

HEALTHCARE

POLICY

Politiques de Santé

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

Volume 13 + Number 2

**What Is Bending the Cost Curve? An Exploration of Possible Drivers
and Unintended Consequences**

KIMBERLYN MCGRAIL AND MEGAN AHUJA

Personal Support Workers in Canada: The New Precariat?

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**What's Involved with Wanting to Be Involved? Comparing Expectations for
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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.

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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Demonstrating the Unique Value a Study Adds

SCIENTIFIC PROGRESS IS CUMULATIVE AND ITERATIVE. ECHOING A METAPHOR that extends back to at least the 12th century, Sir Isaac Newton (1675) famously said, “If I have seen further, it is by standing on ye shoulder of giants.”

Perhaps I have just hit a bad patch, but too many times recently, I’ve been asked to review articles or grant applications that fail to acknowledge the foundations of research and innovation they are building upon. The phrase ‘never been done before’ sends me straight to PubMed and/or Google. If something as simple as a 10-minute online search turns up evidence that refutes this claim, expect a cranky review.

Case in point: development of mHealth apps. I’ve reviewed a wide range of research and investment proposals in this domain for provincial and national funders over the last year. With over 250,000 mHealth apps now available via major app stores (Research2Guidance 2016), there likely is already an app for that. Which is not to say that there is an app that is safe, effective, privacy-sensitive, integrated with consumer/patient and clinical workflow, and tailored to the needs and expectations of a specific target audience. Such gaps may partly explain why most mHealth app developers report less than 5,000 downloads per year for their entire portfolio (Research2Guidance 2016).

In this domain and others, it is important to be clear about what unique value a proposal or journal submission offers. Replication research is fine, indeed important. So is diversity in the market through innovation that delivers value. But being able to demonstrate an understanding of the context in which you will be undertaking a study or developing a product is key. If you show that you understand what has already been done, who the clinical and market leaders are, and where gaps exist, acceptance is much more likely. Likewise, an article that highlights what we knew before and what this research adds is much more apt to be published than one that does not. (And in fast-moving fields or ones where knowledge is often shared through non-traditional mechanisms, reviewing the indexed literature is insufficient. A broader scan is needed to gain an appreciation of the current environment and its evolution.)

This issue of *Healthcare Policy/Politiques de Santé* continues our efforts to help you to keep up-to-date on the latest developments across the health sector. Some authors weigh in on broad issues, such as trends in health spending and public engagement. Others focus on what we can learn from specific situations, ranging from trends in prior authorization

From the Editor-in-Chief

and use of direct-acting oral anticoagulants to the working conditions of personal support workers. Through their work, I hope that you will find useful insights – anchored in an understanding of existing research and practice – that help to advance understanding and perspectives on improving health and healthcare.

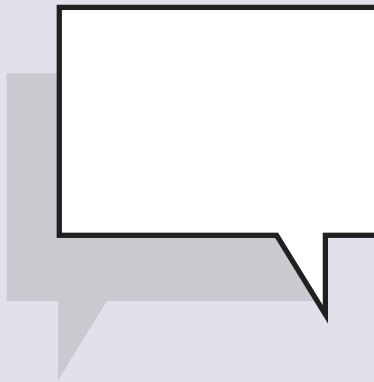
JENNIFER ZELMER, PHD

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Démontrer la valeur unique qu'apporte une étude

DANS LE DOMAINE DE LA SCIENCE, LA PROGRESSION EST CUMULATIVE ET itérative. En écho à une métaphore qui nous vient d'aussi loin que le XII^e siècle, Sir Isaac Newton (1675) a dit : « si j'ai vu plus loin, c'est en montant sur les épaules de géants ».

C'est peut-être simplement un effet du hasard, mais récemment j'ai été réviseure pour plusieurs articles ou demandes de bourses et trop souvent les auteurs omettent de reconnaître les fondements sur lesquels repose leur recherche ou leur innovation. La phrase « ça n'a jamais été fait jusqu'à maintenant » me pousse à consulter directement les sites PubMed ou Google. Si en 10 minutes je trouve une source qui annule cette phrase, alors ma révision sera plus sourcilleuse.

Exemple concret : le développement des applications de santé mobile. Cette année j'ai révisé, au nom de bailleurs de fonds provinciaux ou nationaux, plusieurs propositions de recherche et d'investissement dans ce domaine. Avec plus de 250 000 applications de santé mobile offertes par les boutiques en ligne (Research2Guidance 2016), il y a vraisemblablement déjà une application pour presque tout. Cela ne veut pas dire qu'elle soit sécuritaire, efficace, respectueuse de la vie privée, intégrée aux besoins des patients ou des cliniques et faite sur mesure pour une clientèle cible. De telles lacunes expliquent peut-être pourquoi la plupart des développeurs d'applications de santé mobile indiquent avoir moins de 5 000 téléchargements par année pour l'ensemble de leurs produits (Research2Guidance 2016).

Dans ce domaine, comme dans d'autres, il est important de démontrer clairement la valeur propre qu'apporte une proposition de projet ou une soumission d'article. La reproductibilité est certes une chose importante, mais il est essentiel de savoir démontrer la compréhension du contexte dans lequel a lieu une étude ou le développement d'un produit. Un projet a plus de chance d'être accepté si on montre une compréhension de ce qui s'est fait avant, si on connaît les leaders dans cliniques et sur le marché et si on sait où se trouvent les lacunes. Pareillement, un article qui présente l'état des connaissances actuelles et qui explique ce qu'y apporte la recherche a plus de chance d'être publié qu'un article qui omet ces aspects. (Dans les domaines à développement rapide et où les connaissances cheminent souvent par des voies non traditionnelles, il ne suffit pas de faire une revue de la littérature répertoriée. Il faut élargir son exploration pour avoir une appréciation réelle du contexte actuel et de son évolution.)

Ce numéro de *Politiques de Santé/Healthcare Policy* vous met encore une fois à jour sur les derniers développements dans le secteur de la santé. Certains auteurs se penchent

De la rédactrice en chef

sur de grands enjeux tels que les tendances pour les dépenses de la santé et l'engagement public. D'autres mettent l'accent sur ce que peuvent nous enseigner des situations précises, que ce soient les tendances pour l'autorisation préalable et l'utilisation d'anticoagulants oraux directs, ou encore, les conditions de travail des préposés aux patients. J'espère que ces travaux vous apporteront des pistes intéressantes – ancrées dans une compréhension de la recherche et des pratiques existantes – qui contribueront à l'avancement et à l'amélioration des services et systèmes de santé.

JENNIFER ZELMER, PHD

Rédactrice en chef

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A Survey of Health Equity Practices in Early Psychosis Intