify and fund KT implementation projects. Projects comprise clinical interventions (i.e., evidence-based practices) delivered using effective implementation strategies. Projects are selected based on key criteria and annually selected themes, which align with government (e.g., Ontario Ministry of Health and Long-Term Care) and organizational (e.g., CAHO member) priorities. Table 1 presents descriptive information for the six funded projects. The project selection process includes three stages: (1) letter of intent (LOI) stage, (2) full submission stage and (3) readiness assessment stage. The ARTIC Task Force reviews the LOIs and then requests full submissions for five to eight proposals that are based on robust research evidence, have potential for high system impact, demonstrate implementation feasibility and present an evaluation plan to assess outcomes. They then select the top two to four submissions to proceed to the readiness assessment stage. The readiness assessment stage is the most unique feature of the project selection process. Organizational readiness for change is "the extent to which organizational members are both psychologically and behaviorally prepared to implement change" (Chaudoir et al. 2013; Gagnon et al. 2011; Weiner et al. 2008). Typically, readiness is rarely assessed before implementation (Weiner et al. 2008), yet measuring readiness is associated with better outcomes (Amatayakul 2005; Jones et al. 2005; Kotter 1996). ARTIC requires each project to have a lead project team to coordinate implementation delivery across the hospital; in addition, each participating hospital

delivers the implementation strategies through a local project team. ARTIC works with the lead team to develop a readiness assessment that includes the target population for intervention, resource requirements and key stakeholders to be engaged in the implementation process. CAHO collects data from all sites and creates a readiness report. This report is assessed by the ARTIC program Task Force to determine implementation feasibility and select the funded project. Each lead team is provided with the report to assist in developing their implementation roadmap.

TABLE 1. Description of CAHO ARTIC funded projects

Projects	Funding year	Number of participating sites	Spread* and scale
Canadian C-Spine Rule (CCR) to assess the clinical impact of CCR on reducing emergency department wait times and increasing efficiencies by maximizing the use of inter-professional resources	2011–2012	9	Relevant to emergency department only; no internal spread
HandyAudit to increase the efficiency of hand hygiene compliance reporting in hospitals	2011–2013	16	Delivered hospital-wide; no internal spread; external spread to over 170 hospitals
Antimicrobial Stewardship Program (ASP) in Intensive Care Units (ICUs) to optimize antimicrobial use in ICUs where critically ill patients are the sickest and most vulnerable	2012–2014	12	In progress; internal hospital spread in 6 of 12 sites; implementing a hub and spoke model to spread to community hospitals
Mobilization of Vulnerable Elders in Ontario (MOVE ON) to promote early mobilization and prevent functional decline in older patients admitted to hospital	2012–2014	14	Internal hospital spread in 10 of 14 sites; external spread to over 28 hospitals
Implementing an Enhanced Recovery After Surgery Guideline to Optimize Outcomes following Colorectal Surgery (iERAS) to implement a range of interventions aimed at improving patient outcomes and reducing hospital stay after surgery	2013–2015	15	Data not yet available
Implementing the Transitional Discharge Model (TDM) supports the successful transition from the hospital to the community for people diagnosed with a mental illness	2013–2015	9	Data not yet available

*Internal spread refers to implementation within the same hospital beyond the originally funded units; external spread refers to implementation in other hospitals not funded through ARTIC.

Implementation supports

The funder–fundee partnership is different from a typical grant, in that ARTIC staff are involved in facilitating the implementation strategy: along with the lead project team and executive champions, an ARTIC program manager is one of three key stakeholders who make up the infrastructure in the implementation support system (illustrated in Figure 1). These infrastructure stakeholders build both general capacity for the program and capacity within each participating organization by enhancing leadership skills, improving knowledge of implementation science and developing clinician champions to lead evidence-based change. Together, these three stakeholders provide implementation support in the form of coaching, technical expertise and communities of practice. Lead project teams create timelines, submit progress reports and prepare outcome presentations; the program manager then offers feedback on meeting objectives and timelines. The program manager identifies areas of alignment

and integration within ARTIC projects and with other government initiatives to support a coordinated approach to improving quality implementation and maximize system, organizational and patient impact and outcomes. This approach allows the ARTIC program manager to understand how the lead project teams and local project teams are functioning.

Lead project teams support the local project teams through education and training on implementation. The lead project team provides tools, resources, supports and coaching to local project teams. The lead project team also develops the implementation roadmap to guide participating hospitals through the implementation and evaluation process. The lead project team helps ensure that as projects are tailored to the local context, hospitals maintain fidelity to the goals of implementation. Each project develops a community of practice (CoP), which facilitates communication and peer support (Wenger et al. 2002) across projects.

Education and training for implementation

Scaling up implementation requires education and training, including coaching and written materials, to facilitate the adoption of evidence within and across hospitals. Education materials are designed to produce consistency across the system and build general implementation capacity and clinical intervention capacity (Wandersman et al. 2008). General implementation training is intended to teach implementers (i.e., hospital end users) about best practices in implementation. Clinical intervention education focuses on the content of the project (e.g., changes in clinical practice). The lead project teams provide tools, training, resources and coaching and host a launch event in collaboration with ARTIC.

Executive champions and governance

The governance structure, illustrated in Table 2, ensures that the delivery of the implementation strategy is properly resourced and supported. The three-tiered governance structure includes the CAHO ARTIC program Task Force (ARTIC Task Force), the CAHO Practice and Education Committee (P&E) and the CAHO Council.

Evaluation

Embedded in the ARTIC's structure is an evaluation at two levels: program and project (Figure 1). An interim program evaluation including interviews with 43 senior leaders and relevant stakeholders representing 17 of the 25 CAHO organizations was conducted following the first round of funding. The goal of the interim evaluation was to understand the organizational decision-making practices regarding participation in ARTIC and to recommend ways to improve the selection of future projects. Results of this evaluation provide support for the existing structure and enablers of ARTIC. A second evaluation was conducted to examine reach, sustainability and spread of ARTIC.

At a project level, each team develops and executes a monitoring and evaluation component. Regular performance monitoring and evaluation is designed to ensure greater fidelity to the implementation strategy and clinical intervention and to provide opportunities for continuous quality and process improvement.

TABLE 2. CAHO ARTIC governance structure

	Responsibilities	Members	Meeting frequency	Reports to
CAHO ARTIC Program Task Force	Provides operational oversight of program and responsible for reviewing and assessing proposals submitted for funding consideration	Representation from diverse groups (research, clinical practice, KT and system partners), including the P&E committee, CAHO's research committee, the MOHLTC and HQO	Every two months	P&E Committee
CAHO P&E Committee	Provides strategic guidance and oversees program implementation, including reflecting on the CAHO ARTIC Program Task Force recommendations P&E committee members are executive champions for the projects in their hospitals, providing senior leadership support for implementation projects to obtain staff engagement, create a culture receptive to change, prioritize the initiative, spread the initiative, allocate resources and resolve challenges	Clinical practice leaders from all CAHO hospitals (e.g., chief nursing executives, vice presidents of quality, vice presidents of medical affairs)	Every two months	CAHO Council
CAHO Council	Provides strategic oversight to and ultimate accountability for the CAHO ARTIC Program by being accountable for and approving funding decisions and developing the program's strategic direction	CEOs from each of the CAHO member hospitals	Every two months	N/A

Program Reach, Sustainability and Spread

An evaluation was conducted to examine ARTIC's impact on reach, sustainability and spread. Sustainability is defined as continued implementation of the initiative (Shediac-Rizkallah and Bone 1998), whereas spread is the horizontal diffusion or active dissemination of best practices or programs and implementing these across settings (Institute for Healthcare Improvement 2008). Data for the evaluation were collected through interviews, with 18 program stakeholders (e.g., executive champions and members of governance), interviews with all four lead project teams, surveys with 27 of the 35 participating sites across all projects (79%), interviews with 12 local teams (hospital site leads) and a review of documents from the lead project teams and the ARTIC program office.

Program reach

For the six projects, ARTIC funded $7.6 million in direct costs, which was matched by $12.2 million in in-kind contributions for a total of $19.8 million invested into delivering evidence into practice and a cost to in-kind ratio of 1:1.6. Through ARTIC, over 25 researchers/program developers learned about implementation, over 220 site-level champions connected with researchers and gained implementation experience, over 1,500 staff or volunteers worked on the projects and quality of care was improved for over 18,000 patients (Cathexis Consulting 2013, ARTIC Phase I evaluation report).

Sustainability

Sustainability and spread were assessed in the four projects that had completed the funding phase. Using self-report surveys, sites were asked whether they were still using the implementation strategy to support the clinical intervention 1.5 or 2.5 years after initial implementation (depending on when they were first funded). Of the 50 sites, 46 provided data and 76% (35 of 46 sites) reported fully sustaining the implementation strategy, 13% (6 of 46 sites) reported partially sustaining the implementation strategy and 11% (5 of 46 sites) reported not sustaining the implementation strategy. Given the challenges in sustaining implementation efforts and the typically low rates of sustainability (Stirman et al. 2012), these findings are promising and indicate that the ARTIC model supports a high level of sustainment.

Spread

Program funding spread four projects to 50 sites (Table 1). Two of the four projects subsequently spread internally within the original hospitals. In addition to spreading internally, two of the projects were spread to new sites: one project developed into a commercial venture and spread to over 170 hospitals; the other spread to over 28 additional sites through new funding and hospital-driven initiatives. Patient outcome data from these additional sites are being published by individual projects and therefore cannot be reported here.

Lessons Learned

Based on the program's experiences through three rounds of funding and an evaluation, CAHO ARTIC has identified several lessons learned linked to each of the five implementation enablers/implementation infrastructure.

Strategic selection of evidence for the implementation strategy and clinical intervention

Prior to including the readiness assessment in project selection, hospitals reported that expectations and required resources were not clear before beginning the project, and project teams expressed challenges related to hospitals not committing necessary resources. The readiness assessment was included to make potential participating hospitals aware of the resources required to successfully implement the project and to inform CAHO of each hospital's readiness to deliver the implementation strategy. An external evaluation found the readiness assessment to be brief, focused and valuable for identifying implementation resources prior to committing to the project.

Education and training

Education and training ran more smoothly when hospital teams were provided with ready-to-use implementation materials that required minimal time and effort to adapt to their context. Developing materials *de novo* was a burden on local hospital teams, which

delayed implementation, resulted in duplication and/or reduced the quality of materials. Challenges to education and training included the lack of funding to backfill participants' time in training, lack of buy-in from frontline staff and difficulty identifying the appropriate people to train.

Implementation supports

There were several lessons learned with regards to implementation supports, including understanding the optimal characteristics of project teams, building key implementation enablers into the program and the project design, identifying ways to develop and maintain CoPs and supporting use of KT experts by project teams. Ideally, lead project teams should have the expertise in the development and delivery of evidence-based implementation strategies and be perceived as credible, approachable and flexible. The team should include an appropriate mix of professions/disciplines (e.g., clinical areas, KT, evaluation and project management).

The roles and responsibilities of each group need to be clearly defined at the outset and communicated to all relevant stakeholders. While CoPs were available across all projects, their use was not optimized. Future CoPs could be provided guidance on the purpose, structure and types of CoP activities (e.g., ways to engage participating site leads via teleconference or use of project websites to sustain CoPs).

Executive champions and governance

The executive champion in each hospital should be in a position to prioritize the project administratively (e.g., protecting staff time) and champion the project by encouraging engagement and participation and boosting staff morale.

Project evaluation

The project evaluation was resource intensive in terms of data collection and feedback. Therefore, the monitoring and evaluation requirements of future projects should consider the feasibility of data collection and incorporate an efficient, timely feedback mechanism.

Limitations

Several limitations should be noted. The evaluation and lessons learned did not consistently link the implementation projects with improved patient outcomes, and there is no comparison group that did not receive ARTIC funding. Each funded project improved patient outcomes, but because of the program evaluation research design, we are not able to determine whether the funding model successfully improved outcomes. In addition, the measures of sustainability and spread are self-reported; an organization reporting that they continue to implement the initiative may not be representative of actual behaviour.

Conclusion

With an increased focus on implementing research evidence into practice in the healthcare sector, organizations that fund implementation work have an opportunity to play an integral role in funding and supporting research uptake. The CAHO ARTIC program attempts to fill the KT funding gap and transform the healthcare system by supporting the use of evidence to drive quality, enabling a culture of continuous quality improvement and sustaining and spreading the implementation of evidence across Ontario. To date, 76% of the sites have sustained implementation for at least 1.5-years' post-implementation and the project has spread to over 200 new sites.

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References

Aarons, G.A. and D.H. Sommerfeld. 2012. "Leadership, Innovation Climate, and Attitudes Toward Evidence-Based Practice During a Statewide Implementation." *Journal of the American Academy of Child & Adolescent Psychiatry* 51(4): 423–31.

Amatayakul, M. 2005. "EHR? Assess Readiness First." *Journal of the Healthcare Financial Management Association* 59(5): 112–13.

Balas, E.A. and S.A. Boren. 2000. "Managing Clinical Knowledge for Health Care Improvement." In Bemmel J. and A.T. McCray, eds, *Yearbook of Medical Informatics 2000: Patient-Centered Systems* (pp. 65–70). Stuttgart, Germany: Schattauer Verlagsgesellschaft mbH.

Brownson, R.C., M.W. Kreuter and B.A. Arrington. 2006. "Translating Scientific Discoveries into Public Health Action: How Can Schools of Public Health Move Us Forward?" *Public Health Reports* 121(1): 97–103.

Cathexis Consulting. 2013. *Phase 1 Evaluation of the Adopting Research to Improve Care (ARTIC) program*. Retrieved January 4, 2016. <http://caho-hospitals.com/wp-content/uploads/2013/09/CAHO-ARTIC-Phase-1-Evaluation-Final-Report.pdf>.

Chalmers, I., M.B. Bracken, B. Djulbegovic, S. Garattini, J. Grant, A.M. Gülmezoglu, D.W. Howells and J.P.A. Ioannidis. 2014. "How to Increase Value and Reduce Waste When Research Priorities Are Set." *The Lancet* 383(9912): 156–65.

Chaudoir, S.R., A.G. Dugan and C.H. Barr. 2013. "Measuring Factors Affecting Implementation of Health Innovations: A Systematic Review of Structural, Organizational, Provider, Patient, and Innovation Level Measures." *Implementation Science* 8(22): 1–20. doi:10.1186/1748-5908-8-22.

Davidoff, F., M. Dixon-Woods, L. Leviton and S. Michie. 2015. "Demystifying Theory and Its Use in Improvement." *BMJ Quality and Safety* 24(3): 228–38. doi:10.1136/bmjqs-2014-003627.

Davis, D., M. Evans, A. Jadad, L. Perrier, D. Rath, D. Ryan, G. Sibbald, S. Straus, S. Rappolt, M. Wowk and M. Zwarenstein. 2003. "The Case for Knowledge Translation: Shortening the Journey from Evidence to Effect." *BMJ* 327(7405): 33–35. doi:10.1136/bmj.327.7405.33.

Gagnon, M.P., J. Labarthe, F. Légaré, M. Ouimet, C.A. Estabrooks, G. Roch, E.K. Ghandour et al. 2011. "Measuring Organizational Readiness for Knowledge Translation in Chronic Care." *Implementation Science* 6(72): 1–10. doi:10.1186/1748-5908-6-72.

Graham, I.D. 2000. "More about Knowledge Translation at CIHR." Retrieved February 27, 2014. <www.cihr-irsc.gc.ca/e/39033.html>.

Graham, I.D., J. Logan, M.B. Harrison, S.E. Straus, J. Tetroe, W. Caswell et al. 2006. "Lost in Knowledge Translation: Time for a Map?" *Journal of Continuing Education in the Health Professions* 26(1): 13–24. doi:10.1002/chp.47.

Graham, I.D., J.M. Tetroe and A. Pearson. 2014. *Turning Knowledge into Action: Practical Guidance on How to Do Integrated Knowledge Translation Research*. Philedelphia, PA: Lippincott Williams & Wilkins.

Holmes, B., G. Scarrow and M. Schellenberg. 2012. "Translating Evidence into Practice: The Role of Health Research Funders." *Implementation Science* 7(39): 1–10. doi:10.1186/1748-5908-7-39.

Holmes, B.J., M. Schellenberg, K. Schell and G. Scarrow. 2014. "How Funding Agencies Can Support Research Use in Healthcare: An Online Province-Wide Survey to Determine Knowledge Translation Training Needs." *Implementation Science* 9(71): 1–10. doi:10.1186/1748-5908-9-71.

Institute for Healthcare Improvement. 2008. *5 Million Lives Campaign. Getting Started Kit: Sustainability and Spread*. Cambridge, MA: Institute for Healthcare Improvement.

Jones, R.A., N.L. Jimmieson and A. Griffiths. 2005. "The Impact of Organizational Culture and Reshaping Capabilities on Change Implementation Success: The Mediating Role of Readiness for Change." *Journal of Management Studies* 42(2): 361–86.

Kennedy, J., H. Quan, W.A. Ghali and T.E. Feasby. 2004. "Variations in Rates of Appropriate and Inappropriate Carotid Endarterectomy for Stroke Prevention in 4 Canadian Provinces." *Canadian Medical Association Journal* 171(5): 455–59. doi:10.1503/cmaj.1040170.

Kerner, J.F. 2006. "Knowledge Translation versus Knowledge Integration: A "Funder's" Perspective." *Journal of Continuing Education in the Health Professions* 26(1): 72–80. doi:10.1002/chp.53.

Kitson, A. and M. Bisby. 2008. "Speeding up the Spread: Putting KT Research into Practice and Developing an Integrated KT Collaborative Research Agenda. Background Paper Sponsored by the Alberta Hertiage Foundation for Medical Research." Retrieved January 4, 2016. <http://cihc.ca/files/members/pke/SpeedingUpTheSpread_KT08.pdf>.

Kotter, J. 1996. *Leading Change*. Boston, MA: Harvard Business Review Press.

Madon, T., K.J. Hofman, L. Kupfer and R.I. Glass. 2007. "Public Health. Implementation Science." *Science* 318(5857): 1728–29. doi:10.1126/science.1150009.

McGlynn, E.A., S.M. Asch, J. Adams, J. Keesey, J. Hicks, A. DeCristofaro et al. 2003. "The Quality of Health Care Delivered to Adults in the United States." *New England Journal of Medicine* 348(26): 2635–45. doi:10.1056/NEJMsa022615.

McLean, R.K.D., I.D. Graham, K. Bosompra, Y. Choudhry, S.E. Coen, M. MacLeod et al. 2012. "Understanding the Performance and Impact of Public Knowledge Translation Funding Interventions: Protocol for an Evaluation of Canadian Institutes of Health Research Knowledge Translation Funding Programs." *Implementation Science* 7(57). doi:10.1186/1748-5908-7-57.

McLean, R. and J. Tucker. 2013. "Evaluation of CIHR's Knowledge Translation Funding Program." Retrieved January 4, 2016. <http://www.cihr-irsc.gc.ca/e/47332.html>.

Pimlott, N.J., J.E. Hux, L.M. Wilson, M. Kahan, C. Li and W.W. Rosser. 2003. "Educating Physicians to Reduce Benzodiazepine Use by Elderly Patients: A Randomized Controlled Trial." *Canadian Medical Association Journal* 168(7): 835–39.

Shah, B.R., M. Mamdani, L. Jaakkimainen and J.E. Hux. 2004. "Risk Modification for Diabetic Patients. Are Other Risk Factors Treated as Diligently as Glycemia?" *The Canadian Journal of Clinical Pharmacology* 11(2): e239–44.

Shediac-Rizkallah, M.C. and L.R. Bone. 1998. "Planning for the Sustainability of Community-Based Health Programs: Conceptual Frameworks and Future Directions for Research, Practice and Policy." *Health Education Research* 13(1): 87–108.

Stirman, S.W., J. Kimberly, N. Cook, A. Calloway, F. Castro and M. Charns. 2012. "The Sustainability of New Programs and Innovations: A Review of the Empirical Literature and Recommendations for Future Research." *Implementation Science* 7(17): 1–19. doi:10.1186/1748-5908-7-17.

Tetroe, J.M., I.D. Graham, R. Foy, N. Robinson, M.P. Eccles, M. Wensing et al. 2008. "Health Research Funding Agencies' Support and Promotion of Knowledge Translation: An International Study." *The Milbank Quarterly* 86(1): 125–55. doi:10.1111/j.1468-0009.2007.00515.x.

Timmings, C., K. Kretschmer, J.E. Moore and S.E. Straus. 2015. "Environmental Scan to Inform Development of CIHR's Knowledge Translation Strategy: Final Report on Findings." Knowledge Translation Program, St. Michael's Hospital for the Canadian Institutes of Health Research. Unpublished document.

Wandersman, A., J. Duffy, P. Flaspohler, R. Noonan, K. Lubell, L. Stillman et al. 2008. "Bridging the Gap between Prevention Research and Practice: The Interactive Systems Framework for Dissemination and Implementation." *American Journal of Community Psychology* 41(3/4): 171–81. doi:10.1007/s10464-008-9174-z.

Weiner, B.J., H. Amick and S.Y. Lee. 2008. "Conceptualization and Measurement of Organizational Readiness for Change: A Review of the Literature in Health Services Research and Other Fields." *Medical Care Research and Review* 65(4): 379–436. doi:10.1177/1077558708317802.

Wenger, E., R. McDermott and W. Synder. 2002. *Cultivating Communities of Practice: A Guide to Managing Knowledge*. Boston, MA: Harvard Business Review Press.

An Experiment with Public-Oriented Knowledge Transfer: A Video on Quebec's Bill 10

Expérience de transfert de connaissances axé sur le public : une vidéo sur le projet de loi 10 au Québec

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Abstract

When decision-makers are engaged in a polarized discourse and leaving aside evidence-based recommendations, is there a role for researchers in the dissemination of this scientific evidence to the general public as a means to counterbalance the debate? In response to the controversial Bill 10 in Quebec, we developed and posted a knowledge transfer video on YouTube to help stimulate critical public debate. This article explains our approach and methodology, and the impact of the video, which, in the space of two weeks, had more than 9,500 views, demonstrating the pertinence of such initiatives. We conclude with recommendations for other research groups to engage in public debates.

Résumé

En situation de débat polarisé dans lequel les décideurs laissent de côté les recommandations fondées sur les données probantes, les chercheurs peuvent-ils jouer un rôle dans la diffusion de données de recherche au grand public, dans le but de rééquilibrer le discours? En réponse au controversé projet de loi 10, au Québec, nous avons réalisé et affiché sur YouTube une vidéo de transfert de connaissances afin de stimuler un débat critique dans le grand public. Cette vidéo a été visionnée plus de 9 500 fois en l'espace de deux semaines, ce qui démontre la pertinence d'initiatives de ce genre. Cet article explique notre démarche et notre méthodologie, ainsi que l'impact de la vidéo. En conclusion, nous formulons des recommandations pour d'autres groupes de recherche qui veulent participer aux débats publics.

Dissemination of and discussion about research results are increasingly recognized as a necessary part of research (Barwick et al. 2014; Mitton et al. 2007), to the point that knowledge transfer (KT) is even viewed as an ethical duty and is now expected by funding agencies. The Canadian Institutes of Health Research (CIHR), for example, views KT as a measure of accountability for public investment in research (CIHR 2014). KT is especially important for population health researchers, whose research has a direct impact on the lives of individuals and communities (Estabrooks et al. 2008). However, it is not easy to transfer knowledge to the general public, especially when the subject is political, such as in the case of health system reorganization. KT becomes even more challenging when decision-makers seem to ignore evidence-based recommendations to advance ideologically driven agendas. A good example is Quebec's recently adopted and highly contentious Bill 10, modifying the organization and governance of health and social services (Minister of Health and Social Services 2015). When professional and academic experts are ignored by policy makers, it is imperative to explore innovative means of stimulating evidence-based public debate. In this context, we developed and released a video explaining the current state of knowledge about the likely consequences of the proposed reorganization and centralization of healthcare administration in Quebec. Our goal was to encourage citizens to think critically about Bill 10 and its impact on the healthcare system, and more specifically on service provision (Collectif d'étudiant(e)s en santé publique 2015).

To provide lessons for future video-based KT initiatives, we describe the process used to identify the relevant data to be presented, the communication strategies employed to make our video-based message effective, and the means selected to reach the population. Despite the limitations of a video formatted to be viral (about three minutes), the strategy we adopted proved to be an effective KT tool for generating positive public resonance.

Context

Bill 10 was presented on September 25, 2014, at the Quebec National Assembly. This bill consists in the merger of 182 mid-level organizations (Centres de santé et services sociaux, CSSS) into 33 larger structures (Centres intégrés de santé et services sociaux, CISSS). It also includes the loss of 1,200 administrative positions, and greater power for the Health Minister (Minister of Health and Social Services 2015). The Bill was met with significant opposition from political parties, advocacy groups, unions, professional associations and academics. However, polls had shown that the population was divided on the subject (Léger 2014).

Motivation and KT Approach

On January 26, 2015, four leading healthcare policy and management researchers – Damien Contandriopoulos, Paul Lamarche, Réjean Hébert and François Béland – from the School of Public Health of the Université de Montréal (ESPUM), convened to discuss the impact of Bill 10, in a seminar organized by the Public Health Institute (IRSPUM) and the Department of Health Administration (DASUM). These scholars presented the relevant scientific data and healthcare management theory to a large group of researchers and graduate students. The full seminar was video-recorded but, lasting 95 minutes, it was far too lengthy to be made publicly accessible (IRSPUM 2015). The consensus among this group of specialists was clear: while the provisions presented in Bill 10 are unlikely to yield the expected savings and highly likely to be detrimental to patient care, the political context left no realistic options for stopping the reform. As a group of graduate students from ESPUM, we left the seminar feeling much more informed but also disempowered. We felt that (1) the information we had just received should not remain within the walls of the university, and that (2) the general public was capable of understanding, as well as entitled to be informed about, the implications of the upcoming reform. The Collectif d'étudiant(e)s en santé publique (hereafter, the Collective) was born.

To delineate our KT initiative, we adopted the CIHR (2014) definition of KT as "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". Our initiative was action-oriented and aimed at stimulating critical thinking on the part of the general public; therefore, the use of social media was crucial as a means to create forums for exchange and discussion that are accessible.

When we initiated the project in late January, Bill 10 was still being studied in parliamentary committees, so we expected that we would have time to engage in the ongoing debate. A few days later, rumours started to spread that the government would invoke closure to end parliamentary debate. It became clear that we would not have time to release the video before the Bill's adoption. We could only hope to release it shortly after the Bill passed so that the topic may remain timely. We switched from a general awareness-raising purpose to an action-prompting goal, which in the end allowed us to include more information in our planned three-minute time frame.

Design of the Video and Communication Strategy

Given that we are not experts in healthcare management, we relied primarily on the expert evidence presented at the January 26 seminar and related scientific literature in developing the content of the video. Of course, we reviewed the primary literature behind each information that we planned to include. To build the script for our video, we decided to adopt a six-step process, from the synthesis of relevant information to the *mise en scène* in a dialogue (Table 1a).

TABLE 1. Lessons learned during the writing of the script (a) and the dissemination of the video (b)

a) Writing of the script	
Writing process	**Key lessons learned**
Three authors established the main messages pertinent to the general public	The use of free brainstorming and iterative discussions on the purpose of the message made it possible to identify the essential points for the general public
Three authors extracted the key data from the IRSPUM seminar and relevant scholarly resources into a list of one-line statements to be presented in the video	The challenge of translating scholarly information into lay people's language resides in preserving the meaning of the information, without sounding alarmist, demagogic or ideological
One author transformed the two lists (message and key data) into a dialogue	It was difficult to establish a coherent story with each one-line statement being linked with the previous and subsequent statements; staging the data as a dialogue made for a more coherent and punchier narrative
The authors refined the script iteratively	Comments from students with various expertise and from collaborators from the lay public allowed further specification and simplification of the information presented
Two authors developed the visual concept with the videographer	Owing to time constraints, the use of visual effects, such as numbers, charts or images, had to be ruled out; therefore, we needed a catchy, dynamic and aesthetic visual concept in order to retain viewers' attention
The script was reviewed by the members of the Collective (see Acknowledgements); minor modifications were made to the tone, word selection and emphasis on certain elements	Ensuring each student's approval of the whole text was a good way to ensure their buy-in to the project, but also to make sure that they were comfortable saying their lines during the video shoot
b) Dissemination of the video	
Procedure for disseminating the video	**Key lessons learned**
Synthesis of the message into a press release	The assistance of communications specialists was highly valuable in formatting an efficient press release and developing an effective release strategy
An e-mail account and YouTube channel were created for the Collective. A Twitter account and a Facebook page were also created to disseminate the YouTube link	These channels allowed easy reach to the public and dissemination of the video to the relevant interest groups and individuals, which facilitated discussion of the message and content
Identification of the main point of contact in the traditional media (newspaper, TV and radio)	Support from communication specialists helped in identifying key contacts, something that we had no experience with
Launch of the video	Time was of the essence, as by the time we were able to release the video, Bill 10 was already "old news" for traditional media; many journalists re-tweeted our messages and video and congratulated us, but our initiative did not elicit traditional media interest
During the social media dissemination, political parties and advocacy organizations were excluded from the targets	This allowed us to maintain our independence and remain politically non-partisan

With the videographer, we developed the visual effect of superimposing each speaker in the background and half of his/her face in the forefront. Having a student staring at the camera with a flat affect while their disincarnated face is talking gave the impression of being in the thoughts of each individual, who could not speak aloud, and thus reminded the viewer of the charged political context in which the Bill was adopted.

The concept was chosen to help bridge the gap between scientific research and the general public. So that evidence would be anchored in people's lives, we decided not to play with the epistemic authority of the expertise of academics (and biases that may come with this). Rather than associating the evidence to academics, we chose to create a dialogue between students of the Collective about the impact of this latest healthcare reform in Quebec and the new law's expected consequences for the population. We contemplated the idea of displaying an academic reference for each statement, but since one of our first objectives was inclusivity, considering the low level of health literacy in Canada (Rootman and Gordon-El-Bihbety 2008), we chose to preserve the simplicity of our aesthetic and message. Adding references would have also made video editing longer, and thus would have exacerbated the negative impact of the delay we experienced between the adoption of the law and the video release. However, upon request of some users on YouTube, we posted a short annotated bibliography along with the video. In order to keep it to a "viral" format (Jiang et al. 2014), we wanted the video to be as close to three minutes as possible (the video is 3m20s, excluding credits); this took five hours of shooting and about 20 hours of video editing. In the dissemination process (Table 1b) and in our press release (also posted on our YouTube channel), we included the IRSPUM's link to a webcast of the seminar.

Outcomes and Exchanges

The fact that two weeks after the February 16 launch the video had already hit 9,587 views on YouTube, is a demonstration that a small-scale KT project can have an important public uptake if it is well planned. This number is all the more impressive when one considers some significant barriers that could have mitigated the video's uptake, i.e., the political nature of the subject, the language (the video is only in French and was not translated nor subtitled in English) and the topic's specific relevance to Quebec. A YouTube search for videos on the same topic allows to locate videos posted by health professional unions such as *Fédération interprofessionnelle de la santé du Québec* (FIQ) and *Fédération de la santé et des services sociaux affiliée à la Confédération des syndicats nationaux* (FSSS-CSN). Our video ranks second in views (11,145 after 11 months), next to a press conference of the FIQ president Régine Laurent (15,453 views). It has more views than a series of videos posted by FSSS-CSN, their most popular videos having been viewed 7,936, 7,308 and 6,878 times. Of note, in addition to representing hundreds of thousands of people, both FIQ's and FSSS-CSN's videos are showing political figures well-known to the general public, while the Collective had no recognized notoriety.

Using YouTube's statistical tools, we obtained more details about the viewers (Figure 1) and viewing patterns. Viewing peaked within the first 48 hours after the video's

release (Figure 1a); demographic data (Figure 1b) is consistent with that expected for a French-speaking Quebec-focused initiative (Canada represents 96% of the viewing, followed by France at 1% and the US at 1%); and the gender of viewers is fairly equal. More unexpected is the age stratification: most views (40%) are from the 25–34 age range, which could be explained by the fact that the initiative has been disseminated through social media. Mobile device (phone and tablet) viewing is fairly equal to computer viewing (Figure 1c). On average, viewers watched the video for 2m37s, which may indicate that the provided number of views represents actual viewers.

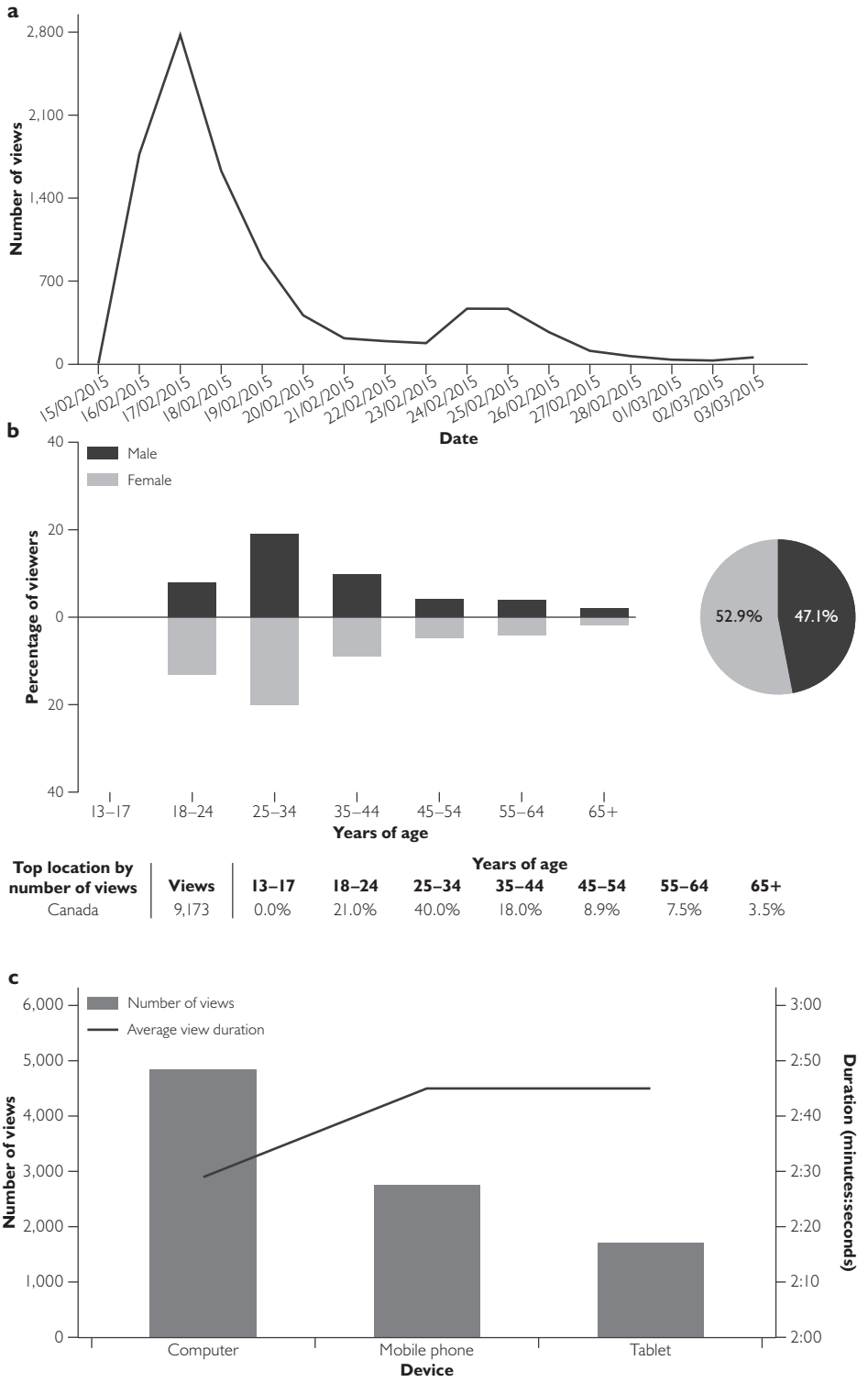
In addition to the YouTube views and presence on social media (Twitter: 340 tweets, 131 re-tweets, 94.1k re-tweet reach, 78 mentions, 11.3k mention reach, 224 favourited; Facebook page: 208 likes for the Collective page and 1.8k video reach/83 video share, in two weeks), the video was presented during the Université de Montréal's Public Health Students Association's Symposium on February 18, which lead to applause from on-stage guest speakers and praise from various students, several of whom asked how they could join the Collective. Various organizations, better established than the Collective, also approached us to discuss the video aftermath, and we received invitations to present our initiative in socio-political events and an article was published in a physiotherapy magazine (Anonymous 2015).

The only negative comments that we received pertained to the fact that we did not use references to back up the statements in the video. For example, on the YouTube channel, three people posted comments questioning our legitimacy, and the validity and reliability of our information. We anticipated this situation when we chose not to include references, and were able to mitigate the negative impact of this decision by answering the comments on YouTube by providing more detailed and referenced information.

The Importance of Acquiring KT Abilities Early in an Academic Career

It is important to remember that it takes a substantial amount of time to carry out such KT projects. Producing a three-minute video took two weeks of full-time work by three people, one full day of shooting involving 10 students and punctual help from several others. Due to the short window of opportunity, we had to put aside our concurrent academic projects. Relatively few people outside of academia (and even within academia) have the liberty to dedicate their full attention to this kind of project, for weeks (Bélisle Pipon et al. 2016). The three authors of the video (and this paper) are doctoral students, and thus benefit from a flexibility that others (such as researchers or clinicians) may not have. Considering that doctoral students generate a good deal of scientific research – for instance, 33% of total research papers published in 2007 by Quebec researchers were written with doctoral students (Larivière 2010: 164) – it is logical to think that these knowledge producers should be more involved in KT. While Graham (2005) found that researchers "lack the skills, experience and confidence" in doing KT, an initiative like ours may help graduate students build their confidence through experience and skill-building to interact efficiently with a broad and diverse audience.

FIGURE 1. Viewing statistics from February 15 to March 3, 2015: a) Views per day; b) Demographic information; c) Devices used for viewing



Top location by number of views	Views	Years of age 13–17	18–24	25–34	35–44	45–54	55–64	65+
Canada	9,173	0.0%	21.0%	40.0%	18.0%	8.9%	7.5%	3.5%

Moreover, it is even more important as KT is increasingly seen as a new expectation by funding agencies, and researchers themselves, as a token of accountability for knowledge producers (CIHR 2014). For instance, leading public health researchers are advocating for increased KT involvement: "A willingness and capacity to engage with mass media was seen as an essential attribute of influential public health researchers" (Chapman et al. 2014: 271). It can be argued that there is a fine line between "politicizing" science and advocating for evidence-based decision-making (Weigold 2001); however, when the goal is to raise awareness in the general public about well-accepted evidences, entering in the media sphere should not be seen as undermining researchers' integrity. Unfortunately, negative views remain against those engaging into debates in the public arena (Müllerleile 2014). Nevertheless, it should be recognized that it is the researchers' duty and that mass media are "an invaluable mechanism [for] influencing policy change" (Chapman et al. 2014: 271).

Concluding Note

Creating a video aimed at transferring knowledge about public policy to the general public is challenging, especially when the political context makes for a tight window of opportunity. However, the experience was a success considering the number of views and positive comments received (online and in person). The framework used to design our KT project can, we hope, provide a useful map for scholars to plan similar KT initiatives that help to bridge the gap between research and the general public.

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References

Anonymous. 2015. *Des étudiants en santé publique contre la loi 10*. Parallèle. Retrieved March 1, 2015. <http://parallelephysio.ca/actupro/au-quebec/un-video-des-etudiants-en-sante-publique-contre-la-loi-10/>.

Barwick, M., D. Phipps, G. Myers, M. Johnny and R. Coriandoli. 2014. "Knowledge Translation and Strategic Communications: Unpacking Differences and Similarities for Scholarly and Research Communications." *Scholarly and Research Communication* 5(3). Retrieved January 9, 2016. <http://src-online.ca/index.php/src/article/view/175>.

Bélisle Pipon, J.-C., M.-E. Lemoine, M. Laliberté and B. Williams-Jones. 2016. "Between Policy and Politics: When Bioethics Ventures into Public Debate." *Narrative Inquiry in Bioethics* 6(1).

Canadian Institute for Health Research (CIHR). 2014. *Knowledge Translation & Commercialization*. Retrieved February 22, 2016. <http://www.cihr-irsc.gc.ca/e/29529.html>.

Chapman, S., A. Haynes, G. Derrick, H. Sturk, W.D. Hall and A.S. George. 2014. "Reaching "An Audience that you would Never Dream of Speaking to": Influential Public Health Researchers' Views on the Role of News Media in Influencing Policy and Public Understanding." *Journal of Health Communication* 19(2): 260–73. doi:10.1080/10810730.2013.811327.

Collectif d'étudiant(e)s en santé publique. 2015. Les faits sur la loi 10. Montréal. Retrieved January 9, 2016. <www.youtube.com/watch?v=khbsgbqtuvQ>.

Estabrooks, C.A., P. Norton, J.M. Birdsell, M.S. Newton, A.J. Adewale and R. Thornley. 2008. "Knowledge Translation and Research Careers: Mode I and Mode II Activity among Health Researchers." *Research Policy* 37(6): 1066–78.

Graham, I. 2005. *How Are Canadian Health Researchers Promoting the Uptake of their Findings*. Presented at the KT ICEBeRG Symposium – Ottawa Health Research Institute, The Ottawa Hospital (Civic Campus), Ottawa, Canada. Retrieved January 9, 2016. <http://www.iceberg-grebeci.ohri.ca/research/ICEBeRG_symposium_Graham.pdf>.

IRSPUM. 2015. *Les implications du projet de loi no. 10*. Montréal. Retrieved January 9, 2016. <www.irspum.umontreal.ca/DOCUMENTATIONETRESSOURCES/M%C3%89DIATH%C3%88QUE/tabid/79/language/fr-CA/Default.aspx?Id=4084>.

Jiang, L., Y. Miao, Y. Yang, Z. Lan and A.G. Hauptmann. 2014. "Viral Video Style: A Closer Look at Viral Videos on YouTube." In *Proceedings of International Conference on Multimedia Retrieval* (p. 193). ACM. Retrieved January 9, 2016. <http://dl.acm.org/citation.cfm?id=2578754>.

Larivière, V. 2010. *A Bibliometric Analysis of Quebec's PhD Students' Contribution to the Advancement of Knowledge*. McGill University. Retrieved January 9, 2016. <www.ost.uqam.ca/Portals/0/docs/Monographies/Thesis_Lariviere_Final.pdf>.

Léger. 2014. *Perceptions du projet de loi 10 sur la réforme de la santé et des services sociaux*. Montréal, Québec. Retrieved January 9, 2016. <http://www.fsss.qc.ca/download/vpp/Rapport-FSSS_CSN-PL10.pdf>.

Minister of Health and Social Services. 2015. *Bill № 10 : An Act to modify the Organization and Governance of the Health and Social Services Network, in Particular by Abolishing the Regional Agencies – National Assembly of Québec, § 41th Legislature*. Retrieved January 9, 2016. <www.assnat.qc.ca/en/travaux-parlementaires/projets-loi/projet-loi-10-41-1.html>.

Mitton, C., C.E. Adair, E. Mckenzie, S.B. Patten and B.W. Perry. 2007. "Knowledge Transfer and Exchange: Review and Synthesis of the Literature." *Milbank Quarterly* 85(4): 729–68. doi:10.1111/j.1468-0009.2007.00506.x.

Müllerleile, A. 2014. "European Studies and Public Engagement: A Conceptual Toolbox." *Journal of Contemporary European Research* 10(4): 505–17. Retrieved January 9, 2016. <www.jcer.myzen.co.uk/index.php/jcer/article/view/647>.

Rootman, I. and D. Gordon-El-Bihbety. 2008. *Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy*. Canadian Public Health Association. Retrieved January 9, 2016. <www.cpha.ca/uploads/portals/h-l/report_e.pdf>

Weigold, M. 2001. "Communicating Science." *Science Communication* 23(2): 164–93.

RESEARCH PAPER

Effectiveness of Reablement: A Systematic Review

Efficacité de l'autonomisation : une revue systématique

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Abstract

The ageing of the population and the increasing need for long-term care services are global issues. Some countries have adapted homecare programs by introducing an intervention called reablement, which is aimed at optimizing independence. The effectiveness of reablement, as well as its different service models, was examined. A systematic literature review was conducted using MEDLINE, CINAHL, PsycINFO and EBM Reviews to search from 2001 to 2014. Core characteristics and facilitators of reablement implementation were identified from international experiences.

Ten studies comprising a total of 14,742 participants (including four randomized trials, most of excellent or good quality) showed a positive impact of reablement, especially on health-related quality of life and service utilization. The implementation of reablement was studied in three regions, and all observed a reduction in healthcare service utilization. Considering its effectiveness and positive impact observed in several countries, the implementation of reablement is a promising avenue to be pursued by policy makers.

Résumé

Le vieillissement de la population et l'augmentation des besoins en services de longue durée sont des préoccupations mondiales. Certains pays ont adapté leurs programmes de soutien à domicile en y intégrant une intervention nommée « autonomisation », laquelle vise à optimiser l'indépendance des clients. Nous avons examiné l'efficacité de l'autonomisation ainsi que ses divers modèles de services. Nous avons procédé à une revue systématique à l'aide des bases de données MEDLINE, CINAHL et PsycINFO ainsi que des revues fondées sur les données probantes, entre 2001 et 2014. Un examen d'expériences internationales a permis de déterminer les caractéristiques clés de l'autonomisation et les facteurs favorisant le succès de son implantation.

Dix études qui représentent un échantillon de 14 742 participants (dont quatre essais cliniques aléatoires, pour la plupart de bonne à excellente qualité) montrent un effet positif de l'autonomisation, particulièrement sur le plan de la qualité de vie liée à la santé et sur le plan de l'utilisation des services. Nous avons étudié l'implantation de l'autonomisation dans trois régions, lesquelles ont toutes connu une réduction de l'utilisation des services de soins de santé. En raison de son efficacité et de l'impact positif observé dans plusieurs pays, l'implantation de l'autonomisation est une avenue prometteuse que devraient considérer les responsables de politiques.

Introduction

The ageing population and the increasing need for long-term care services are global concerns. Some countries have adapted their homecare programs by introducing restorative homecare, or reablement, to optimize the independence of community-dwelling adults. Reablement is defined as services for seniors with physical or mental disabilities that help them adapt to their condition by learning or re-learning the skills needed to function in everyday life (Social Care Institute for Excellence 2013). The objective is to help seniors live independent and fulfilling lives, while appropriately reducing the need for continuing support and reducing the cost of long-term services. Key characteristics are the provision of short-term, goal-oriented interventions developed by an interdisciplinary team with the user, and delivery of the interventions by a non-professional under the supervision of a professional (Table 1). The focus is on promoting and optimizing functional independence rather than resolving health problems.

The objective of this paper is to examine the effectiveness of reablement, and to identify factors that might contribute to successful implementation for Canadian policy makers. A report in French intended for Quebec policy makers regarding implementation of reablement can be consulted for more details (Tessier et al. 2015).

TABLE 1. Core characteristics of reablement

Structure	Interdisciplinary team of varying composition
	Training and ongoing support for team members
Process	Free services for 6–12 weeks
	Programs accessible to everybody, but some prioritize those leaving the hospital
	Generic interventions (not requiring a high degree of professional specialization) offered by non-professionals
	Evaluation of users by professionals via structured and comprehensive assessment
	Goal-oriented plan developed with users and their caregivers
	Treatment plan reviewed regularly
	Weekly team meeting
Outcome	Improved ADL, IADL and HRQoL and less service utilization

ADL = activity of daily living; IADL = instrumental activity of daily living; HRQoL = health-related quality of life.

Methods

Effectiveness of reablement

A systematic review was conducted to evaluate the effectiveness of reablement. For a study to be considered, the participants had to be over 65 years old, have functional limitations and be living at home. The intervention did not need to be called reablement or restorative care, but had to promote functional independence, be of short duration (6–12 weeks) and be provided by paid workers as part of homecare services. The intervention had to be multidisciplinary in nature. The outcomes of interest were functional status in activities of daily living (ADL) and instrumental activities of daily living (IADL), health-related quality of life (HRQoL) and healthcare service utilization. Systematic reviews, meta-analyses, randomized controlled trials (RCTs) and quasi-experimental and qualitative studies were eligible for inclusion. Case reports were excluded: studies had to have a control group in order to address whether the change in outcome was due to the natural evolution of the person's condition or to the intervention.

Literature searching was carried out in MEDLINE (PubMed), CINAHL (EBSCO), PsycINFO (OvidSP) and EBM Reviews (OvidSP); the latter included the Cochrane Central Register of Controlled Trials and the Cochrane Database of Systematic Reviews. Several search terms were used, including *homecare*, *reablement*, *autonomy*, *seniors* and *aged*. Articles had to be published in either English or French between January 2001 and August 2014. The search strategy is available in Appendix 1 (available at: http://www.longwoods.com/content/24594).

Articles were selected independently by two researchers (AT and MDB). Any discrepancies were resolved by consensus. Articles were excluded if they did not pertain to people older than 65 years old receiving an intervention promoting autonomy, or if they did not include the outcomes of interest (function, HRQoL or service utilization). The studies selected from the

literature had to have control groups in order to be able to determine whether the change in outcome was due to the natural evolution of the person's condition or to the intervention. One researcher (AT) extracted information from all articles using a template that included research design, client characteristics, nature of the intervention (e.g., goals, duration and composition of the team), environment (e.g., country, urban or rural setting and multi-ethnic context), comparator, outcomes and adverse events. A second researcher validated the accuracy of the data extraction for 20% of the articles. Methodological quality of each study was assessed independently by two researchers (AT and MDB) with the Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Programme 2014) tool for RCTs, and with the Assessment of Multiple Systematic Reviews (AMSTAR) (Shea et al. 2009) tool for systematic reviews.

Factors contributing to success

Australia, New Zealand and the UK have been at the forefront of developing and testing reablement. Furthermore, their healthcare systems are similar to Canada's. A narrative review of the non-peer-reviewed literature was conducted to examine the service models used in these regions, as well as the facilitators of and barriers to implementation according to this international experience. The Google Scholar search engine was queried to retrieve information. In addition, several websites of reputable societies were explored, including the Guidelines International Network (GIN), the Centre for Reviews and Dissemination (CRD), the International Network of Agencies for Health Technology Assessment (INAHTA), the Social Care Institute for Excellence (SCIE) and the National Institute for Health and Care Excellence (NICE) (Appendix 1).

Results

Effectiveness of reablement

The literature search yielded 621 articles: 43 were identified based on the title and abstract. The full articles were read, resulting in further exclusion. The remaining 13 articles originated from 10 individual studies (Burton et al. 2013a, 2013b; Glendinning et al. 2011; King et al. 2012a, 2012b; Lewin et al. 2013a, 2013b; 2014; Lewin and Vandermeulen 2010; Parsons et al. 2012, 2013; Senior et al. 2014; Tinetti et al. 2002). Seven out of 10 were considered to be of either excellent or good quality, while three were of fair quality. There were four RCTs, four controlled before-and-after studies, one data linkage and one qualitative study, collectively including close to 15,000 participants. All of the included studies referred to the intervention either as reablement or restorative care. Study characteristics, quality and results are reported in Table 2. On average, the service users in the studies were 78–80 years old and required minimal to moderate help with their ADLs.

Seven studies examined the effect of reablement on various aspects of functional capacity (Table 2). Three studies reported no effects of reablement (Burton et al. 2013b; King et al. 2012b; Senior et al. 2014). Two studies looking exclusively at ADLs demonstrated an

improvement in both groups of participants (reablement or usual homecare services) (Lewin et al. 2013a; Tinetti et al. 2002). In three studies, either ADL, IADL or mobility showed greater improvement with reablement than with usual services (Lewin and Vandermeulen 2010; Parsons et al. 2013; Tinetti et al. 2002). Finally, reablement was associated with greater improvement in HRQoL compared to usual homecare services in four studies (total sample of 1,706 participants). This difference was statistically significant in three studies (Glendinning et al. 2011; King et al. 2012b; Parsons et al. 2012), and not significant in one (Lewin et al. 2013a).

TABLE 2. Characteristics of included studies

Study (first author, year; design; sample size; country/region)	Quality	Results (for the intervention group, compared with controls)			
		Functional capacity	HRQoL	Service utilization	Other results
Burton 2013a, 2013b; CBA; *n* = 506; Australia	Fair	No effect on physical activity level (MT, LT)			
Glendinning 2011; CBA; *n* = 1,015; UK	Fair		Greater improvement (clinically significant and SS) (ST)	60% reduction in ongoing homecare needs	NS differences in average costs between the two groups (ST) (initial cost of reablement offset by a 60% decrease in long-term costs)
King 2012a; Qualitative; *n* = 25; New Zealand	Fair				Greater paid-worker job satisfaction; reduced staff turnover
King 2012b; RCT; *n* = 186; New Zealand	High	NS improvement in both groups (ST)	Greater improvement (SS, but not clinically significant) (ST)	Greater proportion of users needing fewer services (SS) (ST)	
Lewin 2010; CBA; *n* = 200; Australia	Moderate	Only the intervention group showed improvement in ADL, IADL and mobility (SS) (ST)		Lower probability of continuing to require services (SS) (ST)	NS improvement on mood in both groups (ST)
Lewin 2013b; Data linkage; *n* = 10,368; Australia	High			Lower probability of continuing to require services (SS) (LT)	Cumulative costs substantially lower in the intervention group (MT and TL); savings of $7,345 CAD per person after 3 years; median cost of first 3 months of intervention about half that of current services and less than a third after 5 years (ST and LT)

TABLE 2. Characteristics of included studies (continued)

Study (first author, year; design; sample size; country/region)	Quality	Results (for the intervention group, compared with controls)			
		Functional capacity	HRQoL	Service utilization	Other results
Lewin 2013a; Lewin 2014; RCT; *n* = 750; (*n* = 300 for data on function and HRQoL); Australia	Moderate	NS difference between the groups: both improved (ST)	NS difference between the groups: both improved (ST)	NS difference between groups for hours of homecare services, hospital admissions, emergency department visits (ST and MT) in the intention to treat analysis, SS difference in the analysis per the actual treatment received	Average total home services costs 22% lower at 1 year and 30% lower at 2 years (NS)
Parsons 2012; Parsons 2013; RCT; *n* = 205; New Zealand	High	Greater improvement (SS) (ST)	Only the intervention group showed improvement (SS) (ST)		NS difference between the groups for social support (ST)
Senior 2014; RCT; *n* = 105; New Zealand	Moderate	NS difference between the groups for ADL, IADL (MT)		NS reduction in the risk of death and/or residential care placement (MT)	SS slower rate of decline in physical health of caregivers (MT); no effect on caregiver burden (MT)
Tinetti 2002; CBA; *n* = 1,382; US	Moderate	Greater improvement in IADL and mobility (SS) (ST); NS difference between groups for ADL: both improved		SS reduction in the risk of residential care placement, emergency department visits and length of homecare episode (ST)	

ADL = activity of daily living; CBA = controlled before-and-after study; HRQoL = health-related quality of life; IADL = instrumental activity of daily living; LT = long term (more than 3 years); MT = medium term (1–3 years); NS = not statistically significant; RCT = randomized controlled trial; SS = statistically significant; ST = short term (less than 1 year).

According to seven studies (eight articles; total sample of 14,006 participants), reablement had a positive effect on service utilization in the first year. Fewer people required homecare services after receiving reablement compared to those receiving usual homecare services (Glendinning et al. 2011; King et al. 2012b; Lewin et al. 2013a, 2013b; 2014; Lewin and Vandermeulen 2010; Senior et al. 2014; Tinetti et al. 2002). The absolute risk reduction ranged across the studies between 55% at three months and 22% at 12 months. However, only one study indicated that the effects were maintained in the long term (five years) (Lewin et al. 2013b). Evidence was limited but suggested benefits of reablement on visits to the emergency department, risk of residential care placement and mortality (Lewin et al. 2014; Senior et al. 2014; Tinetti et al. 2002). One study found no effect on caregivers' burden (Senior et al. 2014), while another reported greater job satisfaction in the group of employees providing reablement when compared to those delivering usual homecare services (King et al. 2012a).

The efficiency of reablement was examined in three studies (total sample of 12,133 participants). Generally, the cost of reablement was higher than that of usual homecare services because reablement requires more resources, including a need for more training, supervision and user evaluation at the outset. In the subsequent months, however, reablement was associated with a decrease in homecare service utilization. In one study, balanced total costs, when both reablement and ongoing homecare services were considered, were achieved within the first year (Glendinning et al. 2011). The results of an RCT suggest that reablement was cost-effective in the long term: the cost of reablement compared with usual homecare was, on average, 22% lower in the first year, and 30% lower over two years (Lewin et al. 2014). According to a large database analysis, the median cumulative cost of all homecare services in the reablement group was approximately half that of the usual homecare group at three months, and less than one-third the cost for the 6,656 persons who were followed for nearly five years (Lewin et al. 2013b).

One of the difficulties in establishing the cost-benefit of reablement is the wide differences in cost across clinical settings. For example, the study of Glendinning and colleagues was carried out in five similar clinical settings and reported an average cost per user ranging from £1,609 to £3,575 (Glendinning et al. 2011).

Factors contributing to success

In Australia, New Zealand and the UK, reablement was first introduced in the setting of pilot projects near the beginning of 2000. Such projects showed a reduction in services needed and enhanced user satisfaction (Ghatorae 2013; McLeod and Mair 2009). Consequently, the projects were expanded to service the general population. Most of these regions have gradually moved from insourcing to outsourcing services to non-governmental organizations. The service model is similar from one country to another. In almost all settings, reablement is available to all who need homecare services without discrimination, including those with cognitive impairment, for whom the evidence actually suggests less benefit. Most of the associated services arise from the community rather than from the hospital setting.

Facilitators of and barriers to the success of reablement have been identified through interviews with service managers, users and frontline staff (McLeod and Mair 2009; Rabiee and Glendinning 2011). Similarly, the Social Care Institute for Excellence (SCIE) in the UK has identified contributing factors in their practical guide entitled "Maximising the potential of reablement to support the implementation and delivery of reablement"; these factors are summarized in Table 3 (Social Care Institute for Excellence 2013). Staff training has been recognized as a key element for success, along with the engagement of patients and their caregivers in the reablement plan to establish realistic expectations. An efficient handover process is required, and the scope of services should address social needs. The Care Services Efficiency Delivery (CSED) program, also in the UK, has developed a toolkit, which provides practical help for the implementation of reablement (Care Services Efficiency Delivery 2011).

TABLE 3. Factors contributing to the success of reablement

Organization	Strong and shared vision of the service
	Thorough and consistent recording system
Service users	User characteristics: greatest benefit for those recovering from falls or fractures; benefit may be less for those likely to need ongoing support such as people with dementia or mental health problems
	Expectations of service users and carers (reablement worked better for newly referred people)
Staff	Staff commitment, attitude and skills
	Training on the principles of delivering a reablement service (e.g., learning to "stand back")
	Professionals not necessarily full-time members of the team but frontline workers need access to specialist skills
Intervention	Although regaining physical ability is central, addressing psychological support as well as social needs is also vitally important
	Access to equipment
	Flexible and prompt intervention
	Goal-oriented intervention: goals are established with the user and informal carers, broken down into achievable targets
Program evaluation	Less focus on time and tasks; instead, reablement should be evaluated on the basis of the outcomes that the service will support the individual to achieve

Discussion

There is good evidence supporting the effectiveness of reablement, particularly regarding HRQoL and service utilization. The added value of recognizing the importance of patient participation in decision-making is well documented, and is likely related to the observed improvement in HRQoL (Legare et al. 2014). Similarly, involving the patient in goal-setting has been shown to lead to significant improvement in HRQoL, possibly via individualized activities (Parsons 2012).

Reablement has shown a positive effect on functional capacity, an effect which is comparable with that of usual homecare services. In the reviewed studies, most users required minimal-to-moderate assistance with their ADL prior to the intervention, and their functional status was assessed with tools that included few complex activities (the Barthel Index and the Nottingham Extended Activity of Daily Living). The small changes reported in functional capacity, which may be surprising considering the reported impact on HRQoL, are possibly due to the limited sensitivity of the assessment tools used. Reablement may be more effective for certain clientele. The homogeneity of the populations studied to date precludes an analysis of who would best benefit from reablement. Specific eligibility criteria may emerge from future studies. Although reablement has the potential to be cost-effective, this is difficult to quantify considering the wide range of costs reported in the literature across settings.

The present results are consistent with two recent systematic reviews. The first was restricted to examining dependency and concluded there was limited evidence for a reduction associated with reablement (Whitehead et al. 2015). The second reported, as in the present study, that reablement had a positive impact on HRQoL, costs and service utilization (Ryburn et al. 2009).

Three regions have implemented reablement for more than 10 years. They have performed extensive program evaluation, documenting positive impact on service utilization and user satisfaction. Their experience has permitted the identification of factors contributing to success, which policy makers can consider when developing strategic plans to improve homecare. For example, appropriate training has been identified as a facilitator, consistent with Ontario's recent decision to increase support for homecare workers. Finally, reablement can be successfully delivered by non-professionals among whom it has been associated with greater job satisfaction. This offers additional advantages given that recruitment and retention of qualified employees are major challenges in the homecare industry.

In general, seniors wish to live at home. However, in Quebec, as well as in the rest of Canada, almost one in four disabled seniors report unmet homecare needs, one of these being walking outside (Dubuc et al. 2011; Turcotte 2014). One of the challenges of our society is to reduce the barriers to social participation of older people. With this in mind, reablement, which targets both psychosocial and physical needs, is a promising approach.

Conclusion

One of the objectives of the Quebec Health Ministry's action plan for 2015–2020 is to improve homecare services through systematic evaluation of needs and treatment plans for all elderly (Ministère de la Santé et des Services Sociaux 2015). The reablement approach is in keeping with this objective, with a focus on independence in the community rather than services in institutions. It promotes investment in staff and greater participation of users and their families in decision-making about their care. In addition to improving HRQoL and reducing healthcare service utilization in the short term, reablement can potentially increase employee satisfaction at a reasonable marginal cost.

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References

Burton, E., G. Lewin and D. Boldy. 2013a. "Barriers and Motivators to being Physically Active for Older Home Care Clients". *Physical & Occupational Therapy in Geriatrics* 31(1): 21–36. doi:10.3109/02703181.2012.751474.

Burton, E., G. Lewin and D. Boldy. 2013b. "Physical Activity Levels of Older Adults Receiving a Home Care Service". *Journal of Aging and Physical Activity* 21(2): 140–54.

Care Services Efficiency Delivery. 2011. *Home Care Re-Ablement*. UK: Department of Health. Retrieved March 30, 2015. <http://webarchive.nationalarchives.gov.uk/20120907090129/http:/www.csed.dh.gov.uk/homeCareReablement/Toolkit/>.

Critical Appraisal Skills Programme (CASP). 2014. *CASP Checklists*. Oxford: CASP. Retrieved March 23, 2015. <http://media.wix.com/ugd/dded87_40b9ff0bf53840478331915a8ed8b2fb.pdf>.

Dubuc, N., M.F. Dubois, M. Raiche, N.R. Gueye and R. Hebert. 2011. "Meeting the Home-Care Needs of Disabled Older Persons Living in the Community: Does Integrated Services Delivery Make a Difference?" *BMC Geriatrics* 11: 67. doi:10.1186/1471-2318-11-67.

Ghatorae, H. 2013. *Reablement in Glasgow: Quantitative and Qualitative Research*. Glasgow, UK: Glasgow City Council.

Glendinning, C., K. Jones, K. Baxter, P. Rabiee, L.A. Curtis, A. Wilde et al. 2011. Home Care Re-Ablement Services: Investigating the Longer Term Impacts (Prospective Longitudinal Study). York: Social Policy Research Unit, University of York. Retrieved January 20, 2014. <http://socialwelfare.bl.uk/subject-areas/services-activity/social-work-care-services/spru/135160Reablement10.pdf>.

King, A.I., M. Parsons and E. Robinson. 2012a. "A Restorative Home Care Intervention in New Zealand: Perceptions of Paid Caregivers". *Health & Social Care in the Community* 20(1): 70–79. doi:10.1111/j.1365-2524.2011.01020.x.

King, A.I., M. Parsons, E. Robinson and D. Jorgensen. 2012b. "Assessing the Impact of a Restorative Home Care Service in New Zealand: A Cluster Randomised Controlled Trial". *Health & Social Care in the Community* 20(4): 365–74. doi:10.1111/j.1365-2524.2011.01039.x.

Legare, F., D. Stacey, S. Turcotte, M.J. Cossi, J. Kryworuchko, I.D. Graham et al. 2014. "Interventions for Improving the Adoption of Shared Decision Making by Healthcare Professionals". *Cochrane Database of Systematic Reviews* 12(5): CD006732. doi:10.1002/14651858.CD006732.pub3.

Lewin, G. and S. Vandermeulen. 2010. "A Non-Randomised Controlled Trial of the Home Independence Program (HIP): An Australian Restorative Programme for Older Home-Care Clients". *Health & Social Care in the Community* 18(1): 91–99. doi:10.1111/j.1365-2524.2009.00878.x.

Lewin, G., K. De San Miguel, M. Knuiman, J. Alan, D. Boldy, D. Hendrie et al. 2013a. "A Randomised Controlled Trial of the Home Independence Program, an Australian Restorative Home-Care Programme for Older Adults". *Health & Social Care in the Community* 21(1): 69–78. doi:10.1111/j.1365-2524.2012.01088.x.

Lewin, G.F., H.S. Alfonso and J.J. Alan. 2013b. "Evidence for the Long Term Cost Effectiveness of Home Care Reablement Programs". *Clinical Interventions in Aging* 8: 1273–81. doi:10.2147/cia.s49164.

Lewin, G., J. Allan, C. Patterson, M. Knuiman, D. Boldy and D. Hendrie. 2014. "A Comparison of the Home-Care and Healthcare Service Use and Costs of Older Australians Randomised to Receive a Restorative or a Conventional Home-Care Service". *Health & Social Care in the Community* 22(3): 328–36. doi:10.1111/hsc.12092.

McLeod, B. and M. Mair. 2009. *Evaluation of City of Edinburgh Council Home Care Re-Ablement Service*. Edinburgh, UK: Scottish Government Social Research.

Ministère de la Santé et des Services Sociaux. 2015. *Plan stratégique 2015–2020*. Québec, QC. Publication №: 15-717-02W.

Parsons, J., P. Rouse, E.M. Robinson, N. Sheridan and M.J. Connolly. 2012. "Goal Setting as a Feature of Homecare Services for Older People: Does it Make a Difference?" *Age Ageing* 41(1): 24–29. doi:10.1093/ageing/afr118.

Parsons, J.G., N. Sheridan, P. Rouse, E. Robinson and M. Connolly. 2013. "A Randomized Controlled Trial to Determine the Effect of a Model of Restorative Home Care on Physical Function and Social Support among Older People." *Archives of Physical Medicine and Rehabilitation* 94(6): 1015–22. doi:10.1016/j.apmr.2013.02.003.

Rabiee, P. and C. Glendinning. 2011. "Organisation and Delivery of Home Care Re-Ablement: What Makes a Difference?" *Health & Social Care in the Community* 19(5): 495–503. doi:10.1111/j.1365-2524.2011.01010.x.

Ryburn, B., Y. Wells and P. Foreman. 2009. "Enabling Independence: Restorative Approaches to Home Care Provision for Frail Older Adults." *Health & Social Care in the Community* 17(3): 225–34. doi:10.1111/j.1365-2524.2008.00809.x.

Senior, H.E., M. Parsons, N. Kerse, M.H. Chen, S. Jacobs, S.V. Hoorn et al. 2014. "Promoting Independence in Frail Older People: A Randomised Controlled Trial of a Restorative Care Service in New Zealand." *Age Ageing* 43(3): 418–24. doi:10.1093/ageing/afu025.

Shea, B.J., C. Hamel, G.A. Wells, L.M. Bouter, E. Kristjansson, J. Grimshaw et al. 2009. "AMSTAR Is a Reliable and Valid Measurement Tool to Assess the Methodological Quality of Systematic Reviews." *Journal of Clinical Epidemiology* 62(10): 1013–20. doi:10.1016/j.jclinepi.2008.10.009.

Social Care Institute for Excellence (SCIE). 2013. *SCIE guide 49: Maximising the Potential of Reablement*. London: SCIE.

Tessier, A., M.D. Beaulieu, R. Latulippe and C.A. McGinn. 2015. *L'autonomisation des personnes en perte d'autonomie liée au vieillissement*. Québec : Institut national d'excellence en santé et en services sociaux (INESSS).

Tinetti, M.E., D. Baker, W.T. Gallo, A. Nanda, P. Charpentier and J. O'Leary. 2002. "Evaluation of Restorative Care vs Usual Care for Older Adults Receiving an Acute Episode of Home Care." *JAMA* 287(16): 2098–105.

Turcotte, M. 2014. *Canadians with Unmet Home Care Needs. Insights on Canadian Society*. Ottawa, ON: Statistics Canada. Catalogue № 75 006 X.

Whitehead, P.J., E.J. Worthington, R.H. Parry, M.F. Walker and A.E. Drummond. 2015. "Interventions to Reduce Dependency in Personal Activities of Daily Living in Community Dwelling Adults Who Use Homecare Services: A Systematic Review." *Clinical Rehabilitation* 29(11):1064–76. doi:10.1177/0269215514564894.

RESEARCH PAPER

The Search is on for Coherent Performance Measurement in Healthcare Organizations. Has Quebec Reached a Crossroads?

Pour une évaluation cohérente de la performance des organismes de santé. Le Québec est-il à la croisée des chemins?

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Abstract

Objective: This research looks back at a 10-year period (2004–2014) to understand the development and outlook for healthcare organization performance measurement in the Quebec healthcare system, in an attempt to objectivize relationships within the configuration of its principal institutional actors.

Methods: This is a qualitative study combining the use of official publications and fieldwork based on 13 semi-directed interviews, conducted in 2014, with informers in key performance measurement positions within the Quebec healthcare system.

Results: Performance measurement has generated tensions, both internally between different branches of the Department of Health and externally against a strong coalition of external

institutional actors, which were defending a shared homogeneous vision of performance. Four major types of political power plays, owing to the power struggles around performance models and indicators, converged around the same implicit issue of the need to attain greater legitimacy in order to impose an authoritative frame of reference.

Résumé

Objectif : Cette recherche se penche sur une période de 10 ans (2004–2014) afin de comprendre le développement et le panorama de l'évaluation de la performance des organismes dans le système de santé québécois, et ce, pour tenter d'objectiviser les relations dans la configuration des principaux acteurs institutionnels.
Méthodes : Il s'agit d'une étude qualitative qui combine l'utilisation de publications officielles et le travail de terrain, à l'aide de 13 entrevues semi-dirigées menées en 2014 auprès d'informateurs qui œuvrent dans des postes clés de l'évaluation de la performance au sein du système québécois de la santé.
Résultats : L'évaluation de la performance a créé des tensions tant à l'interne, entre diverses directions générales du ministère de la Santé, qu'à l'externe, face à une forte coalition d'acteurs institutionnels en faveur d'une vision homogène et commune de la performance. Quatre principaux types de jeux de pouvoir politique, causés par les luttes de pouvoir quant aux modèles et indicateurs de la performance, convergent vers le même enjeu implicite, soit l'atteinte d'une plus grande légitimité afin d'imposer un cadre de référence qui fasse autorité.

Introduction

For the past decade, the Quebec health system has been committed to achieving a "shift to performance." Responsibility for being transparent and accountable to the population and more demanding efficiency requirements in its healthcare organizations has imposed performance assessment as a strategic priority. The new role assigned to Quebec healthcare organizations in 2005 has encouraged the emergence of such an orientation. As the Department of Health (DOH) has gradually introduced reforms, healthcare organizations have been integrated into a more hierarchical architecture with comprehensive governance, under a "symbolic quest for coordination" (Dupuis and Farinas 2010). The publication, a few years later, of the Castonguay Report (Castonguay et al. 2008) reinforced the need to systematize facility performance assessments vis-à-vis health objectives in both clinical and economic terms. However, the quest to objectify performance measurements in a coherent manner had so far been in vain.

This article investigates how the Quebec principal institutional actors pursued this quest for coherence in terms of performance measurement by examining the issues raised within what became a relatively fragmented process. Although considerable work has been performed designing performance measurement systems in healthcare organizations (e.g. Deber 2014; Kruk and Freedman 2008; Marchal et al. 2014), the underlying

institutional issues remain relatively unexplored. In this sense, an analysis of the development of public policies offers a useful conceptual framework, particularly when one gets beyond the "statist vision," based on the observation that there has been a reduction in the number of institutional actors involved in these processes. By focusing on the role played by specialists, the conflicts between actors and their influential resources, we have based our work on currents of analysis such as the Advocacy Coalition Framework (Sabatier and Jenkins-Smith 1999) and the "epistemic community" (Haas 1992) to answer the following question: What was the role played by institutional actors in framing how performance is measured in Quebec healthcare organizations? With this in mind, we analyzed the tensions that have been generated by this process in Quebec's healthcare system over the last 10 years.

Methods

This work is based on the methodology typically used in surveys of public action, combining the use of the official publications of the public authorities and the interviews with key institutional actors concerned. Thirteen semi-directed interviews were conducted in 2014 by two authors (PF and CS) with a panel of the main institutional actors involved in performance assessment in Quebec's healthcare system. Participants were selected to meet two requirements (Belorgey 2012): the need to collect the personal accounts of the high-level actors involved, and the need to conduct a complete institutional review by integrating all four levels of governance:

- *Local:* healthcare organizations that, over a given geographical area, are responsible for acute hospital care, extended and residential care and primary care and services.
- *Regional:* healthcare agencies.
- *Provincial:* DOH; Auditor General of Quebec; Commissioner of Health and Well-Being (CHWB), mandated by law to monitor the Quebec healthcare performance; Quebec Association of Healthcare Organizations (QAHO); and Accreditation Québec.
- *National:* Canadian Institute for Health Information (CIHI); Accreditation Canada.

The survey protocol was part of a diachronic perspective based on both the retrospective dimension of participants' accounts and our "informative and narrative" use of the discussions (Pinson 2007). The strategy for conducting and analyzing the interviews was based on the "life stories" methodology (Bertaux 1997) and on systematically cross-checking the various discussions and comparing them to the written information to ensure that the researchers would have the critical distance required from the subjective views of each interviewee (Friedberg 1997). The protocol dealt with the origins, development and outlook for performance measurement in an attempt to objectivize relationships within this configuration of actors (Sabatier 1986).

Results

Piecemeal start to performance appraisal

The legitimacy of performance appraisal in the Quebec healthcare system would now appear to be broadly established. All the institutional actors agree that it is essential in order to improve the health system and the quality of service provided by healthcare organizations. These actors represent, first and foremost, a true "epistemic community," a network of professionals with recognized expertise and competencies in specific fields, who can articulate relevant knowledge on public policies in their fields (Haas 1992). Yet, this consensus on the merits of performance appraisal was accompanied by a scattered series of initiatives. It was developed within numerous institutional frameworks that were relatively independent of each other, through isolated approaches and efforts. The DOH has undoubtedly played an ambiguous role over the last few years, maintaining a certain dissonance between rhetoric that was resolutely favourable to performance assessment and a relative lack of involvement in the field in terms of concrete initiatives to encourage such developments. In terms of policy timing, the DOH has been late in dealing with these issues. This has resulted in reprimands from the Auditor General of Quebec, which, in its 2010–2011 report, underscored the department's failure to monitor the performance of organizations in the health and social services system. It was criticized for not exercising the necessary leadership and lagging behind other public administrations (VGQ 2011). This public blame came with recommendations on how to clarify actors' roles and responsibilities in the monitoring of performance by setting up a structured program, including a definition of performance and a measurement model (VGQ 2011).

A historical review of departmental action on these issues attests to a process that has been considered abnormally slow by several institutional partners. The first departmental task forces were established in 2008–2009 and resulted in creating a position of assistant director general of performance in 2010, followed by a commitment to performance assessment in DOH strategic planning and, finally, to a 2012–2015 action plan (MSSS 2012). The plan was largely inspired by recommendations from the Auditor General, for whom the sine qua non condition of successful performance assessment was collaboration and coordination among all the institutional actors involved (VGQ 2011). However, it is important to note prior substantial efforts made by these external institutional actors regarding the adoption of formal performance assessment mechanisms. Indeed, in response to the priorities set by public authorities 15 years earlier (including in the *Public Administration Act* of 2000), three major institutional actors – CHWB, QAHO and one regional agency – had already adopted firm approaches and designed operational tools to measure the performance of healthcare organizations, undertaking their own initiatives and experiments due to an absence of concrete DOH action. These efforts led to the publication of several analytical reports that were diffused widely.

This prolonged history of performance assessment helped create an asymmetry of expertise regarding the skills acquired in assessment methodology, indicator development and data interpretation. The result was a *de facto* climate of mistrust, shared by these various actors who had developed strong expertise that was, in some ways, superior to that of the DOH.

In particular, this was because the DOH clearly intended to play a role of leadership and control, which was perceived as an attempt to unilaterally control the domain. Pointing to a loss of legibility in assessment approaches and the absence of a shared vision, the DOH was struggling to become a "conductor" as affirmed in their own terms. To convince pioneers in this area, the DOH used its "nodality," meaning "the property of someone in the middle of a social network or an information network" (Baudot 2014; Hood 1986) through the manufacture and mastery of instruments, in this case, performance assessment indicators and models.

So even if this initiative was conducted with a reassuring "desire to work together," it has been very poorly received due to a lack of consultation and transparency. Several interviews revealed that many institutional actors regretted the failure to listen, and the top-down approach adopted by the DOH, which appeared to want to operate in a vacuum, with no transparency, making a clean sweep of the past. They saw this as a way to take control of the situation, particularly in terms of design (by imposing a DOH performance model [ARSSM 2013] that was different from the model adopted by most of the external institutional actors), metrology (by re-beginning the work of selecting, defining and calculating indicators from scratch) and access to source data (through an effort to impose an exclusive control of the databanks needed to calculate indicators). Furthermore, economic factors related to budget cuts were exacerbating uncertainties around the political use of this performance assessment expertise. As a result, the stakeholders who developed the approach and instruments based on the public discourse of the time feared that it would be misused politically and applied for the sole purposes of control and sanctions. These issues were especially apparent in the tense relations between the DOH and the CHWB, at the crossroads between rationales of power and expertise (Box 1).

BOX 1. The agile Commissioner of Health and Well-Being

The Commissioner of Health and Well-Being (CHWB) was created in 2006 out of the government's desire to have a strongly independent organization, removed from politics, to assess performance in the healthcare system. With a small team of 16 people, the CHWB published its initial performance report in 2008, adopting the EGIPSS performance model (an acronym for comprehensive and integrated assessment of the performance of healthcare systems). This model was developed by a team of researchers at the Department of health administration at Université de Montréal (Marchal et al. 2014; Minvielle et al. 2008; Sicotte et al. 1998). One of the advantages of the model was that it related production indicators to quality indicators, allowing for inter-organizational benchmarking. Since then, the CHWB has proven to be extremely active and entrepreneurial, taking risks due to its independence, but also its credibility, which it obtained through the publication of an annual report on the performance of the entire Quebec system, as well as work carried out in Quebec's regions. To this end, it established strong partnerships with other major institutional actors, such as the Quebec Association of Healthcare Organizations (QAHO) and the Canadian Institute for Health Information (CIHI), for discussion and pooling practices. On the other hand, its relations with the Department of Health (DOH) were characterized by tensions and misunderstandings, largely fed by the strong will of the DOH to impose the use of the department's performance indicators and model rather than the EGIPSS performance model that was used by several other institutional actors. The CHWB has regretted the top-down imposition and standardization of a performance appraisal approach. On the other hand, it has praised the comprehensive approach taken to measuring performance in Quebec. This diversity was seen as enriching the discussion and providing a source of creativity and innovation, as models were adapted and adjusted to the missions of each facility. This vision had direct links to CHWB's institutional experience, as its survival strategy was largely based on its ability to innovate and stay ahead of other, larger institutions (such as the DOH), which, for structural reasons, were slower to break new ground. The CHWB was more productive with limited human and financial means, and it intended to defend this agility.

Stresses and strains in performance appraisal

The legitimation of the DOH's emerging governance has generated tensions, both internally between different branches of the department, which presented a fragmented vision

of performance appraisal, and externally against a strong coalition of external institutional actors, which were defending a shared homogeneous vision of performance.

First, there was an inherent paradox between the rhetoric of the DOH's performance branch, which spoke to external institutional actors about a need for consistency (in fact, about the need to rally around its own vision) and the department's structure, which divided the work among different branches. Structurally, there were three divisions working independently of each other involved in performance appraisal: performance, quality and finance, each of which was developing its own set of performance indicators. Two key thrusts of the DOH's policy were the need to achieve balanced budgets in healthcare facilities and manage waiting lists for access to care, mainly in surgery and cancer treatment. These key dimensions of performance were still the responsibility of the finance division, which closely monitored budget adherence and signed performance contracts with healthcare facilities to ensure that service levels would reduce waiting lists. The quality and performance divisions were smaller and were created more recently. The quality division was concerned with quality of care and patient safety, a broader definition of performance that was also manifest in other Canadian jurisdictions (e.g., Ontario: Kromm et al. 2014). The performance division was trying to define an area of performance, while, internally, the finance division already exercised considerable power through its control of budgets. The DOH was, therefore, notable for its fragmented approach to performance appraisal, which lacked a coherent vision that could formalize and organize it, while, externally, powerful institutional actors had already adopted a homogeneous approach by using the same comprehensive and integrated model of performance assessment.

So there were two opposing visions of performance: external institutional actors notable for a comprehensive approach to performance, which was seen as an integrated phenomenon in which several types of indicators interact with each other, and the DOH, which operated under a fragmented vision of performance, parsimoniously developing limited sets of indicators for various sectors (e.g., balanced budgets, performance contracts, several waiting times, etc.).

This fragmented approach to performance appraisal had a corollary in the problems experienced by healthcare organizations trying to operate under a consistent concept of performance. In the healthcare organizations, considerable effort was being made to find an optimal balance between the different sets of DOH indicators and the model – the performance model (Marchal et al. 2014; Minvielle et al. 2008; Sicotte et al. 1998) – that was supported by the main institutional actors, which had high visibility in performance appraisal (CHWB, QAHO, a regional agency). Once these various frameworks were superimposed, it was very difficult to create a coherent whole.

Performance appraisal in search of a scientific foundation

When the DOH entered the field of performance assessment, it took several courses of action. It refused to endorse the dominant model promoted by external institutional actors and began building its own indicators. This took more time than necessary because existing work was ignored. Simultaneously, there were attempts to take exclusive control of the data used to calculate indicators, i.e., the critical resources needed by external actors.

The DOH's positioning was based on the idea of a system "inundated with indicators," so it was attempting, in a sense, to step in and curb their uncontrolled proliferation. This was the recurring theme of "indicator chaos" that was so readily brandished both quantitatively (too many indicators) and qualitatively (different measures for the same indicator). The DOH's interpretation was that this plethora of indicators was incompatible with management requirements, and there was a need to take back control and install order. The DOH employed a two-pronged strategy. It was trying to distinguish its action from that of other institutional actors while, at the same time, saying that it wanted to encourage more consistent performance appraisal. This strategy involved the selection of a different model from the one adopted by the three major institutional actors. The DOH model was unilaterally created from internal resources and its own experts. This contrasted with the approach taken by external actors, who collaborated with one another and drew on the expertise of academic researchers to develop and operationalize their performance indicators. The DOH argued that while the existing performance models can be used to make comparisons, its approach was suitable for *managing* performance. But this argument was contradicted by the experiences of two important institutional actors who had specifically framed their approach as a path to improve performance (AQESSS 2013; Roy 2008) (Box 2).

BOX 2. The Montérégie regional agency and what was learned

This regional agency was highly innovative, taking inspiration from all the latest currents of thought in performance management. The Montérégie regional agency carried out sustained work on comprehensive and integrated analysis of performance under the EGIPSS model (in partnership with the Université de Montréal), testing various methodological approaches for measuring clinical continuums, sharing performance results and comparing facilities (AQESSS 2013; Roy 2008). The strategic focus was on counterbalancing an approach based on control of performance that was limited to the financial dimension. The performance assessment was legitimized with particular concern for maximizing the odds that it would be approved and accepted. It was, therefore, developed with a focus on "self-assessment," giving the healthcare organizations control over which aspects of their activities should provide the basis for assessment based on their own questions about their performance level, and then converting them into a series of indicators selected from a bank of indicators in the EGIPSS model. Beginning in 2004, the agency developed a structure for supporting the region's healthcare organizations in the performance improvement process, creating a separate performance improvement branch (in other regions, performance was often associated with or even confused with management agreements ["performance contracts"]). Having achieved this, the agency was able to adopt an approach focused on continuous performance improvement rather than simply on accountability. These experiments highlighted an aspect of the performance appraisal approach regarding the conditions for achieving its expected virtues: they encouraged the sharing of good practices in the system and, as priority had been given to collaboration and joint reflection, brought actors together who had previously not known each other. This galvanization of the regional system therefore operationalized the concept that had led to the creation of those healthcare organizations in 2005. It proved to be a positive approach, whose efficiency was based in part on how these new public policy instruments (assessment models, indicators) gave value to learning effects and broke down silo mechanisms as soon as one became aware of them in an "open coordination" method (Kerber and Eckardt 2007).

The performance reports were conceived as a tool for emulating, disseminating and transferring good practices to healthcare organizations, but, above all, as a management tool rather than an accountability instrument. This rationale was in line with the idea of sharing lessons learned in different organizations, with some organizations serving as true laboratories for experiments. The Montérégie agency's strategy reveals a tension that arises where accountability and continuous improvement meet. These two paradigms for action were not part of the same approach, neither in the healthcare organizations nor even in public actions taken by the DOH. The modes for appropriating performance assessment and management were, in effect, based on the specific structural dimensions of each organization: the existence of a quality manager (in which case the approach was more easily accepted) and performance management through the finance branch (in which case, there was more reluctance to accept external control). Similarly, based on various factors such as the economic environment, the configuration of actors or the vision advocated by stakeholders, one paradigm took precedence over the other, producing a variation. But such variations were not neutral to external institutional actors: continuous improvement (through a comprehensive vision of population health) was generally perceived as a more inspiring model, while accountability was perceived as prone to produce more bureaucratic and coercive shifts. This oscillation between the two in the deployment of an appraisal approach was the source of ambivalence. Rather than being a linear process, moving assuredly through the development of instruments and methodologies, it was rather fragile, with a constant risk of encountering pitfalls. This fragility was apparent in the rhetoric of certain actors who had long been involved in the process, often saw future changes and feared getting bogged down or, worse, losing ground.

Objectifying the inter-relationships between the various institutional actors allows us to see how they were characterized by several political power plays, owing to the power struggles around performance instruments. Bringing together these power plays helps clarify the rhetoric, positioning and rivalries among the various institutional actors. Table 1 organized these power plays into four major types converging around the same implicit issue of the need to attain greater legitimacy in order to impose an authoritative frame of reference. This issue was particularly important to the DOH's new performance division, which was having difficulty carving out a place for itself and creating legitimacy in the performance field, where it competed with actors that had very well-established relations with healthcare organizations (the CHWB, through its legal mandate; the QAHO, as a lobbyist of healthcare organizations; and a regional agency, with its excellent reputation for innovation).

TABLE 1. Power plays in performance measurement

Type of power play	Concrete examples
Choice of a performance measurement model	The fight over the selection of a legitimate performance measurement model. The DOH developed its own in-house system, while several institutional actors were already using the same performance measurement model. The main institutional actors selected the same model, developed out of research conducted by academics and published in scientific journals.
Selection of a series of indicators for performance appraisal	Tensions around the perimeter of the indicators.* Issues around expanding the financial indicators. Political use of the "chaos of indicators" slogan. The DOH's parsimony in contrast with the more comprehensive lists of indicators selected by the external institutional actors.
Metrological construction of indicators§	Rhetoric around the "complexity defining and measuring indicators." Arguments over the "quality of the existing data" as a tactic to delay the current approach (the department's timing). Exclusive use of the DOH's internal experts to the detriment of external experts (academic research).
Access to the data and the various information systems needed to calculate performance indicators	Issue of controlling and sharing the source databases. Project by the DOH to exclusively control the databases needed to calculate the indicators. Many battles and rivalries around combining all the databases to analyze care paths. Potential discovery of perverse effects of management agreements.

*It should be noted that the institutional actors – external to the DOH – agreed on the quality and rigour of their respective approaches to performance. In addition, many of them met to share their expertise, often drawing inspiration from each other for more standardized performance appraisal. This collaboration went as far as sharing services (e.g., the Montérégie agency produced the QAHO indicators).

§Examples of methodological choices and indicator selection may be consulted online, including the CHWB ("Document méthodologique de l'analyse globale et intégrée de la performance," 2014, <http://www.csbe.gouv.qc.ca/publications.html>) and the QAHO ("Performance en ligne. Formation sur le rapport méthodologique du rapport performance," 2013, <www.aquesss.qc.ca>).

Conclusion

In both theoretical and political terms, the selection of which definitions and models will be used as a basis for public action to assess performance is important. They situate actors as "political entrepreneurs" (Baumgartner and Jones 2009) who, cognitively, play a role in framing or reframing governance.

Hence, the existence of inter-institutional power games aimed at imposing legitimate definitions and models that can be authoritative for public action. In the specific case of performance appraisal, we have shown that they were due to a conflict-laden implementation dynamic, in the sense that the DOH initiative was fragmented and multi-faceted,

with highly contrasting timelines for change (Hill and Hupe 2009). Various institutional actors in the network have undergone "instrumental learning" (May 1992) in their use of models and indicators, with independent capacities for appropriation. This has allowed them to propose an alternative path to the DOH's attempt to reformulate policy design.

Similarly, the analysis of performance could lead to a reframing of the issues and problems at the core of health system governance, as it helps reveal and objectivize certain mechanisms. It is from this perspective that we can best understand the DOH's position over the last few years – one that was prudent but also characterized by a wait-and-see attitude – in the sense that the performance appraisal process may lead to the emergence of issues beyond its control. This is demonstrated by the openly multidimensional nature of the performance models used by external institutional actors, which introduced indicators of available resources. It may reveal cases of "non-performance" due to limited budget resources that could raise doubts about the department's role in resource allocation (for example, by determining that a healthcare organization was efficient but that it nevertheless was in deficit due to a shortage of funds). Hence, the DOH's strategy – which is well illustrated at the structural level where responsibilities were split into three divisions – appeared to eliminate the dimension of the budget granted to the facility (balanced budgets) from performance. In public policy, it reveals the problems encountered trying to reconcile the stated intention of good public management practices, including performance appraisal, with highly pragmatic imperatives such as balanced budgets and restoring the health of public finances.

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References

AQESSS. 2013. *Le réseau en 4 questions, un regard cible sur la performance*. Québec : Association québécoise de la santé et des services sociaux.

ARSSSM. 2013. *Info Performance*. № 1, Direction de la performance et des connaissances, Agence de la santé et des services sociaux de la Montérégie, Québec.

Baudot, P.Y. 2014. "Le temps des instruments. Pour une sociohistoire des instruments d'action publique." In Halpern C.P., P. Lascoumes and Le Galès, eds., *L'instrumentation de l'action publique* (pp. 193–225), Paris: Sciences Po Les Presses.

Baumgartner, F. and B. Jones. 2009. *Agendas and Instability in American Politics*. Chicago, IL: University of Chicago Press.

Belorgey, N. 2012. "De l'hôpital à l'Etat : le regard ethnographique au chevet de l'action publique." *Gouvernement et action publique* 2(avril–juin): 11–40.

Bertaux, D. 1997. *Les récits de vie*. Paris: Nathan.

Castonguay, C., J. Marcotte and M. Venne. 2008. *En Avoir Pour Notre Argent – Rapport du Groupe de Travail sur le Financement du Systeme de Santé*. Québec, PQ: Gouvernement du Québec.

Deber, R.B. 2014. "Thinking about Accountability." *Healthcare Policy* 10 (SP): 12–24. doi:10.12927/hcpol.2014.23932.

Dupuis, A. and L. Farinas. 2010. "La gouvernance des systèmes multi-organisationnels. L'exemple des services sanitaires et sociaux du Québec." *Revue française d'administration publique* 135(3): 549–65.

Friedberg, E. 1997. "L'entretien dans l'approche organisationnelle de l'action collective : le cas des universités et des politiques culturelles municipales." In Cohen S. eds., *L'art d'interviewer des dirigeants* (pp. 85–106). Paris: PUF.

Haas, P. 1992. "Introduction: Epistemic Issue on Epistemic Communities." *International Organization* 46(1): 1–35.

Hill, M. and P. Hupe. 2009. *Implementing Public Policy*. Thousand Oaks: Sage.

Hood, C. 1986. *The Tools of Government*. Chatham: Chatham House.

Kerber, W. and M. Eckardt. 2007. "Policy Learning in Europe: The Open Method of Co-Ordination and Laboratory Federalism." *Journal of European Policy* 14(2): 227–47.

Kromm, S.K., G.R. Baker, W.P. Wodchis and R.B. Deber. 2014. "Acute Care Hospital's Accountability to Provincial Funders." *Healthcare Policy* 10(SP) 25–35. doi:10.12927/hcpol.2014.23852.

Kruk, M.E. and L.P. Freedman. 2008. "Assessing Health System Performance in Developing Countries: A Review of the Literature." *Health Policy* 85(3): 263–76.

Marchal, B., T. Hoerée, V. Campos da Silveira, S. Van Belle, N.S. Prashanth and G. Kegels. 2014. "Building on the EGIPPS Performance Assessment: The Multipolar Framework as a Heuristic to Tackle the Complexity of Performance of Public Service Oriented Health Care Organisations." *BMC Public Health* 14(1): 378.

May, J.P. 1992. "Policy Learning and Failure." *Journal of Public Policy* 12(4): 331–54.

Minvielle, É., C. Sicotte, F. Champagne, A.P. Contandriopoulos, M. Jeantet, N. Préaubert et al. 2008. "Hospital Performance: Competing or Shared Values?" *Health Policy* 87(1): 8–19.

MSSS. 2012. P*lan d'action ministériel 2012–2015 en matière d'évaluation de la performance du système de santé et de services sociaux à des fins de gestion*. Ministère de la santé et des services sociaux, Gouvernement du Québec.

Pinson, G. 2007. "Peut-on vraiment se passer de l'entretien en sociologie de l'action publique?" *Revue française de science politique* 57(5): 555–97.

Roy, D.A. 2008. *Gouvernance et performance en Montérégie*. Agence de la santé et des services sociaux de la Montérégie. Direction de la gestion de l'information et des connaissances. Longueuil.

Sabatier, P. 1986. "Top-Down and Bottom-Up Approaches to Implementation Research: A Critical Analysis and Suggested Synthesis." *Journal of Public Policy* 6(1): 21–48.

Sabatier, P. and H. Jenkins-Smith. 1999. "The Advocacy Coalition Framework, an Assessment." In P. Sabatier ed., *Theories of the Policy Process* (pp. 117–66). Boulder (Co): Westview Press.

Sicotte, C., F. Champagne, A.P. Contandriopoulos, F. Béland, J.L. Denis, H. Bilodeau et al. 1998. "A Conceptual Framework for the Analysis of Health Care Organizations' Performance." *Health Services Management Research* 11(1): 24–48.

VGQ. 2011. *Rapport du Vérificateur Général du Québec à l'Assemblée Nationale pour l'année 2010–2011*, Tome II, Chapitre 7, Gouvernement du Québec.

RESEARCH PAPER

Some Numbers behind Canada's Decision to Adopt an Orphan Drug Policy: US Orphan Drug Approvals in Canada, 1997–2012

Quelques chiffres derrière la décision du Canada d'adopter une politique sur les médicaments orphelins : approbations pour les médicaments orphelins des États-Unis, 1997–2012

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Abstract

We examined whether access to US-approved orphan drugs in Canada has changed between 1997 (when Canada chose not to adopt an orphan drug policy) and 2012 (when Canada reversed its policy decision). Specifically, we looked at two dimensions of access to US-approved orphan drugs in Canada: (1) *regulatory* access; and (2) *temporal* access. Whereas only 63% of US-approved orphan drugs were granted regulatory approval in 1997, we found that regulatory access to US-approved orphan drugs in Canada increased to 74% between 1997 and 2012. However, temporal access to orphan drugs is slower in Canada: in a head-on comparison of 40 matched drugs, only two were submitted and four were approved first in Canada; moreover, the mean review time in Canada (423 days) was longer than that in the US (mean = 341 days), a statistically significant difference ($t[39] = 2.04$, $p = 0.048$). These results raise questions about what motivated Canada's apparent shift in orphan drug policy.

Résumé

Nous avons examiné dans quelle mesure l'accès aux médicaments orphelins des États-Unis s'est transformé, au Canada, entre 1997 (alors que le Canada décidait de ne pas adopter une politique sur les médicaments orphelins) et 2012 (tandis que le Canada décidait de renverser sa décision sur la politique). Plus précisément, nous avons examiné deux aspects de l'accès aux médicaments orphelins des États-Unis approuvés au Canada : (1) l'accès *réglementaire* et (2) l'accès *temporel*. Bien que seulement 63 % des médicaments orphelins des États-Unis approuvés avaient reçu l'approbation pour un accès réglementaire en 1997, nous avons observé que l'accès réglementaire aux médicaments orphelins des États-Unis au Canada a augmenté de 74 % entre 1997 et 2012. Cependant, l'accès temporel aux médicaments orphelins est plus lent au Canada : une comparaison de 40 médicaments appariés a permis d'observer que seulement deux médicaments ont été soumis et quatre ont reçu l'approbation au Canada en premier; de plus, le temps moyen de l'évaluation au Canada (423 jours) était plus long que celui aux États-Unis (moyenne = 341 jours), une différence statistiquement significative ($t[39] = 2.04$, $p = 0.048$). Ces résultats soulèvent des questions sur ce qui a motivé ce changement apparent de politique sur les médicaments orphelins au Canada.

Introduction

The term "orphan drug" is generally used to refer to pharmaceutical interventions that target one or more rare diseases. The threshold of rarity varies by jurisdiction; more recent orphan drug policies have utilized incidence-based definitions of rare disease (e.g., disease occurring in five or fewer persons per 10,000) (Herder 2013; Panju and Bell 2010). The term orphan drug can also encompass drugs targeting more prevalent diseases for which research and development (R&D) is considered commercially unviable, for instance, because a disease disproportionately affects an impoverished population. But since the US first enacted its *Orphan Drug Act* in 1983 and other jurisdictions followed suit, very few orphan drugs targeting such "neglected diseases" have been developed. In contrast, hundreds of orphan drugs geared towards rare diseases have been approved for sale (Herder 2013).

In 1997, Canada's drug regulator determined that there was no need for an orphan drug policy. In 2012, Canada's Minister of Health reversed that decision, announcing plans to develop an "orphan drug framework" (Health Canada 2012a). What precisely lies behind this policy shift is not known, but several factors are likely in play. First, the pharmaceutical industry's interest in developing drugs for rare diseases is clearly greater now than it was in the late 1990s; such orphan drugs account for an increasing proportion of all drugs approved by the US Food and Drug Administration (FDA) (Coté et al. 2010; Wellman-Labadie and Zhou 2010). Second, the Canadian Organization for Rare Disorders (CORD) came to increasing prominence in the early 2000s, urging federal policy reform (Embrett 2014). Third, Health Canada has an interest in harmonizing its regulatory policies with other influential jurisdictions owing to expectations from industry as well as pressure from its main trading partners in the US and Europe (Lexchin 2012a). What is not known is whether access to US-approved orphan drugs in Canada, measured in terms of the number and timing of regulatory approvals, changed between 1997 and 2012 when Canada changed policy directions.

Policy context

The *US Orphan Drug Act* of 1983 created a specialized regulatory pathway for therapeutic drugs targeting diseases that occur in 200,000 or fewer persons in the US, and established a variety of market-based incentives (e.g., tax credits, seven-year market exclusivity upon regulatory approval) to encourage orphan drug R&D. Several other jurisdictions have followed suit, including Japan (1993), Australia (1997) and Europe (2000). The precise details differ across jurisdictions. But the US-led, two-part model of a specialized regulatory pathway plus market-based incentives has been consistently emulated on the strength of the assumption that such a model will spur orphan drug R&D (Herder 2013).

In 1996–1997, Health Canada's Food and Drugs Directorate assessed whether an orphan drug policy was needed in Canada (Health Canada 1997). The Directorate examined whether the orphan drugs that had been approved by the US regulator (the FDA) since the adoption of the *Orphan Drug Act* in 1983, had also been approved for sale in Canada (albeit without a formal orphan drug designation). The Directorate determined that a clear majority of the US-approved orphan drugs were also available in Canada. In total, 63% of all of the orphan drugs approved between 1983 and 1997 in the US had also been approved in Canada. And, of the remaining US-approved orphan drugs that had not yet received Canadian approval, most were available through the "Emergency Drug Release Program" – a program that was shortly thereafter replaced by the "Special Access Program" (which still exists today). Those programs allow physicians to apply, on a case-by-case basis, for access to unapproved drugs in order to address the needs of patients who have exhausted available treatment options (Health Canada 1997).

Although the drugs approved in Canada did not always "correspond with the indication for which the drug received its Orphan Drug designation in the US," (Health Canada 1996: 17–18), the Directorate noted that medical "practitioners involved in the treatment of patients with rare diseases are aware of research in their area of expertise" and thus are able to prescribe drugs approved for use in Canada for unapproved orphan indications (Health Canada 1996: 18). In this regard, off-label prescribing is reported as widely used by Canadian medical practitioners in treating rare diseases (SSCSAST et al. 2014).

Finally, the Directorate argued that its priority review program and (then proposed) conditional licensing program (later implemented in 1998) provided two mechanisms "for faster access to drugs, including [o]rphan [d]rugs, which treat life threatening conditions for which no other therapy exists" (1996: 18). Given the availability of US-approved orphan drugs in Canada and these existing mechanisms to spur orphan drug R&D, the Directorate recommended:

> That there be no change to the *Food and Drugs Act* or its Regulations to accommodate an Orphan Drug policy. Canadians already have access to drugs which have received an Orphan Drug designation and marketing approval in the U.S. through the normal drug approval process [the *Emergency Drug Release Program*]/[*Special Access Program*], or potentially through the conditional [*Notice of Compliance*] initiative. (Health Canada 1996)

The Directorate's analysis apparently proved persuasive. No orphan drug policy or changes to Canadian law were made.

The 1997 decision not to follow the US policy lead was, however, met with strong criticism from rare disease patients. By 2000, the CORD (originally formed in 1996) had brought 150 small rare disease associations together under its umbrella (Embrett 2014). CORD gained increasing profile through the 2000s and advocated strongly for policy change at the federal, as well as provincial/territorial levels of government. For several years, however, federal policy makers remained silent.

Policy change

To CORD's relief (Wong-Rieger 2013: 20), in October 2012, the federal government announced plans for an orphan drug framework. A 2012 "Initial Draft Discussion Document" produced by Health Canada's Office of Legislative and Regulatory Modernization (OLRM) soon surfaced online (OLRM 2012). The Discussion Document explains that the objective of the "new" proposal" is to establish a comprehensive framework that will provide access to orphan drugs for Canadians without compromising patient safety (OLRM 2012: 4), and outlines some of the framework's potential parameters. First, the Discussion Document suggested that in order to qualify as an orphan drug, the drug must:

- [be] intended for the diagnosis, treatment, mitigation or prevention of a life-threatening, seriously debilitating, or serious and chronic disease or condition affecting not more than 5 in 10,000 persons in Canada; and
- not [be] currently authorized by the Minister or if currently authorized, it will provide a potentially substantial benefit for the patient distinguishable from the existing therapy (OLRM 2012).

Second, the Discussion Document noted that while a number of incentives would, by virtue of the above definition, be available to orphan drugs, including expedited reviews and data exclusivity for "innovative therapies," no additional market exclusivity akin to the specialized exclusivity for orphan drug indications provided in other jurisdictions would be put into place as part of Canada's orphan drug framework.

However, more than three years after the framework was announced, Health Canada has yet to share any concrete details. Health Canada has stated that it will implement the orphan drug framework by creating a new division in the Food and Drug Regulations specifically focused on orphan drugs (personal communication with MH). With the passage of Bill C-17 in November 2014 – a key piece of patient safety legislation that includes a number of provisions that could be important in the orphan drug context – those new regulations are anticipated soon.

In the meantime, in this paper, we seek to explore what motivated the policy change in favour of a Canadian orphan drug framework. Specifically, we assess whether Health Canada's stated rationale for not pursuing an orphan drug policy in 1997 still held in 2012. No mention of Health Canada's 1997 policy analysis or countervailing data was included in the 2012 announcement; our research here is intended to fill in this gap.

Methods

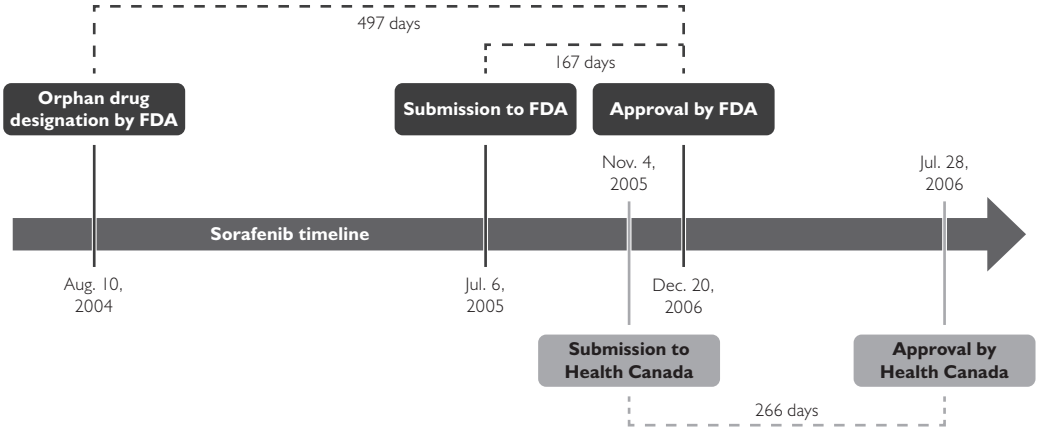
We carried out a retrospective comparison between orphan drugs approved by the FDA during the period 1997–2012 and market authorizations of the same drugs (although not designated as orphan drugs per se) by Health Canada.

Our retrospective comparison was based primarily on publicly available information obtained from the websites of the FDA and Health Canada. We began by searching the FDA website page for orphan drug designations and approvals. Limiting our search to 1997–2012 and setting the search results to "Only approved products", we retrieved the records of all US orphan drug approvals along with key information related to each drug, including orphan drug designation date, approval date, orphan drug designation(s), generic drug name and drug trade-name. Many orphan drugs were approved for multiple orphan drug indications during the time frame under investigation.

A research assistant (a professional pharmacist) then went to the "Health Canada Drug Products Notice of Compliance (NOC) Online Query" website and searched for each unique US-approved orphan drug (using the FDA-generated generic name as the search term for "Medicinal Ingredient") in the Health Canada NOC database. If a drug with the same generic name had been approved by Health Canada, the NOC database yielded similar information as the FDA website, including the drug's trade name and Canadian market authorization date. For a subset of drugs approved in Canada and identified through the NOC database, Health Canada's website also provided a hyperlinked "Summary Basis of Decision" (SBD) containing further information about the drug in question. Most importantly, the SBD provided the date upon which the drug's manufacturer formally submitted its drug for review and potential market approval from Health Canada. This enabled us to calculate review times for each drug approved in this subset of drugs.

We repeated this process of searching Health Canada's NOC database for each orphan drug approved by the FDA during 1997–2012. We used the assembled data to develop two points of comparison: (1) regulatory access, i.e., whether the US-approved orphan drugs were granted regulatory approval in Canada and, if so, whether that Canadian approval was for the same orphan indications; and (2) temporal access, i.e., when US-approved orphan drugs also available in Canada were granted regulatory approval by Health Canada, and the length of the time frame in which the Canadian regulatory reviews occurred as compared to the duration of the US review for a subset of 40 drugs with matched orphan indications. The size of this head-on comparison was limited to 40 because Health Canada only creates SBDs for a subset of its regulatory decisions (Health Canada 2012b). In our case, only 33 had an accompanying SBD that made the Canadian submission date publicly available on the Health Canada website. In an effort to expand our head-on comparison, we contacted two researchers who had recently published a study of drug approval times (Shajarizadeh and Hollis 2014). Those researchers obtained submission data by directly contacting Health Canada (and other drug regulators). The researchers shared their submission data with us; however, because their study was not focused specifically on orphan drugs, we were only able to identify seven additional orphan drugs with matched US–Canada indications that we did not already have submission date data for. Figure 1 uses one drug (sorafenib) to illustrate the various dates (i.e., orphan drug designation, date of submission and approval) that we collected for each drug in our sample.

FIGURE 1. Orphan drug designation, submission and approval: the example of sorafenib

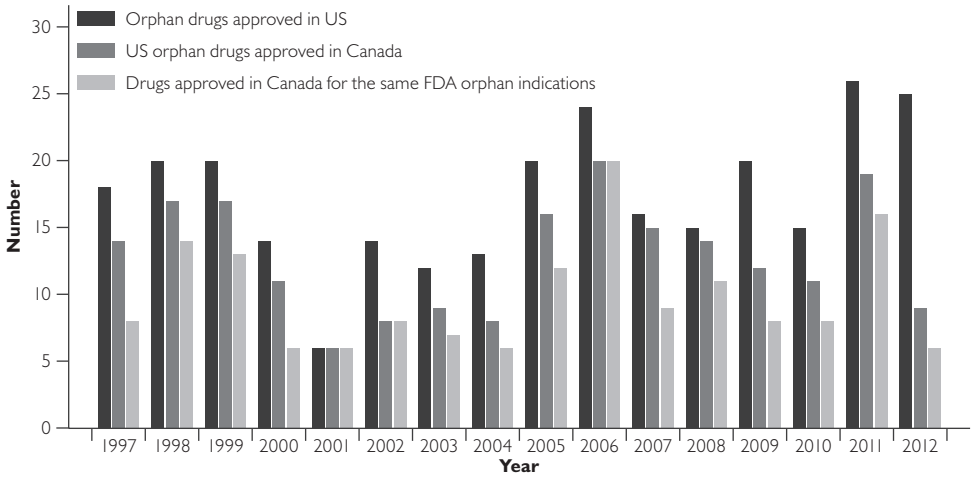


Results

Regulatory access

Of the 278 orphan drugs approved by the FDA during 1997–2012, 206 (or 74%) received at least one market authorization in Canada (see Figure 2 for a year-by-year comparison of approvals). The majority of those drugs (150 of 206, or 73%) were approved for the same indication as the corresponding US orphan drug.

FIGURE 2. Comparing dimensions of regulatory access



Temporal Access

We performed a head-on comparison of total days in review before full approval was granted for US-approved orphan drugs versus those same drugs as approved between 1997 and 2012 by Health Canada for the same indications. Consistent with the findings of Shajarizadeh and Hollis (2014), only two drugs in our head-on comparison were submitted to Health Canada prior to being submitted to the FDA. Similarly, only four out of those 40 drugs

received Canadian regulatory approval before US approval. Thus, delays in access to orphan drugs in Canada were, in part, due to when manufacturers submitted the relevant drugs for regulatory review to Health Canada as compared to when they submitted to the FDA.

Temporal access also depends on the length of regulatory reviews. As shown by Table 1, Health Canada's review times (i.e., the number of days between submission and approval) are almost always longer than the FDA's for the sample of 40 drugs that we were able to examine. The mean review time for the FDA was 341 days (standard deviation [SD] = 259) versus a mean of 423 days (SD = 219) for Health Canada, representing a 19% faster review rate in the US. This difference of, on average, 82 days between the review times in the two jurisdictions is statistically significant ($t[39] = 2.04$, $p = 0.048$), although only at the $p < 0.05$ level. (The seven drugs for which SBDs were not available did not have a statistically different mean review time than the 33 remaining drugs.)

TABLE 1. Comparing dimensions of temporal access. Entries appear in descending order (from oldest to most recent) according to US market approval dates

Generic name US	Trade name US	Number of days from designation to approval, US	Number of days from submission to approval, US	Number of days from submission to approval, Canada	Submission in Canada first?	Approval in Canada first?
Temozolomide	Temodar	364	458*	571	Yes	Yes
Nitric oxide	Inomax	920	2,375	814	No	No
Imatinib	Gleevec	72	Designated after approval	202	No	Yes
Bosentan	Tracleer	368	528	248	No	No
Oxybate	Xyrem	887	2,928	605	No	No
Pegvisomant	Somavert	823	1,735	1,005	No	No
Laronidase	Aldurazyme	278	2,044	530	No	No
Miglustat	Zavesca	832	1,889	217	No	No
Pemetrexed disodium	Alimta	128	890	197	No	No
Cinacalcet	Sensipar	185	94	269	No	No
Azacitidine	Vidaza	145	1,164	211	No	No
Clofarabine	Clolar	274	910	434	No	No
Nelarabine	Arranon	182	385	724	No	No
Deferasirox	Exjade	187	1,077	481	No	No
Sorafenib	Nexavar	167	497	266	No	No
Lenalidomide	Revlimid	264	698	339	No	No
Recombinant human acid alpha-glucosidase	1. Myozyme 2. Lumizyme	275	3,174	228	No	No

Some Numbers behind Canada's Decision to Adopt an Orphan Drug Policy: US Orphan Drug Approvals in Canada, 1997–2012

Generic name US	Trade name US	Number of days from designation to approval, US	Number of days from submission to approval, US	Number of days from submission to approval, Canada	Submission in Canada first?	Approval in Canada first?
Idursulfase	Elaprase	243	1,699	211	No	No
Vorinostat	Zolinza	184	934	349	No	No
Eculizumab	Soliris	182	1,304	215	No	No
Temsirolimus	Torisel	237	895	396	No	No
Ambrisentan	Letairis	184	1,065	352	No	No
Lanreotide	Somatuline Depot	307	2,485	419	Yes	Yes
Nilotinib	Tasigna	395	550	644	No	No
Sapropterin	Kuvan	202	1,414	274	No	No
Romiplostim	Nplate	304	1,975	461	No	No
Rufinamide	Banzel	1,093	1,557	351	No	No
Eltrombopag	Promacta	338	199	765	No	No
Plerixafor	Mozobil	182	1,896	352	No	No
Ofatumumab	Arzerra	269	23	413	No	No
Aztreonam	Cayston	829	2,626	535	No	Yes
Velaglucerase-alfa	Vpriv	179	204	345	No	No
Ipilimumab	Yervoy	273	2,575	476	No	No
Vemurafenib	Zelboraf	112	240	212	No	No
Crizotinib	Xalkori	149	347	322	No	No
Ruxolitinib phosphate	Jakafi	166	1,286	203	No	No
Ivacaftor	Kalydeco	105	1,862	210	No	No

*The path to regulatory approval is subject to vary. In most cases, drugs are designated as orphan drugs long before a formal submission for regulatory review is made. However, in other cases, the drug will have been submitted for one indication (a non-orphan disease), but then the indication will be changed to that of a rare disease, or such an indication will be added. In this way, a drug may receive an orphan designation after submission.

It is important to note that the time lag between when a drug is designated by the FDA as an orphan drug and the date of market approval is substantially longer (mean = 1,285 days; SD=881) than the average review time in the US of 341 days. Manufacturers often sponsor further studies of a drug after receiving an orphan drug designation before the evidence is submitted to the regulator. As a result, orphan drugs are typically in the US system (i.e., from the time of designation as an orphan drug through to market approval) approximately three times as long as the period of review, from submission to approval, in Canada. It stands to reason that if Canada were to follow the US model and adopt a regulatory pathway, specifically for drugs targeting rare diseases as orphan

drugs, this might serve to expedite the review process from submission to approval in Canada. However, this would often occur only after a considerable period of back and forth between the regulator and manufacturer over the orphan drug designation and the evidence required for submission on the front end of that review.

Discussion

Interpretation of key findings

By Health Canada's estimate, 63% of orphan drugs approved in the US by 1997 were available in Canada at that time; in contrast, our findings demonstrate that this percentage of *regulatory* access grew to 74% during 1997–2012. Although a sizeable number of these approvals (56 of 206) were not for the same orphan indication approved by the FDA, as in 1997, Canadian medical practitioners still have the ability to prescribe such drugs off-label to treat the rare diseases in question, at least in instances where the drug's dosage could be adjusted without unduly compromising patient safety or prescription adherence. This finding suggests that the rationale the government invoked to decide against enacting an orphan drug policy in 1997 still held when it reversed its position in 2012.

It is plausible that the timing of drug approvals lies behind the federal government's decision in 2012 to develop an orphan drug policy. Indeed, nearly all of the drugs we examined entered the Canadian market after the US market. Thus, there is likely pressure to harmonize Canada's regulatory framework with that of other major jurisdictions, most notably the US and Europe. Health Canada officials stated at a CORD meeting held in late 2013 that, once Canada's orphan drug regulations are in place, manufacturers will be able to electronically submit essentially the same package for review as that which is submitted to the FDA. In theory, this will position Health Canada to review the file in lock-step with the FDA, and make a decision about market approval within roughly the same time frame. Therefore, the goal of making it simpler for companies to file a submission to Health Canada creates an incentive to mirror the US orphan drug policy.

However, our findings complicate this rationale. We found a significant difference not just for when drugs were approved in the US versus Canada, but also in terms of how long reviews took in the US versus Canada. In our sub-sample of 40 US-approved orphan drugs that were approved for the same indication in Canada and for which the submission date data were available, review-for-approval times were 19% faster in the US than in Canada. This suggests that achieving comparable temporal access to orphan drugs may be more complex than facilitating submission of a drug file to Health Canada contemporaneously with submission to the FDA. Health Canada does not have the same resources at its disposal as the FDA. Unless Health Canada intends to simply rubber stamp FDA approvals, there is no guarantee that decisions will be made simultaneously.

Moreover, aiming to synchronize orphan drug approvals with the FDA discounts the potential advantages of delayed market entry in terms of patient safety. We suspect that the longer average review times we observed for the 40 drugs in our comparative sub-sample were due not only to differences in terms of its available institutional resources, but also to the fact that more safety and effectiveness data flowing from use of the drug in the US would have been part of the package

submitted to Health Canada. Within our sample, it should be noted that Health Canada issued a number of notices of non-compliance and deficiency notices owing to a variety of quality, safety and efficacy issues. More specifically, for the 33 drugs with SBDs available, Health Canada issued:

1. seven screening deficiency notices;
2. six notices of non-compliance, including concerns related to quality, safety and efficacy and adequate communication of risks; and
3. two notices of deficiency, citing safety issues.

It is plausible that these issues noted in the SBDs explain the longer review times we observed with Health Canada.

While rare disease patients desire timely access to orphan drugs, knowledge about the safety and effectiveness of such drugs tends to be limited at the time of market approval. Owing to the small number of patients afflicted with a given rare disease, "alternative trial designs" (e.g., lacking randomization and blinding) are frequently employed in pre-market studies, which "can lead to identifying benefits that are not real or missing risks that are" (Kesselheim and Avorn 2011: 1546). In addition, drugs that address unmet patient needs, which orphan drugs should target almost by definition, are usually fast-tracked through review by regulators. Yet fast-tracked drugs have been shown to have a significantly higher incidence of post-market safety warnings than regularly reviewed drugs (Graham and Nuttall 2013; Lexchin 2012b). Accordingly, attempting to parallel FDA decision-making in real time may cut out from the review process access to added safety and effectiveness information that Canadian rare disease patients might otherwise benefit from.

Limitations

There are three main limitations to our study. First, a significant percentage of orphan drug access in Canada depends on physicians' ability to prescribe off-label. Little information about the extent of such off-label prescribing is currently available in Canada; more knowledge about off-label prescribing is needed to understand the level of access to rare disease therapies. Second, our comparison of temporal access to orphan drugs was limited to a relatively small number of drugs (n = 40) for the reasons stated above. Third, Health Canada's assessments referenced by the federal government's policy decision against adopting an orphan drug policy in 1997 did not include information about comparative timely access to US-approved orphan drugs between the two jurisdictions up until that point of time. Thus our analysis of this dimension is limited to inter-regulatory comparisons for the time period of 1997–2012 and does not include intra-regulatory comparisons between Health Canada's average review times of US-approved orphan drugs *up to* 1997 versus *after* 1997 up to 2012.

Conclusion

We have attempted to measure access to US-approved orphan drugs in Canada in terms of the number and timing of regulatory approvals by Health Canada for the period of

1997–2012. On the one hand, regulatory access seems to have moderately improved since 1997. On the other hand, temporal access remains a challenge in Canada. In a subset of drugs approved for the same orphan indication(s) in both jurisdictions, most of these drugs received regulatory approval in the US before Canada, and review times were, on average, longer in Canada. This could be a contributing factor to Canada's shift towards an orphan drug policy in 2012.

However, we suspect that other factors, including a desire to harmonize regulatory pathways with US and European regulators (which have orphan drug laws in place), industry's steadily increasing interest in developing orphan drugs, and the influence of patient groups such as CORD, were more salient in Canada's policy shift in the orphan drug arena. Even though relevant regulatory access may have improved since 1997, stakeholder expectations for what counts as an acceptable threshold for access has changed and/or stakeholders have become more effective in having this recognized by government. A recent paper underscores the influential role that CORD played in Canada's policy-making process (Embrett 2014). These factors were beyond the scope of our study, but we believe that CORD's role, influence and practices merit further study, particularly as Health Canada starts to integrate patients directly into its regulatory review process – a move currently being piloted with two rare disease treatments undergoing review (Health Canada 2014). While policy making is never just an evidence-based exercise, it is troubling that there is no indication that evidence, whether an updated picture of the number and timing of US-approved orphan drugs granted regulatory approval in Canada, or the growing body of scholarship documenting the trade-offs involved in copying the US's orphan drug policy, informed Canada's shift in policy.

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References

Coté, T.R., K. Xu and A.R. Pariser. 2010. "Accelerating Orphan Drug Development." *Nature Reviews Drug Discovery* 9(12): 901–02.

Embrett, M.G. 2014. "Examining Why the Canadian Federal Government Placed an Orphan Drug Strategy on Their Decision Agenda Now." *Health Reform Observer/Observatoire des réformes de santé* 2: 1–10.

Graham, J.E. and R.K. Nuttall. 2013. "Faster Access to New Drugs: Fault Lines between Health Canada's Regulatory Intent and Industry Innovation Practices." *Ethics in Biology, Engineering and Medicine: An International Journal* 4(3): 231–39.

Health Canada. 1996. *Orphan Drug Policy (961127.INT)*. Food and Drugs Directorate, Government of Canada.

Health Canada. 1997. *Policy Issues: Orphan Drug Policy. Correspondence*. Food and Drugs Directorate, Government of Canada. Retrieved January 16, 1997.

Health Canada. 2012a. *An Orphan Drug Framework for Canada*. Government of Canada. Retrieved 2 December, 2013. <www.hc-sc.gc.ca/ahc-asc/media/nr-cp/_2012/2012-147a-eng.php>. On file with authors.

Health Canada. 2012b. *Frequently Asked Questions: Summary Basis of Decision (SBD) Project: Phase II [Frequently Asked Questions]*. Government of Canada. Retrieved 15 April, 2016. <http://www.hc-sc.gc.ca/dhp-mps/prodpharma/sbd-smd/sbd_qa_smd_fq-eng.php>.

Health Canada. 2014. "Canada News Centre – Minister Ambrose Announces Patient Involvement Pilot for Orphan Drugs [News Releases]." Government of Canada. Retrieved 15 April, 2016. <http://news.gc.ca/web/article-en.do?nid=873619>.

Herder, M. 2013. "When Everyone Is an Orphan: Against Adopting a U.S.-Styled Orphan Drug Policy in Canada." *Accounts of Chemical Research* 20(4): 227–69.

Kesselheim, A.S. and J. Avorn. 2011. "Clinical Trials of Orphan Drugs for Cancer—Reply." *JAMA: The Journal of the American Medical Association* 306(14): 1545–46. doi:10.1001/jama.2011.1464.

Lexchin, J. 2012a. "Harmony in Drug Regulation, but Who's Calling the Tune? An Examination of Regulatory Harmonization in Health Canada." *International Journal of Health Services* 42(1): 119–36.

Lexchin, J. 2012b. "New Drugs and Safety: What Happened to New Active Substances Approved in Canada between 1995 and 2010?" *Archives of Internal Medicine* 172(21): 1680–81.

Office of Legislative and Regulatory Modernization (OLRM). 2012. *Initial Draft Discussion Document for a Canadian Orphan Drug Regulatory Framework*. Retrieved 15 April, 2016. <http://www.orpha.net/national/data/CA-EN/www/uploads/Initial-Draft-Discussion-Document-for-A-Canadian-Orphan-Drug--Regulatory-Framework.doc>.

Panju, A.H. and C.M. Bell. 2010. "Policy Alternatives for Treatments for Rare Diseases." *Canadian Medical Association Journal* 182(17): E787–92.

Shajarizadeh, A. and A. Hollis. 2014. "Delays in the Submission of New Drugs in Canada." *Canadian Medical Association Journal* 187(1): E47–51.

SSCSAST, K. Ogilvie and A. Eggleton. 2014. *Prescription Pharmaceuticals in Canada: Off-Label Use*. Standing Senate Committee on Social Affairs, Science and Technology. Retrieved 15 April, 2016. <www.parl.gc.ca/Content/SEN/Committee/412/soci/rep/rep05jan14-e.pdf>.

Wellman-Labadie, O. and Y. Zhou. 2010. "The US Orphan Drug Act: Rare Disease Research Stimulator or Commercial Opportunity?" *Health Policy* 95(2/3): 216–28.

Wong-Rieger, D. 2013. "Canada's Long Journey toward an Orphan Drug Framework." *Advocate* 20(2): 20–21.

RESEARCH PAPER

Examining Privacy Regulatory Frameworks in Canada in the Context of HIV

Examen des cadres réglementaires relatifs à la vie privée dans le contexte du VIH au Canada

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Abstract

In the process of receiving perinatal care, women living with HIV (WLWH) in Canada have experienced disclosure of their HIV status without their express consent. This disclosure often occurs by well-intentioned healthcare providers; however, from the perspective of WLWH, it is a breach of confidentiality and leaves WLWH to manage the consequences. This paper is a critical review of the regulatory and legislative infrastructure that exists to protect the personal health information of WLWH in Ontario and Canada; the recourse that WLWH have in the event that their confidentiality is breached; and potential approaches that could be applied to organize the system differently to decrease the chance of a privacy breach and to facilitate appropriate collection, use and disclosure of personal health information.

Résumé

Dans le cadre des soins périnataux, des femmes qui vivent avec le VIH (FVIH) au Canada ont vu leur état divulgué sans leur consentement. Ces divulgations sont souvent faites par des prestataires de soins de santé bien intentionnés; cependant, du point de vue des FVIH, il s'agit d'un manquement à l'obligation de confidentialité, lequel les force à en gérer les conséquences. Cet article est une revue critique des infrastructures réglementaires et législatives en vigueur pour protéger les renseignements médicaux personnels des FVIH en Ontario et au Canada; des recours auxquels elles peuvent faire appel en cas de manquement à l'obligation

de confidentialité; et des démarches éventuelles qui pourraient servir à une réorganisation du système afin de réduire le risque de manquement à l'obligation de confidentialité et faciliter la collecte, l'utilisation et la divulgation appropriées des renseignements médicaux personnels.

The evolution of HIV into a complex chronic illness has implications across many healthcare and social care contexts (Scandlyn 2000) including the health services that women living with HIV (WLWH) interface during pregnancy, at the time of childbirth and in the postpartum period. The delivery of healthcare includes the collection, use and disclosure of personal health information (PHI). For WLWH, the disclosure of their HIV status during a healthcare encounter may have particular consequences including explaining to family and friends, who they may not have planned to disclose to, what it means to live with HIV (Greene et al. 2016; Ion et al. 2016). From the perspective of WLWH, the HIV status can be disclosed in a number of ways in the course of providing care to both WLWH and their babies during the perinatal period, for example, labelling "HIV" on intravenous medication administered to WLWH during childbirth; when discussing women's HIV medications including potential allergies; while administering HIV medications to the baby including explicitly referring to "AZT" or the baby's "HIV medications;" leaving hospital records open in the woman's room for all to see, and writing "HIV" directly on the front or inside of the woman's chart; and when discussing breastfeeding avoidance and the availability of formula as an infant feeding alternative. When disclosure occurs in the presence of people who were unaware of the woman's HIV status, for example, visitors or other people present in the ward within earshot, WLWH can experience a loss of choice and self-determination (Ion et al. forthcoming). Furthermore, while some WLWH may choose to speak frankly with visitors after disclosure occurs, this is not a realistic choice for many WLWH.

Considering the myriad ways that the HIV status of WLWH can be disclosed in the course of receiving perinatal care signals a critical examination of the system of care that WLWH navigate during the perinatal period and how notions of privacy and confidentiality are conceptualized in these spaces. This paper presents a critical review of privacy policy and regulatory frameworks as it relates to the PHI of WLWH in Ontario, Canada and aims to explore the following questions: 1) What regulatory infrastructure exists to protect the PHI of WLWH in Ontario? 2) What recourse do WLWH have in the event that their confidentiality is breached, for example, their HIV status is disclosed without their express consent? 3) Are there any approaches that could be applied to organize the system differently to facilitate appropriate collection, use and disclosure of PHI?

Regulatory Frameworks and Privacy: What Legislative Infrastructure Exists in Canada?

The *Human Rights Act* of 1977 followed by the *Privacy Act* of 1982 were the first legislative acts to protect personal information across the Canadian public sector (Peekhaus 2008).

In 1987, at a time when the HIV epidemic was gaining momentum across Canada, the *Freedom of Information and Protection of Privacy Act* was the first legislation to outline "principles of conscientious and cautious handling" of PHI that institutions were responsible to adhere to (Cavoukian 1990). What followed was legislation that extended the protection of personal information in the private sector in Canada, and in 2001, the *Personal Information Protection and Electronic Documents Act* (PIPEDA) came into effect (Canadian HIV/AIDS Legal Network 2004; Peekhaus 2008). Since 1997, provinces have adopted privacy legislation that specifically applies to healthcare providers regardless of whether they are engaged in commercial activities (Peekhaus 2008), and, currently, nine provinces have specific laws that protect PHI and impose obligations on healthcare providers to protect that information (Canadian HIV/AIDS Legal Network 2014).

The *Personal Health Information Protection Act* in Ontario

The *Personal Health Information Protection Act* (PHIPA) was enacted in 2004 and governs the collection, use and disclosure of PHI within the Ontario health sector and aims to keep PHI confidential and secure while allowing for the effective delivery of healthcare and the effective operation of the healthcare system (Beardwood and Kerr 2004, 2005; Cavoukian 2008; OIPC n.d.). PHI is broadly defined under PHIPA as identifying information about an individual in oral or recorded form that could be used to identify a specific individual, for example, the physical and/or mental health of the individual (including the health history of the individual's family), the provision of healthcare to the individual, payments or eligibility for healthcare, and the individual's health number (Beardwood and Kerr 2004); HIV status is included under this definition (Canadian HIV/AIDS Legal Network 2004). Under PHIPA, persons and organizations that provide healthcare are collectively known as "health information custodians," or HICs (OIPC n.d.; Peekhaus 2008) as they "have custody or control of personal health information in connection with performing their duties or work" (Beardwood and Kerr 2004: 63). Whether individuals are HICs or agents of a HIC, their obligation to abide by PHIPA and ensure the security, confidentiality, accuracy and integrity of PHI in their custody is the same (Fletcher 2014; Peekhaus 2008). PHIPA requires that HICs take "reasonable steps" to ensure PHI is protected against theft, loss and unauthorized use or disclosure regardless of the type of records being used (Beardwood and Kerr 2005; Cavoukian and Rossos 2009).

Consent, disclosure and "circle of care" are key constructs outlined in PHIPA that have important implications on the activities and decision-making of HICs with regard to PHI. HICs may imply consent for the collection, use and disclosure of PHI for the delivery of healthcare services (Cavoukian 2008), for example, consent is implied if a patient accepts a referral and shows up for care (Fletcher 2014). With regard to disclosure, under PHIPA, PHI may only be disclosed by HICs if the individual consents or if PHIPA specifically permits the disclosure without consent (OIPC n.d.). PHIPA was "specifically designed so that it would not prevent a barrier to the disclosure of personal health information among healthcare providers" (Cavoukian and Rossos 2009: 7). As such, HICs are permitted to disclose

PHI for the purposes of providing or assisting in providing care on the basis of implied or assumed implied consent (Canadian HIV/AIDS Legal Network 2014; Cavoukian and Rossos 2009). A patient's express consent, that is verbal or written consent, is not required to share information within the "circle of care" to other healthcare providers (Canadian HIV/AIDS Legal Network 2014). At the same time, PHIPA permits disclosure of PHI without implied consent in a number of vague and unspecified circumstances including "providing healthcare" (as an individual healthcare provider or as a facility); "managing risks and error" (Beardwood and Kerr 2004); "planning and management of the health system"; and "analysis of the health system," etc. (OIPC n.d.). The assumption of implied consent is no longer true, however, when the HIC is aware that the individual wishes to withhold or withdraw their consent. Furthermore, when PHI is disclosed to a non-HIC outside of the "circle of care," or for purposes other than delivery of healthcare, express consent is required (Beardwood and Kerr 2004; Cavoukian 2008).

Implied consent and disclosure within the "circle of care" for the purposes of providing or assisting in the provision of healthcare is "arguably the most significant provision in PHIPA" yet it is "buried" in a sub-section of the legislation (Beardwood and Kerr 2004: 65). Permitting disclosure of PHI in a variety of circumstances for the broad purposes of "providing healthcare" vis-à-vis a focus on implied consent means that HICs need to "use little or no effort to comply with the requirements of PHIPA" (Beardwood and Kerr 2004: 67). Therefore, while it is essential that people who use health services trust that their privacy will be protected, at the same time, the "delivery of high quality healthcare depends on the availability of accurate and complete health information" (Cavoukian and Rossos 2009: 6). PHIPA attempts to strike a balance between protecting privacy and facilitating care delivery (Fletcher 2014).

Although identifying information in oral form falls under the category of PHI (Beardwood and Kerr 2004), it appears that sharing information verbally amongst HICs and to non-HICs is not the central focus of PHIPA nor is it explicitly mentioned in the legislation compared to other forms of information sharing practices. Instead, PHIPA focuses on health records, in particular paper and electronic records (Cavoukian and Rossos 2009). Furthermore, PHIPA does not lend itself to how information is currently exchanged in healthcare institutions with the advent of new technologies and increasing use of e-mail and digital interfaces to facilitate communication between and amongst HICs (Fletcher 2014).

Although healthcare providers may mention HIV status in the process of delivering care to the patient, it may result in disclosure of PHI to a non-HIC or someone outside of the "circle of care", for example, hospital visitors. Healthcare providers may use HIV status as a label, reminder, and/or communication tool, both for themselves and within the healthcare team, to prevent "risks and error" in the process of delivering care (Beardwood and Kerr 2004). Employing HIV in this way may help those providing care to ensure appropriate checks and balances within a woman's care plan (Gagnon 2014, 2015). Healthcare providers may also assume hospital visitors are aware of one's HIV status, especially if the patient does not explicitly discuss with them the importance of keeping it private. Regardless of whether

a patient articulates if it is safe to disclose their HIV status is not the point; when HIV status is disclosed without a person's express consent, the attempt to strike a balance between maintaining privacy while delivering high quality healthcare is not achieved. What recourse do WLWH have? What mechanisms are in place for service users to take action in the event that their privacy is breached? How would management of the institution in which care is provided respond to this situation and take "reasonable steps" to right this wrong?

Enforcing PHIPA

There are many consequences when privacy is not respected including reputational consequences and changes in therapeutic relationships with healthcare providers (Fletcher 2014). Most privacy breaches are avoidable, even if conducted by well-intentioned healthcare providers; regardless of the intention behind the behaviour, the effect and consequences are the same (Fletcher 2014) and HICs who "willfully" collect, use or disclose PHI in contravention of PHIPA can be found liable (Beardwood and Kerr 2005). At a provincial level, enforcement of PHIPA falls to the Information and Privacy Commissioner. Individuals have up to one year to file a complaint concerning a breach of privacy under PHIPA (Canadian HIV/AIDS Legal Network 2012). Enforcement involves an adversarial system whereby the Commissioner, viewed as an impartial adjudicator, has discretion to determine the course of action including initiating a review or ordering a HIC to modify, cease or implement a particular information practice (Beardwood and Kerr 2005). Patients have the choice to withdraw their consent for the use and disclosure of PHI to other healthcare providers who deliver care, but the details of how this would be achieved, as well as how the HIC would monitor patient consent, are unclear. It is one thing to have policies in place that conform to PHIPA legislation. How policies and practices that align with PHIPA are disseminated, interpreted and enforced by the HIC and its agents, especially within a fast-paced and overburdened healthcare system, presents a whole different set of challenges. The bottom line is that healthcare institutions implicated under PHIPA do not do an optimal job to keep PHI private. Patients are encouraged to stand up for and assert their rights to privacy (Canadian HIV/AIDS Legal Network 2014; Fletcher 2014), but is this a realistic expectation and outcome?

Although disclosure of PHI often occurs by well-intentioned healthcare providers, WLWH believe there will be serious repercussions if they call on healthcare providers who have disclosed their HIV status to account for their inappropriate behaviour (Ion et al. forthcoming). As a result, many WLWH who experience disclosure of PHI will not report the actions of their healthcare providers. Why? Is there something unique about having HIV that positions WLWH in a particular way while in hospital?

Early in the HIV epidemic, there was virtually no privacy protection for those living with HIV because of fear, ignorance and "AIDS hysteria" within the healthcare system. Despite significant advances in the clinical management of HIV and its evolution into a complex chronic illness (Scandlyn 2000; Thompson et al. 2010), WLWH around the world continue to face a number of health, social and legal challenges including access to HIV treatment, HIV-related

stigma, discrimination and the criminalization of HIV (deBruyn 2004; Greene et al. 2015; Mahajan et al. 2008). WLWH continue to report stigmatizing interactions with healthcare providers, for example, being treated differently in the Labour and Delivery Unit because of their HIV status and the societal perception that WLWH should not be having children (Greene et al. forthcoming; Ion and Elston 2015; Ion et al. forthcoming). The current experiences of WLWH may reflect a long and enduring history of fear and ignorance of HIV within the healthcare system. Women's experiences may also reflect an enduring lack of knowledge and awareness about HIV amongst healthcare providers who do not work in settings that specialize in HIV care.

It is critical to consider the legislative frameworks pertaining to privacy through the lens of HIV because HIV has been classified as PHI that is particularly "sensitive" (Cavoukian 1990; Gostin 1995). It is also apparent that healthcare practices within non-HIV-specific services have not kept pace with the evolution of HIV as a chronic condition. It is clear why WLWH continue to perceive HIV-related stigma when they access care, in particular, during pregnancy and early postpartum, as well as why a climate of fear, ignorance and stigma continues to surround the HIV epidemic across Canada (Canadian HIV/AIDS Legal Network 2004).

Although patients have every right to hold HICs accountable, expecting health service users to stand up for their rights is not always optimal or possible, especially when they are ill, in hospital, are not comfortable speaking up for themselves, or feel powerless to do so (Fletcher 2014; Greene et al. 2015; Ion and Elston 2015; Ion et al. forthcoming; McCoy 2005; Pryce 2000). Moreover, healthcare providers and trainees may not truly understand their accountability and duty of confidentiality requirements (Canadian HIV/AIDS Legal Network 2004). Power dynamics may be at play between WLWH and their healthcare providers within the healthcare system. The choice of WLWH not to respond to or hold healthcare providers accountable for disclosing their HIV status sheds some light on how power dynamics may flourish within healthcare systems and may not always position the patient at the centre of care. Furthermore, expecting patients to express their privacy complaints to individual healthcare providers, then channel these complaints to the upper echelons of a healthcare corporation, as well as a provincial body like the Office of the Information and Privacy Commissioner, is a tall order. Although HICs may not do an optimal job to protect the privacy of patients (Fletcher 2014), expecting patients to advocate for themselves when privacy concerns arise and submit complaints to an adversarial system after disclosure has occurred may not be a perfect solution. Could the healthcare system be organized differently to decrease the chance of a privacy breach and to facilitate the appropriate collection, use and disclosure of PHI, including HIV status?

Recommendations for System Redesign: Optimizing Information Practices

A number of steps can be taken to optimize information practices to ensure the PHI of WLWH is protected and remains confidential. These steps are relevant not only to WLWH, but all people living with HIV (PLWH) and other patients who experience challenges related to privacy and confidentiality when navigating the healthcare system. Any system changes

must first be grounded in the perspective that, as a matter of public policy, the right to privacy is a fundamental human right for all PLWH (Canadian HIV/AIDS Legal Network 2004). Privacy is essential to freedom and revolves around personal control and freedom of choice (Cavoukian 2014). It must also be recognized that not only do PLWH have a right to privacy regarding their PHI, HICs owe a duty to PLWH to keep their PHI confidential (Canadian HIV/AIDS Legal Network 2004). Confidentiality of PHI is fundamental to the preservation of the ethical values of autonomy, dignity and respect for the individual; "patient confidentiality is not only an essential pre-condition to successful treatment … it's an issue of human dignity and respect" (Canadian HIV/AIDS Legal Network 2004: 3).

The concept of Privacy by Design (PbD) offers a framework for ensuring that privacy is embedded directly into the design specifications of information technologies, business practices and operational processes (Cavoukian 2014). PbD emphasizes service user privacy and the need to embed privacy as a default condition by transforming service user privacy issues from a "pure policy or compliance issue into a business imperative" (Cavoukian 2014: 13). PbD is focused on process rather than singular, technical outcomes and recognizes the need to introduce privacy principles during architecture planning, system design including networked infrastructure, and the development of operational procedures including work processes and management structures (Cavoukian 2014).

Scholars have suggested a number of recommendations at the macro-, meso- and micro-levels of policy and practice regarding how information practices could be optimized to ensure the appropriate collection, use and disclosure of PHI. At the macro level of legislation, the Canadian HIV/AIDS Legal Network has taken issue with the discretionary disclosure clauses inherent in health privacy legislation noting that these clauses fail to provide the level of privacy protection accorded to health information under the Canadian Charter of Rights and Freedoms (Canadian HIV/AIDS Legal Network 2004). As such, the Canadian HIV/AIDS Legal Network (2004) recommends that only in exceptional and circumscribed situations should a HIC be permitted to disclose health information without the express and informed consent of PLWH, rather than the vague and unspecified circumstances that are currently permitted. The Legal Network also recommends that HICs be prohibited from disclosing any information that may reasonably reveal a person's health information to family and friends without the person's consent (Canadian HIV/AIDS Legal Network 2004).

At the meso level of systems, Buffet and Kosa (2006) have investigated how HICs ensure that patient preferences regarding disclosure of PHI are acted upon. The authors note that heath information network providers, for example, digital interfaces used to facilitate communication between HICs and its agents, bear some responsibility for tracking and monitoring patient consent (Buffet and Kosa 2006). The authors propose a systematic consent management program, which they believe will minimize, if not eliminate, risk for the HIC and health information network provider (Buffet and Kosa 2006). The consent management system relies on utilities and assigns a valuation to patient attitudes with regard to the handling of PHI. The utilities are applied as part of a risk-based consent management

framework and could be updated and reviewed each time a patient's records are accessed. At any time a HIC performs an action that involves a patient's PHI, an analysis would be conducted to help the HIC determine whether to proceed based on the patient's valuations and the likelihood that the patient's preferences would be violated in the process (Buffet and Kosa 2006). The system for consent and risk management would assist HICs to meet their legal obligations under PHIPA by managing a patient's consent for releasing PHI.

Scholars have also highlighted how training and professional development initiatives for healthcare providers and learners are important domains where the PbD framework could be enacted. For example, privacy may only be a small portion of orientation modules trainees are expected to complete; these modules may present privacy in very theoretical terms and lack practical and applied elements (Fletcher 2014). Training programs could be redesigned to better prepare and orient healthcare providers and learners to privacy protection and duty of confidentiality. Concrete examples of privacy breaches could be included as a way to apply knowledge to practice including the nuances of privacy in the context of HIV and other chronic and/or stigmatizing health conditions (Fletcher 2014). Health professional licensing bodies also need to educate their members about legal and ethical obligations regarding privacy and confidentiality. For example, just because discretionary disclosure clauses permit disclosure of PHI under privacy legislation does not mean that the disclosure is necessary and valuable for the provision of care (Canadian HIV/AIDS Legal Network 2004). Regulatory bodies could make the protection of PHI a performance metric for meeting licensing requirements. Enhancing education, training and resources for healthcare providers within regulatory licensing bodies, as well as healthcare corporations, could result in important meso- and macro-level changes.

The Canadian HIV/AIDS Legal Network (2004) has offered recommendations regarding how the healthcare system, and its legislative and regulatory structures, could be better organized to protect the privacy of PLWH. The Legal Network believes that the meso-level "remedies" currently in place for PLWH whose privacy rights have been violated could be improved. The current adversarial system in Ontario, for example, which investigates complaints brought forward by service users, could be made more accessible *vis-à-vis* increasing the modes through which people could file a complaint such as audio or videotape in addition to written form, and eliminating fees associated with filing a complaint (Canadian HIV/AIDS Legal Network 2004). Accessibility could also be enhanced by increasing the public's awareness of the system and improving transparency; for example, the Privacy Commission of Ontario could develop education programs to inform the public about the existence of and rights under privacy legislation including information about the complaint process and remedies (Canadian HIV/AIDS Legal Network 2004). The Legal Network (2004) believes that remedies currently available to PLWH whose privacy rights have been violated should also be strengthened; for example, a system of deterrents should be implemented if HICs improperly use and disclose PHI including increased enforcement and compensation to patients.

At the micro level of patient and provider, the Legal Network (2014a) reminds us that healthcare providers should only ask questions that are relevant to providing care,

for example, there is no need to ask about HIV status if that information is not required to examine or treat someone. PLWH have often remarked about being asked how they acquired HIV during a routine clinical encounter; when telling these stories they are always outraged and annoyed because healthcare providers, who they often have never met before, are driven more by their curiosity than delivering high quality, patient-centred care. Asking relevant questions during a healthcare encounter is incredibly important for PLWH and highlights one of the nuanced ways that the sensitivity of HIV can be considered in practice because it prioritizes the person's privacy. Healthcare providers should have a confidential, one-on-one conversation with their patients in advance so that a plan to maintain privacy and respect confidentiality is co-created and agreed to.

How will we get there, especially considering that policies in the current political climate are considered within the micro-space of marginal incremental objectives, continually building out from the current situation (Lindblom 1959)? At the same time, healthcare decisions are also influenced by economic, social, environmental and political forces; policy makers and governments make decisions based on public opinion, electoral considerations, personal preferences and crisis management (Fafard 2008). Luckily, PbD has received global acceptance and endorsement by public and private sector privacy regulators around the world (Cavoukian 2014). Also, a number of scholars have spoken out to highlight public opinion regarding how governments handle PHI (Peekhaus 2008); why HIV should be framed as health information that is particularly sensitive (Canadian HIV/AIDS Legal Network 2004, 2012, 2014); and how issues of privacy and HIV-related stigma complicate access to care and result in negative care experiences for PLWH (Carter et al. 2013; Greene et al. 2015; Greene et al. forthcoming; Hodgson 2006; Ion and Elston 2015; Ion et al. forthcoming; McCoy 2005; OHTN 2010; Wong-Wylie and Jevne 1997). As a result, community champions, social workers, researchers, activists and legal experts working in the HIV sector, as well as those concerned with privacy and its protection more broadly, are positioned with sufficient ammunition to enable a paradigm shift. The time is now to ensure that policy and practice decisions that affect privacy at the micro-, meso- and macro-levels are on the government's agenda, and at the very least, are informed by evidence (Fafard 2008), and grounded in the lived experiences and current realities of service users.

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References

Beardwood, J.P. and J.A. Kerr. 2004. "Coming Soon to a Health Sector Near You: An Advance Look at the New Ontario Personal Health Information Protection Act (PHIPA)." *Healthcare Quarterly* 7(4): 62–67.

Beardwood, J.P and J.A. Kerr. 2005. "Coming Soon to a Health Sector Near You: An Advance Look at the New Ontario Personal Health Information Protection Act (PHIPA): Part II." *Healthcare Quarterly* 8(1): 76–83.

Buffet, S. and T.A. Kosa. 2006. *Towards a Model for Risk and Consent Management of Private Health Information*. National Research Council of Canada. Report published at the Conference on Privacy, Security and Trust. Toronto, ON. October 31, 2006. Retrieved April 27, 2015. <http://nparc.cisti-icist.nrc-cnrc.gc.ca/npsi/ctrl?action=rtdoc&an=5764504&lang=en>.

Canadian HIV/AIDS Legal Network. 2004. *Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada*. Report. Retrieved March 6, 2015. <http://www.aidslaw.ca/site/privacy-protection-and-the-disclosure-of-health-information-legal-issues-for-people-living-with-hivaids-in-canada/>.

Canadian HIV/AIDS Legal Network. 2012. *Privacy and Disclosure: Questions and Answers on HIV-Related Privacy and Disclosure Issues for Women's Service Providers*. Factsheet. Retrieved April 24, 2015. <http://www.aidslaw.ca/site/our-work/womens-rights/>.

Canadian HIV/AIDS Legal Network. 2014. *Know Your Rights – Disclosure as a Patient*. Factsheet. Retrieved November 20, 2014. <http://www.aidslaw.ca/site/know-your-rights-5-disclosure-as-a-patient/>.

Carter, A.J., S. Bourgeois, N. O'Brien, K. Abelsohn, W. Tharao, S. Greene et al. 2013. "Women-Specific HIV/AIDS Services: Identifying and Defining the Components of Holistic Service Delivery for Women Living with HIV/AIDS." *Journal of the International AIDS Society* 16: 17433.

Cavoukian, A. 1990. *HIV/AIDS: A Need for Privacy*. Discussion Paper. Office of the Information & Privacy Commissioner of Ontario. Retrieved April 24, 2015. <https://www.ipc.on.ca/English/Resources/Discussion-Papers/Discussion-Papers-Summary/?id=324>.

Cavoukian, A. 2008. *The Impact of New Technology in Health Care on Privacy*. Office of the Information & Privacy Commissioner of Ontario. Presentation to Ontario College of Social Workers and Social Service Workers. Retrieved April 21, 2015. <http://www.ocswssw.org/wp-content/uploads/2015/02/ann-cavoukian.pdf>.

Cavoukian, A. 2014. *Privacy by Design: From Rhetoric to Reality*. Retrieved March 30, 2015. <https://www.ipc.on.ca/english/Resources/Discussion-Papers/Discussion-Papers-Summary/?id=1373>.

Cavoukian, A. and P.G. Rossos. 2009. *Personal Health Information: A Practical Tool for Physicians Transitioning from Paper-Based Records to Electronic Health Records*. Office of the Information & Privacy Commissioner of Ontario. Retrieved April 22, 2015. <https://www.ipc.on.ca/images/Resources/phipa-toolforphysicians.pdf>.

deBruyn, T. 2004. *A Plan of Action for Canada to reduce HIV/AIDS-related stigma and discrimination*. Canadian HIV/AIDS Legal Network Report. Toronto, ON. Retrieved December 28, 2014. <http://www.aidslaw.ca/site/a-plan-of-action-for-canada-to-reduce-hivaids-related-stigma-and-discrimination/>.

Fafard, P. 2008. *Evidence and Healthy Public Policy: Insights from Health and Political Sciences*. National Collaborating Centre for Healthy Public Policy. Canadian Policy Research Networks. Retrieved January 19, 2015. <http://www.cprn.org/documents/50036_EN.pdf>.

Fletcher, M. 2014. *Privacy: It's Everyone's Business*. Presentation by Director of Health Information Management and Chief Privacy Officer, St. Joseph's Healthcare Hamilton. Bridging the Gap: Coordinating Care for Women Living with HIV in Hamilton, Halton, Haldimand, Norfolk, Brant & Niagara: Knowledge to Action Meeting. Grimsby, Ontario. March 28, 2014.

Gagnon, M. 2014 *Rethinking HIV-Related Stigma in Health Care Settings: A Research Brief*. Ottawa, ON. Retrieved December 23, 2014. <http://www.cocqsida.com/assets/files/Research-Brief_RethinkingHIV-17juillet2014.pdf>.

Gagnon, M. 2015. "Re-Thinking HIV-Related Stigma in Health Care Settings: A Qualitative Study." *Journal of the Association of Nurses in AIDS Care* 26(6): 703–19.

Gostin, L.O. 1995. "Genetic privacy." *The Journal of Law, Medicine & Ethics* 23(1): 320–30.

Greene, S., A. Ion, D. Elston, G. Kwaramba, S. Smith and M. Loutfy. 2015. "(M)othering with HIV: Resisting and Reconstructing Experiences of Health and Social Surveillance." In J. Minaker and B. Hogeveen eds.,

Criminalizing Motherhood (pp. 231–63). Toronto, ON: Demeter Press.

Greene, S., A. Ion, G. Kwaramba, S. Smith and M.R. Loutfy. 2016. "Why Are You Pregnant? What Were You Thinking?: How Women Navigate Experiences of HIV-Related Stigma in Medical Settings During Pregnancy and Birth." *Social Work in Health Care* 55(2): 161–79.

Hodgson, I. 2006. "Empathy, Inclusion and Enclaves: The Culture of Care of People with HIV/AIDS and Nursing Implications." *Journal of Advanced Nursing* 55(3): 283–90.

Ion, A. and D. Elston. 2015. "Examining the Healthcare Experiences of Women Living with HIV and Perceived HIV-Related Stigma." *Women's Health Issues* 25(4): 410–19.

Ion, A., S. Greene, K. Mellor, G. Kwaramba, S. Smith, F. Barry et al. 2016. "Perinatal Care Experiences of Mothers Living with HIV in Ontario, Canada." Manuscript submitted for publication.

Lindblom, C.E. 1959. "The Science of Muddling Through." *Public Administration Review* 19(2): 79–88.

Mahajan, A.P., J.N. Sayles, V.A. Patel, R.H. Remien, S.R. Sawires, D.J. Ortiz et al. 2008. "Stigma in the HIV/AIDS Epidemic: A Review of the Literature and Recommendations for the Way Forward." *AIDS* 22(Suppl 2): S67–79.

McCoy, L. 2005. "HIV-Positive Patients and the Doctor-Patient Relationship: Perspectives from the Margins." *Qualitative Health Research* 15(6): 791–806.

Office of the Information & Privacy Commissioner of Ontario (OIPC). (n.d.). *PHIPA: Personal Health Information Protection Act, 2004*. Retrieved March 30, 2015. <https://www.ipc.on.ca/english/phipa/>.

Ontario HIV Treatment Network (OHTN) 2010. *Rapid Review: Knowledge and Training Needs of Health Professionals Working with People with HIV: With Considerations for Mixed Urban Rural Care Settings*. OHTN Rapid Response Service. Toronto, ON. Retrieved September 8, 2013. <http://www.ohtn.on.ca/rapid-response-index/>.

Peekhaus, W. 2008. "Personal Health Information in Canada: A Comparison of Citizen Expectations and Legislation." *Government Information Quarterly* 25(4): 669–98.

Pryce, A. 2000. "Frequent Observation: Sexualities, Self-Surveillance, Confession and the Construction of the Active Patient." *Nursing Inquiry* 7(2): 103–11.

Scandlyn, J. 2000. "When AIDS Became a Chronic Disease." *The Western Journal of Medicine* 172(2): 130–33.

Thompson, M., J. Aberg, P. Cahn and J. Montaner. 2010. "Antiretroviral Treatment of Adult HIV Infection – 2010: Recommendations of the International AIDS Society–USA Panel." *JAMA* 304(3): 321–33.

Wong-Wylie, G. and R.F. Jevne. 1997. "Patient Hope: Exploring the Interactions between Physicians and HIV Seropositive Individuals." *Qualitative Health Research* 7(1): 32–56.

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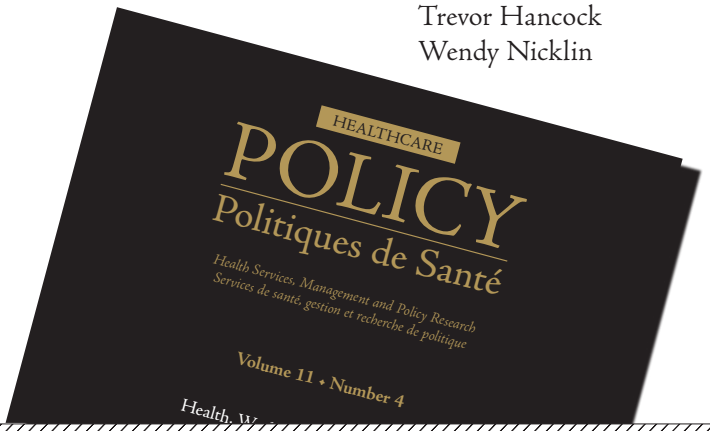

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ONLINE EXCLUSIVE

A Decade Lost: Primary Healthcare Performance Reporting across Canada under the Action Plan for Health System Renewal

Une décennie de perdue : rendre compte du rendement du système de soins primaires au Canada en vertu du plan d'action pour le renouvellement du système de santé

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Abstract

In 2004, Canada's First Ministers committed to reforms that would shape the future of the Canadian healthcare landscape. These agreements included commitments to improved performance reporting within the primary healthcare system. The aim of this paper was to review the state of primary healthcare performance reporting after the public reporting mandate agreed to a decade ago in the Action Plan for Health System Renewal of 2003 expired. A grey literature search was performed to identify reports released by the governmental and independent reporting bodies across Canada. No province, or the federal government, met their performance reporting obligations from the 2004 accords. Although the indicators required to report on in the 2004 Accord no longer reflect the priorities of patients, policy makers and physicians, provinces are also failing to report on these priorities. Canada needs better primary healthcare performance reporting to enable accountability and improvement within and across provinces. Despite the national

mandate to improve public health system reporting, an opportunity to learn from the diverse primary healthcare reforms, underway across Canada for the past decade, has already been lost.

Résumé

En 2004, les premiers ministres du Canada s'engageaient à mener des réformes pour les soins de santé. Ces ententes comprenaient des engagements pour mieux rendre compte du rendement du système de soins primaires. L'objectif de cet article était d'évaluer l'état de la production de comptes rendus sur le rendement des soins primaires après l'entente conclue en ce sens, il y a une décennie, dans le cadre du plan d'action pour le renouvellement du système de santé de 2003. Une étude de la littérature grise a permis d'identifier les rapports publiés par les entités gouvernementales et indépendantes au Canada. Aucune province, pas plus que le gouvernement fédéral, n'a rempli ses obligations de rendre compte en vertu des ententes de 2004. Bien que les indicateurs obligatoires en vertu de l'entente de 2004 ne reflètent plus les priorités actuelles pour les patients, les décideurs et les médecins, les provinces ne remplissent pas leurs obligations de produire des rapports sur ces priorités. Le Canada doit se doter d'une meilleure façon de rendre compte du rendement des soins primaires afin de permettre l'obligation redditionnelle et l'amélioration dans les provinces. Malgré le mandat national d'améliorer les façons de rendre compte dans le système de santé, nous avons perdu l'occasion d'apprendre des diverses réformes de soins primaires qui ont eu lieu au Canada pendant les 10 dernières années.

Introduction

More than a decade ago, Canada's provincial and territorial health ministers and the federal government produced the Action Plan for Health System Renewal (Canadian First Ministers 2003) and the First Ministers' Accords of 2004, which promised annual and comprehensive public reporting to Canadians using agreed-upon indicators of health status, outcomes and service quality. The goal of this agreement was to shape the future of the public health system with governments, providers and citizens working together towards reform. This mandate ended in 2014, and the Health Council of Canada, tasked with monitoring the implementation of the Accord, including annual public reporting, was disbanded in March 2014.

The rationale and impetus for health system performance reporting have not diminished since the First Ministers' Accord. Public performance reporting may increase accountability, enable public participation in healthcare (Ellins and McIver 2009; Powell et al. 2003), impact societal and professional values surrounding our healthcare decision-making, direct attention to issues not currently on the policy agenda (Oxman et al. 2009a, 2009b) and improve performance (Hibbard et al. 2012; Smith et al. 2012; The Commonwealth Fund 2011; Watson 2009).

While some sectors, such as hospitals, witnessed growing initiatives for public reporting over the past decade (Canadian Institute for Health Information [CIHI] 2014b), the primary healthcare (PHC) sector performance reporting continued to lag behind other health system sectors despite the

significant reforms and investments during that time (CIHI 2009; Health Council of Canada 2012; Hutchison 2013). The First Minister's Communiqués and Accords from 2000, 2003 and 2004 required each province and the federal government to report on many elements of the health system but mandated only a few specific to the PHC system: access to care, the composition of the groups providing care, patient satisfaction with care and the degree to which technology is being incorporated into the primary care system (Table 1).

TABLE 1. Reporting requirements mandated in the First Minister's Communiqués and Accords from 2000, 2003 and 2004, as well as whether Canada and its provinces met them (shaded)

First Minister requirement	Hogg attribute	CA	AB	BC	MB	NB	NL	NS	ON	PE	QC	SK
Annual reporting	N/A	■	■	■	■				■		■	
Access												
Percentage of population with a regular doctor	Availability	■	■			■	■		■		■	
Percentage of doctors accepting new patients	Availability											
Number of multidisciplinary PHC organizations or teams by region	Group composition		■			■					■	
Percentage of population having access to 24/7 primary care provider (e.g., NP, doctor)/telehealth/online health information	First-contact accessibility		■			■			■		■	
Percentage of population routinely receiving needed care from a multi-disciplinary PHC organization or team	Availability		■			■					■	
Quality Indicators												
Reported medical errors/events	Adverse events/ patient safety		■			■					■	
Patient satisfaction with physician care	Patient-reported outcomes		■			■	■		■		■	
Patient satisfaction with community-based healthcare	Patient-reported outcomes		■			■						
Patient satisfaction with telehealth/online health information	Patient-reported outcomes											
Sustainability												
Progress on building information systems	Information technology		■	■		■			■		■	
Degree of standardization of information collected and shared for evidence-based decision-making	Coordination/ collaboration					■						
Degree of technology utilization based on evidence	Technical quality of care		■						■		■	

Limited though the mandate for PHC reporting was, the national interest in ensuring high quality PHC across the country should be strong. Countries with a high-functioning

PHC system have healthier populations, a more equitable distribution of health and lower healthcare expenditures (Starfield et al. 2005). Canada, however, does not have a single PHC system but rather 13 distinct provincial and territorial health systems linked by a set of guiding principles enshrined in the *Canada Health Act* (Government of Canada 1985). While this Act calls for universal public insurance of physician and hospital services, a great deal of variation exists across these systems. The last decade has seen a range of primary care reforms across the country in such areas as physician remuneration, team-based care and regional governance (Hutchison et al. 2011). In fact, as the end of the First Ministers' agreement on public reporting was drawing near, there were growing calls for public reporting on primary care performance to support quality improvement and accountability as a minimum requirement for continuous progress in achieving our goals for the PHC system (Aggarwal and Hutchison 2012; Health Quality Ontario 2014a).

We conducted a review of PHC reporting in Canada to identify the impact and legacy of the health accords. The aims of the work are to determine what performance attributes are being reported on, by whom and how, and what attributes of PHC are most important for reporting. The overall goal of the project was to ascertain what we could learn about the public reporting on the PHC system, which occurred while there was a national mandate for common reporting, to identify opportunities to improve performance reporting across the PHC systems serving Canadians and meet the growing demands for better evidence and information.

Methods

We performed a scoping review of PHC performance reporting in Canada, accessing provincial health ministry reports and websites, as well as provincial quality councils, federal health organizations and national professional bodies. The search was performed between September 20 and November 16, 2012. See Appendix 1 (available at: http://www.longwoods.com/content/24593) for the complete list of sources reviewed. Each ministry's or organization's website was scanned using the site's embedded search function when applicable, incorporating terms such as "primary care" or "primary health care" along with "performance," "measurement" or "indicators". The websites were also scanned by parsing through sitemaps, uncovering sub-pages such as "reports," "publications," "resources" or the likes thereof. Publications intended to report on the performance or status of the healthcare system and which presented quantitative data on PHC-specific indicators were selected for further analysis. Documents without PHC-specific data were excluded.

We included reports dating back to 2004 when the provinces agreed to public reporting on the health system. However, we restricted our in-depth analysis to reporting between 2009 and 2012 to reflect the best available reporting, as performance measures and data collection systems have continued to improve since 2004, and provinces had access to CIHI's Pan-Canadian Primary Care Indicators since its 2006 release (CIHI 2006). We limited our focus in public reporting to PHC, adopting Starfield's definition of PHC as the "products or services designed to address acute and episodic health conditions

and to manage chronic health conditions. [PHC] is also where health promotion and education efforts are undertaken, patients receive first care and where those in need of more specialized services are connected with other parts of the system" (Starfield 1998). This definition is broad enough to capture the diverse and emerging models of PHC delivery across Canada, though it is purposefully narrower than the WHO definition to narrow the scope of our search (WHO 1978). We focused on public PHC performance reporting at the provincial level, as this is what all provinces had agreed to.

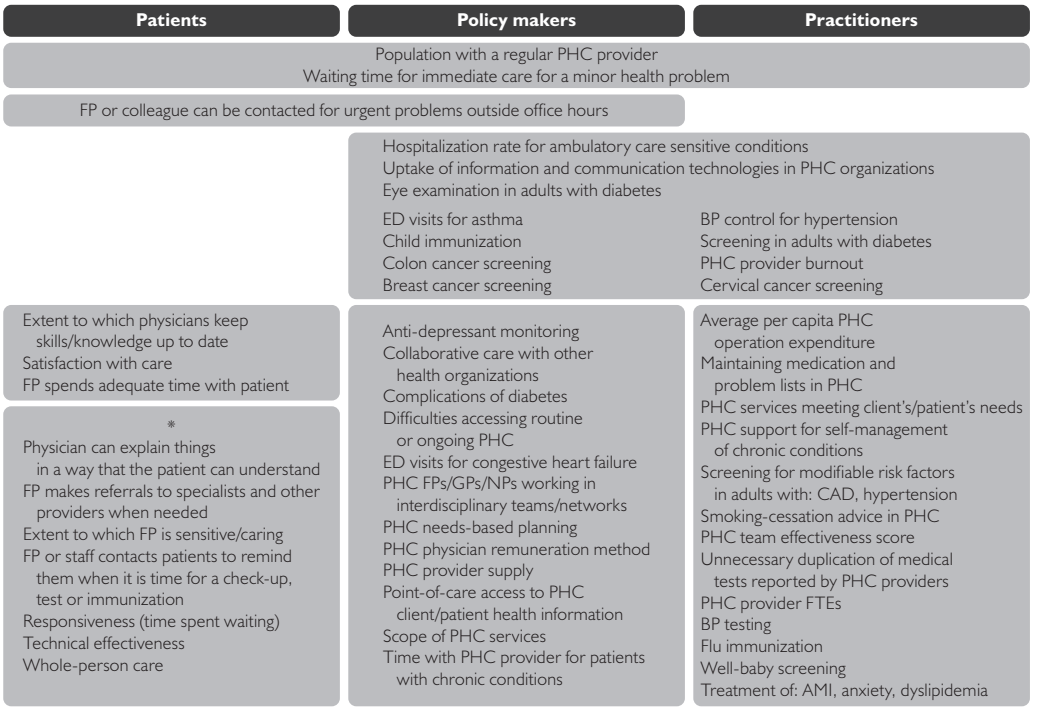
We were guided by the Hogg et al. conceptual framework for the systematic evaluation of PHC performance (Hogg et al. 2008). This broad framework has been used for several Pan-Canadian research studies aiming to measure comprehensive PHC performance. It enabled consideration of the range of activities occurring within PHC beyond only those elements included in the First Ministers' agreements (Dahrouge et al. 2009). The framework integrates the health system and community context with the practice and recognizes that the organization of a practice also influences performance. Finally, this framework considers quality of care at the individual patient level, allowing an exploration of attributes of care of potentially greater interest to patients, a key stakeholder group for public reporting. Each PHC-specific indicator from the reports selected for further analysis was extracted and matched to an attribute from a modified Hogg framework to facilitate comparison of performance reporting where variations of a similar indicator might be used.

In order to identify PHC attributes important to the patient population for public reporting, we reviewed two Canadian studies which directly surveyed Canadians on their perceptions of the most important aspects of their PHC (Berta et al. 2008; Wong et al. 2008). The common PHC system attributes important to the participants in both studies included accessibility, responsiveness, interpersonal communication, technical effectiveness and whole-person care.

Provider and policy maker priorities were identified from a recent report by the CIHI, in which the members of the two stakeholder groups were recruited to participate in the focus groups and rank the importance of CIHI's previously published 105 Pan-Canadian Primary Health Care Indicators (CIHI 2012).

These stakeholder priorities were compiled for comparative purposes and are displayed in Figure 1. The two studies and the national consultation report by CIHI did not present participants with identical sets of attributes of care and offered varying levels of specificity at the indicator level. In order to compare, identify common interests and link these to reported information, we labelled the stakeholder priority features of PHC, linking each one to the relevant performance attribute in the Hogg framework. We then looked for alignment between the PHC performance information reported and the priority PHC features for different stakeholders. We adopted the attribute of the PHC from the Hogg framework such as access or care of chronic conditions as our unit of comparison because many different indicators, often varying slightly yet reflecting the same attribute of PHC, were reported.

FIGURE 1. PHC reporting priorities for patients, policy makers and providers



*Patient priority indicators that could not be matched to the CIHI indicators.

Results

Who has reported on PHC performance over the last decade?

There is a great deal of variation in the method, quantity and quality of PHC reporting across the provinces. All provinces have a governmental ministry responsible for legislating and enacting health-related policy, and many have an arm's-length body, such as a provincial Quality Council, for overseeing and reporting on the quality of care and/or patient safety.

Since the final instalment of the First Minister's Health Accords was convened in 2004, no province has met the requirement to report annually on the performance of their PHC system. Based on the study search strategy, which sought to identify and retrieve publicly available reports containing PHC-related performance indicator data, seven of the 10 provinces were identified as having reported at least once on some element of the performance of the PHC system. Manitoba and British Columbia's Health Ministry annual reports have included one (total number of general practitioners [GPs]) and two (percentage of physicians implementing electronic medical record [EMR] systems, and percentage of GPs providing chronic disease management) PHC performance indicators, respectively, until 2012 when Manitoba incorporated an additional six indicators. Newfoundland and Labrador, Nova Scotia, Prince Edward Island and Saskatchewan did not report on the performance of their *primary* healthcare systems between 2008 and 2012.

In addition to the provinces, national reports on PHC performance have been released by the Federal Department of Health (Health Canada), by the federally

funded independent Health Council of Canada; the federally funded, independent Canadian Foundation for Healthcare Improvement; the College of Family Physicians of Canada; and as joint ventures between the federally funded independent CIHI and Statistics Canada.

What is being reported?

The indicators contained in each report released from 2009 to 2012 were matched to PHC performance attributes and are presented in Table 2. While there were a few common PHC attributes frequently reported on, often many different indicators were reported for a single attribute. Access to care was the most commonly reported attribute; however, over 20 different indicators (some examples include: percentage of Albertans enrolled in a primary care network, patient-reported perception of access to healthcare, and wait times at community health centres) were reported for this attribute. The majority of provinces releasing performance reports in the last four years also reported on elements of the technical quality of PHC, such as immunization rates, as well as the outcomes of PHC, relating to patient safety and satisfaction.

The attributes of care coordination and collaboration, through indicators on the quality of transfer of care between providers, as well as the attribute of interpersonal communication, were also incorporated into the reports of the provinces most frequently reporting. Attributes reported on the organization of PHC practices were group composition and roles, the organization of clinical information and the degree of implementation of information technology. Only Quebec reported on attributes related to the structure of the PHC system such as provider remuneration. The quality of the relationships between physician and patient (incorporating aspects such as trust and advocacy) and quantity of services offered by the providers were also not reported on.

Are provinces meeting PHC reporting obligations?

Not one of the provinces, or the federal government, met all of the obligations committed to in the Health Accords, even more than five years after the agreements were made. Table 1 shows how the provinces and the federal government have met the reporting requirements specific to PHC performance laid out in the Health Accords in their reporting between the years 2009 and 2012. Only five provinces and the federal government are reporting annually on any element of the PHC performance.

Of the bodies that at least reported annually on some elements of the PHC system from 2009 to 2012, the reporting varied from a single indicator (Canada, via Health Canada, CHFI and CIHI, who reported only on the percentage of the population with a regular doctor) to reporting seven performance indicators (Alberta). Some provinces, such as Quebec, reported indicators related to the attributes of PHC mandated in the First Ministers' Accord, such as access to care but did not match the specific indicators listed in the Accords for access to care, focusing on other elements of the attribute of access.

TABLE 2. Performance indicator contents of PHC reports released from 2009 to 2012, as matched to the Hogg framework*

	National					AB			BC	MB	NB	NL	NS	ON	PE	QC	SK
	Health Canada	Health Council of Canada	CHSRF	CIHI	CCFP	Alberta Health and Wellness	Alberta Health Services	Health Quality Council of Alberta	BC Ministry of Health	Manitoba Health	NB Health Council	NL Centre for Health Information		Health Quality Ontario		CSBE	
Healthcare system	**0**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**0**		**0**		**6**	
Clinical accountability	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*		*0*		*0*	
Clinical quality improvement process	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Resources and technical provisions	*0*	*0*	*0*	*0*	*1*	*0*	*0*	*0*	*0*	*0*	*0*	*0*		*0*		*6*	
Provider remuneration	0	0	0	0	1	0	0	0	0	0	0	0		0		6	
Funding	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Regional context	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**		**0**		**0**	
Surrounding medical and social services	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*		*0*		*0*	
Population and community characteristics	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*		*0*		*0*	
Community integration	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Organization of the practice	**0**	**2**	**5**	**0**	**14**	**11**	**6**	**2**	**8**	**4**	**9**	**0**		**10**		**59**	
Health human resources	*0*	*0*	*0*	*0*	*0*	*3*	*4*	*1*	*0*	*4*	*5*	*0*		*0*		*4*	
Group composition	0	0	0	0	0	3	4	1	0	4	5	0		0		4	
Training	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Office infrastructure	*0*	*1*	*4*	*0*	*6*	*7*	*2*	*0*	*4*	*0*	*2*	*0*		*7*		*23*	
Information technology	0	1	4	0	6	7	2	0	4	0	2	0		7		23	
Medical technology	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Office space design	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Organizational structure and dynamics	*0*	*1*	*1*	*0*	*8*	*1*	*0*	*1*	*4*	*0*	*2*	*0*		*3*		*31*	
Job descriptions and team functioning	0	0	0	0	1	1	0	1	0	0	2	0		0		9	

	National					AB			BC	MB	NB	NL	NS	ON	PE	QC	SK
	Health Canada	Health Council of Canada	CHSRF	CIHI	CCFP	Alberta Health and Wellness	Alberta Health Services	Health Quality Council of Alberta	BC Ministry of Health	Manitoba Health	NB Health Council	NL Centre for Health Information		Health Quality Ontario		CSBE	
Management and practice governance	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Clinical information management	0	1	1	0	5	0	0	0	4	0	0	0		1		18	
Organizational adaptiveness	0	0	0	0	2	0	0	0	0	0	0	0		2		4	
Organizational culture	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Practice integration	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*		*0*		*1*	
Healthcare service delivery	**5**	**48**	**19**	**12**	**11**	**2**	**11**	**26**	**0**	**3**	**40**	**1**		**43**		**86**	
Access	*5*	*20*	*11*	*8*	*4*	*2*	*11*	*11*	*0*	*2*	*32*	*1*		*27*		*42*	
First-contact accessibility	2	9	4	5	0	0	10	6	0	1	20	0		17		15	
Availability	2	2	3	2	4	2	1	4	0	1	7	1		8		9	
Accommodation	0	2	0	1	0	0	0	1	0	0	3	0		1		7	
Economic accessibility	1	7	4	0	0	0	0	0	0	0	2	0		1		11	
Patient–provider relationship	*0*	*7*	*6*	*3*	*1*	*0*	*0*	*10*	*0*	*0*	*4*	*0*		*3*		*7*	
Interpersonal communication	0	6	4	2	1	0	0	6	0	0	2	0		2		5	
Respectfulness	0	0	0	0	0	0	0	3	0	0	0	0		0		1	
Trust	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Whole-person care	0	0	1	1	0	0	0	1	0	0	2	0		0		1	
Cultural sensitivity	0	0	0	0	0	0	0	0	0	0	0	0		1		0	
Family-centred care	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Advocacy	0	1	1	0	0	0	0	0	0	0	0	0		0		0	
Continuity	*0*	*9*	*1*	*1*	*0*	*0*	*0*	*2*	*0*	*1*	*2*	*0*		*9*		*12*	
Continuity-relational	0	1	0	1	0	0	0	1	0	1	2	0		0		3	
Continuity-information	0	8	1	0	0	0	0	1	0	0	0	0		9		9	

TABLE 2. Continued

	National					AB			BC	MB	NB	NL	NS	ON	PE	QC	SK
	Health Canada	Health Council of Canada	CHSRF	CIHI	CCFP	Alberta Health and Wellness	Alberta Health Services	Health Quality Council of Alberta	BC Ministry of Health	Manitoba Health	NB Health Council	NL Centre for Health Information		Health Quality Ontario		CSBE	
Cooperative care	*0*	*12*	*1*	*0*	*0*	*0*	*0*	*3*	*0*	*0*	*1*	*0*		*4*		*24*	
Coordination	0	12	1	0	0	0	0	3	0	0	0	0		4		24	
Collaboration	0	0	0	0	0	0	0	0	0	0	1	0		0		0	
Service delivery	*0*	*0*	*0*	*0*	*1*	*0*	*0*	*0*	*0*	*0*	*1*	*0*		*0*		*0*	
Services offered	0	0	0	0	1	0	0	0	0	0	1	0		0		0	
Services provided	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Population orientation	0	0	0	0	0	0	0	0	0	0	0	0		0		0	
Provider satisfaction	*0*	*0*	*0*	*0*	*5*	*0*	*0*	*0*	*0*	*0*	*0*	*0*		*0*		*1*	
Technical quality of care	**1**	**0**	**13**	**4**	**2**	**6**	**19**	**4**	**4**	**4**	**19**	**10**		**27**		**34**	
Health promotion and primary prevention	*1*	*0*	*5*	*1*	*0*	*4*	*13*	*4*	*0*	*1*	*5*	*1*		*6*		*4*	
Secondary prevention	*0*	*0*	*3*	*0*	*0*	*2*	*6*	*0*	*0*	*2*	*6*	*7*		*15*		*8*	
Care of chronic conditions	*0*	*0*	*5*	*3*	*2*	*0*	*0*	*0*	*4*	*1*	*8*	*2*		*6*		*22*	
Care of acute conditions	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*		*0*		*0*	
Immediate and intermediate outcomes of care	**2**	**8**	**10**	**3**	**1**	**6**	**3**	**25**	**0**	**0**	**7**	**5**		**11**		**22**	
Adverse events/patient safety	*0*	*0*	*2*	*0*	*0*	*3*	*0*	*2*	*0*	*0*	*1*	*0*		*0*		*9*	
Patient self-efficacy or activation	*0*	*1*	*3*	*0*	*1*	*0*	*0*	*1*	*0*	*0*	*0*	*1*		*1*		*6*	
Acceptability of health services	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*		*0*		*0*	
Confidence in the health system	*1*	*1*	*3*	*0*	*0*	*0*	*0*	*1*	*0*	*0*	*0*	*0*		*0*		*4*	
Patient-reported outcomes	*1*	*2*	*1*	*3*	*0*	*3*	*3*	*20*	*0*	*0*	*6*	*4*		*5*		*3*	
Unmet needs for care	*0*	*4*	*1*	*0*	*0*	*0*	*0*	*1*	*0*	*0*	*0*	*0*		*5*		*0*	

*Numbers in group headings (bold) and subgroup headings (italics) represent the sum of the categories held within those groups and subgroups.

Are provinces reporting on indicators important to stakeholders?

The priority PHC features for patients, policy makers and physicians included 29 PHC features of priority to physicians, 26 of priority to policy makers and 13 of priority to patients. The three groups only had 16 priority features common between at least two of them (Figure 1). Of the 52 PHC features prioritized by the three groups, only two, access to a regular PHC provider and wait time for immediate care for a minor health problem, were shared by all three. There were 11 features that overlapped between policy makers and providers. Comparing the reporting obligations mandated by the First Minister's Accord (Table 1) with the more recent stakeholder priorities (Figure 1), only five overlap. These include access to a regular family doctor, the number of multidisciplinary PHC organizations or teams, access to after-hours care, patient satisfaction with care and the progress on information systems. Seven of the 12 indicators mandated for annual reporting in the First Ministers' agreements did not match any of the remaining 47 stakeholder priority features of the PHC system.

To determine if recent PHC reporting efforts matched current stakeholder priority features of PHC, we analyzed the degree to which the features listed in Figure 1 were reported on in federal and provincial reports from 2009 to 2012 (Table 3). As Alberta, New Brunswick, Ontario and Quebec performed the most consistent and thorough PHC reporting between 2009 and 2012, we focused solely on their performance for additional analysis. The actual reporting of the priority indicators for the four provinces examined decreased with the strength of the indicator priority. For the two indicators, which were priorities to all three stakeholder groups, the four provinces had 100% coverage. For the 13 indicators that were shared priorities for two of the three stakeholder groups, the four provinces reported on an average of 69% of them. In the set of 38 indicators uniquely prioritized by a single stakeholder group, the four provinces reported on an average of 22% of them.

TABLE 3. Degree of reporting on performance indicators prioritized by patients, policy makers and providers by AB, NB, ON and QC from 2009 to 2012

Priority indicators	AB	NB	ON	QC	Average	Percentage coverage
Shared by all three stakeholder groups	2	2	2	2	2	100%
Shared by two of three stakeholder groups	6	9	11	10	9	69%
Unique to a single stakeholder group	8	7	8	11	8.5	22%

What are provinces reporting on?

The number of indicators reported on from 2009 to 2012 by the four provinces leading the field in quantity and quality of reporting were classified by the PHC attribute they measure. Only eight performance domains were represented: access, services provided, continuity or care coordination, patient satisfaction, information technology and information management, group composition or roles, physician services provided and medical errors. All of these provinces reported on access to care and elements of the technical services provided,

such as cancer-screening rates or immunizations and care of chronic conditions. Beyond those two attributes, different provinces had very different reporting patterns. Alberta focused on patient satisfaction in their reports, while Quebec presented a large number of indicators on continuity/coordination of care. New Brunswick had almost none of these.

Where is the information coming from?

Many different strategies were used by the provinces to obtain and present data on a given attribute of PHC performance. Among the two attributes most frequently reported by the leading provinces, access to care and technical services provided, Alberta obtained its information mostly from a combination of provincial administrative databases and provincial surveys, New Brunswick obtained its data from provincial surveys and national/international surveys, Ontario relied on provincial administrative databases and national/international surveys and Quebec reported entirely using data from an international survey – specifically the Commonwealth Fund International Survey of PHC Providers. The Canadian Community Health Survey (CCHS) was the source of data for only some provinces on indicators of the technical quality of care such as mammography rates, and New Brunswick was the only province that used the CCHS data to report on access to PHC. The provinces which developed their own surveys used different indicators, suggesting they were not standardized or shared instruments. Finally, public reporting based on data extracted from EMRs, as is done in the Quality and Outcomes Framework in the UK, was notably absent (Prescribing and Primary Care Services 2014).

Discussion

As the demands on and investments in the health system increase, the need for accountability and good-quality data to track progress and guide investment only grows. Most provinces have an arm's-length organisation tasked with public reporting on healthcare quality, such as a quality council, and all provinces and the federal government have ministries or departments capable of reporting on the health system. Nonetheless, at the end of the decade-long mandate of the Action Plan for Health System Renewal, there is limited PHC system performance reporting and no systematic comparative capacity across the country. Further public reporting priorities need to be updated to ensure they match information needs for policy makers, patients and the public and providers.

This retrospective search for public PHC performance reporting identified reporting efforts by most provinces; however, a number of public reports from the past decade are no longer publicly accessible. The major overviews of health system performance reporting covering our search period, issued by the Health Council of Canada (2012) and the Conference Board of Canada (The Conference Board of Canada 2013), did not reference any public reporting, which we had not retrieved, suggesting that the major publicly accessible information available to decision-makers and the general public was captured in our search.

Current reporting by the four leading provinces matched poorly against mandated reporting. While some priorities for stakeholders will shift over time, provincial reporting

also only partially covered more recent priority features for PHC identified by patients, physicians and policy makers. Despite the call for comprehensive performance reporting to drive progress in the PHC system reform (Lester and Roland 2009), provinces continue to use different data sources and non-standardized indicators, resulting in a lack of comparable indicators on most features of interest in PHC performance.

The current diversity in reporting across the provinces may reflect different provincial priorities in the decentralized governance model of Canadian healthcare, with differing short- and medium-term goals between provinces. While the provinces are each unique, they face many similar challenges and must work within broadly similar resources and resource constraints. The inability to systematically compare PHC performance over time across the provinces through the past decade, due to a dearth of common publicly reported indicators, is a vital missed opportunity for the Canadian health system. Further, regular reporting and benchmarking within each province is still important for effective evaluation of reform efforts and accountability of policy makers and the healthcare system (Aggarwal and Hutchison 2012; Best et al. 2012; Smith 2009) and citizen engagement (Ellins and McIver 2009; Powell et al. 2003). Comparing the effect of different strategies within and also across the provinces is likely to yield more relevant solutions and lessons for all Canadians than most other sources of guidance. There are only so many solutions which make sense for similar problems (Blumenthal and Osborn 2013).

Improving PHC performance reporting to fuel a smarter PHC system with greater capacity to learn and improve requires regular and comparable sources of data, which can be relied on by stakeholders to enable timely assessments of performance. As several provinces are currently building their PHC performance reporting strategies, such as Ontario's Health Quality Council's PHC performance framework and measurement and reporting strategy (Health Quality Ontario 2014b), a shared focus on developing high-quality and cost-effective data collection that enables provinces to further analyze and report on their priorities is needed. In some instances, existing national and international sources of data can play that role. The CCHS, administered and analyzed by Statistics Canada, is deployed annually, yet had limited and variable uptake by provinces over the past decade. This is despite the fact that it offers comparable provincial and health region information such as access to care provided by a regular family doctor or PHC provider. Regularly deployed international surveys can also offer valuable provincial-level reporting. In January 2016, CIHI publicly reported the results of The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians, presenting comparative data for each province on a range of measures from timely access to primary care appointments to proportion of primary care doctors who wait more than 15 days to receive a report from the hospital after a patient has been discharged (CIHI 2016). These data were possible because CIHI, the Canadian Institutes for Health Research and Canada Health Infoway, as well as the Provinces of Ontario and Quebec, agreed to pay extra for larger samples of providers in each province, enabling not only Pan-Canadian comparisons but also comparisons with nine other countries.

In 2013, CIHI launched a national toolkit of PHC performance measurement surveys, including a patient survey, provider survey and PHC organization survey (CIHI 2013a, 2013b, 2013c). These tools could also represent an efficient cost saver for provinces, eliminating the cost of developing new surveys in each province, while promoting standardized data collection.

EMRs are another source of patient and organizational data. The CIHI explored the potential for data extracted from EMRs to contribute to health system performance reporting as it currently does in the UK's Quality and Outcomes Framework program. However, that project concluded that EMR penetrance still does not cover most of the population, and usage patterns vary widely across healthcare providers, making attempts to extract standardized data labour-intensive and EMRs currently inadequate as a data source for comprehensive public reporting (CIHI 2014a). The focus on developing better EMR standards and the increasing uptake of EMRs may lead to EMRs as a valuable data source in the future. While Canada lost a decade of reporting and the learning opportunities that might have ensued, the UK, one of the most advanced countries for public PHC performance reporting, has just completed a review of its first 10 years of major reporting efforts (Dixon et al. 2015). Some lessons from the UK may offer guidance to Canada's next efforts; specifically, more is not always better. Rather than multiple initiatives reporting on the health system, a single site for public reporting is recommended with different interfaces aimed at specific audiences such as the public, providers and decision-makers. The different interfaces should be linked, ensuring full transparency, but the one aimed at the public should contain fewer indicators focusing on those most important to the public, such as access and satisfaction. These experiences can help guide our approach to PHC reporting. In 2013, CIHI conducted a large consultation with Canadians to identify their priorities for health system reporting in building their ourhealthsystem.ca website. Only a single PHC system indicator, access to a regular family physician, is reported on that website. The wealth of information available from existing sources ranging from the CCHS to the Commonwealth Fund's primary care physician survey should enable a richer assessment of the performance of the PHC system across Canada.

The promise of a new health accord between the Federal Government and the Provinces (Liberal Party of Canada 2015a, 2015b) offers an opportunity to accelerate ongoing learning from national innovations through publicly reported performance information. As the Federal and Provincial Governments look forward to the next decade of health system reform and accountability, they should aim for a shared commitment to updating priorities for public reporting, developing a small common core set for the public and a broader set for decision-makers and ensuring comparability of data across the country using stable and accessible data sources including existing national and international sources. PHC is too important to this country to continue to lag behind in accountability and capacity for improvement.

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References

Aggarwal, M. and B. Hutchison. 2012. *Toward a Primary Care Strategy Canadian Foundation for Healthcare Improvement*. Ottawa, ON: Canadian Foundation for Healthcare Improvement. Retrieved March 31, 2016. <http://www.cfhi-fcass.ca/sf-docs/default-source/reports/Primary-Care-Strategy-EN.pdf?sfvrsn=0>.

Berta, W., J. Barnsley, A. Brown and M. Murray. 2008. "In the Eyes of the Beholder: Population Perspectives on Performance Priorities for Primary Care in Canada." *Healthcare Policy* 4(2): 86–100.

Best, A., T. Greenhalgh, S. Lewis, J.E. Saul, S. Carroll and J. Bitz. 2012. "Large-System Transformation in Health Care: A Realist Review." *Milbank Quarterly* 90(3): 421–56.

Blumenthal, D and R. Osborn. 2013. *In Pursuit of Better Care at Lower Costs: The Value of Cross-National Learning*. Retrieved June 11, 2013. <www.commonwealthfund.org/Blog/2013/Apr/The-Value-of-Cross-National-Learning.aspx>.

Canadian First Ministers. 2003. *First Ministers' Accord on Health Care Renewal*. Retrieved February 25, 2013. <www.hc-sc.gc.ca/hcs-sss/delivery-prestation/fptcollab/2003accord/index-eng.php>.

Canadian Institute for Health Information (CIHI). 2006. *Pan-Canadian Primary Health Care Indicators (Rep. No. 1)*. Ottawa, ON: CIHI.

Canadian Institute for Health Information (CIHI). 2009. *Health Care in Canada 2009: A Decade in Review*. Ottawa, ON:CIHI.

Canadian Institute for Health Information (CIHI). 2012. *Pan-Canadian Primary Health Care Indicator Update Report*. Ottawa, ON: CIHI.

Canadian Institute for Health Information (CIHI). 2013a. *Attributes of Primary Health Care: Provider Survey*. Ottawa, ON: CIHI.

Canadian Institute for Health Information (CIHI). 2013b. *Measuring Organizational Attributes of Primary Health Care Survey*. Ottawa, ON: CIHI.

Canadian Institute for Health Information (CIHI). 2013c. *Measuring Patient Experiences in Primary Health Care Survey*. Ottawa, ON: CIHI.

Canadian Institute for Health Information (CIHI). 2014a. *Chronic Disease Management in Primary Health Care: A Demonstration of EMR Data for Quality and Health System Monitoring*. Toronto, ON: CIHI.

Canadian Institute for Health Information (CIHI). 2014b. *The Hospital Morbidity Database*. Retrieved August 1, 2014. <www.cihi.ca/cihi-ext-portal/internet/en/document/types+of+care/hospital+care/acute+care/hmdb_metadata>.

Canadian Institute for Health Information (CIHI). 2016. *How Canada Compares: Results from The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians*. Ottawa, ON: CIHI.

Dahrouge, S., W. Hogg, G. Russell, R. Geneau, E. Kristjansson, L. Muldoon et al. 2009. "The Comparison of Models of Primary Care in Ontario (COMP-PC) Study: Methodology of a Multifaceted Cross-Sectional Practice-Based Study." *Open Medicine* 3(3): e149–64.

Dixon, J., E. Spencelayh, A. Howells, A. Mandel and F. Gille. 2015. *Indicators of Quality of Care in General Practices in England: An Independent Review for the Secretary of State for Health*. London, UK: Health Foundation.

Ellins, J.L. and S.A. McIver. 2009. *Supporting Patients to Make Informed Choices in Primary Care: What Works?* Birmingham: University of Birmingham.

Government of Canada. 1985. *Canada Health Act*. C-6. Retrieved April 17, 2016. <http://laws-lois.justice.gc.ca/eng/acts/C-6/>.

Health Council of Canada. 2012. *Measuring and Reporting on Health System Performance in Canada: Opportunities for Improvement*. Toronto, ON: Health Council of Canada.

Health Quality Ontario. 2014a. *A Primary Care Performance Measurement Framework for Ontario: Report of the Steering Committee for the Ontario Primary Care Performance Measurement Initiative: Phase One*. Toronto, ON: Queen's Printer for Ontario.

Health Quality Ontario. 2014b. *Public Reporting in Primary Care*. Retrieved August 1, 2014. <www.hqontario.ca/public-reporting/primary-care>.

Hibbard, J.H., J. Greene, S. Sofaer, K. Firminger and J. Hirsh. 2012. "An Experiment Shows that a Well-Designed Report on Costs and Quality can Help Consumers Choose High-Value Health Care." *Health Affairs* 31(3): 560–68.

Hogg, W., M. Rowan, G. Rowan, R. Geneau and L. Muldoon. 2008. "Framework for Primary Care Organizations: The Importance of a Structural Domain." *International Journal for Quality in Health Care* 20(5): 308–13.

Hutchison, B. 2013. "Reforming Canadian Primary Care – Don't Stop Half-Way." *Healthcare Policy* 9(1): 12–25.

Hutchison, B., J.F. Levesque, E. Strumpf and N. Coyle. 2011. "Primary Health Care in Canada: Systems in Motion." *Milbank Quarterly* 89(2): 256–88.

Lester, H. and M. Roland. 2009. "Performance Measurement in Primary Care." In P.C. Smith, E.M. Mossialos and I. Papanicolas, eds., *Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects*. Cambridge: Cambridge University Press.

Liberal Party of Canada. 2015a. A New Health Accord. Retrieved April 17, 2016. <www.liberal.ca/realchange/a-new-health-accord/>.

Liberal Party of Canada. 2015b. *Policy Resolution 38*. Retrieved April 17, 2016. <www.liberal.ca/policy-resolutions/38-deal-health-care/>.

Oxman, A.D., J.N. Lavis, S. Lewin and A. Fretheim. 2009a. "SUPPORT Tools for Evidence-Informed Health Policymaking (STP) 1: What Is Evidence-Informed Policymaking?" *Health Research Policy and Systems* 7(Suppl 1): S1.

Oxman, A.D., S. Lewin, J.N. Lavis and A. Fretheim. 2009b. "SUPPORT Tools for Evidence-Informed Health Policymaking (STP) 15: Engaging the Public in Evidence-Informed Policymaking." *Health Research Policy and Systems* 7(Suppl 1): S15.

Powell, A.E., H.T. Davies and R.G. Thomson. 2003. "Using Routine Comparative Data to Assess the Quality of Health Care: Understanding and Avoiding Common Pitfalls." *Quality & Safety in Health Care* 12(2): 122–28.

Prescribing and Primary Care Services, H. a. S. C. I. C. 2014. *Quality and Outcomes Framework – Prevalence, Achievements and Exceptions Report Leeds*. Retrieved April 17, 2016. <http://www.hscic.gov.uk/qof>.

Smith, M.A., A. Wright, C. Queram and G.C. Lamb. 2012. "Public Reporting Helped Drive Quality Improvement in Outpatient Diabetes Care among Wisconsin Physician Groups." *Health Affairs* 31(3): 570–77.

Smith, P. 2009. *Performance Measurement for Health System Improvement Experiences, Challenges and Prospects*. Cambridge: Cambridge University Press.

Starfield, B. 1998. *Primary Care: Balancing Health Needs, Services and Technology*. 2nd ed. New York, NY: Oxford University Press.

Starfield, B., L. Shi and J. Macinko. 2005. "Contribution of Primary Care to Health Systems and Health." *Milbank Quarterly* 83(3): 457–502.

The Commonwealth Fund. 2011. *Commonwealth Fund International Health Policy Survey*. Retrieved April 12, 2013. <www.commonwealthfund.org/Surveys/2011/Nov/2011-International-Survey.aspx>.

The Conference Board of Canada. 2013. *How Canada Performs – A Report Card on Canada*. Ottawa: The Conference Board of Canada.

Watson, D.E. 2009. "For Discussion: A Roadmap for Population-Based Information Systems to Enhance Primary Healthcare in Canada." *Healthcare Policy* 5: 105–20.

Wong, S.T., D.E. Watson, E. Young and S. Regan. 2008. "What do People Think Is Important about Primary Healthcare?" *Healthcare Policy* 3(3): 89–104.

World Health Organization (WHO). 1978. *Declaration of Alma-Ata*. Geneva: WHO.

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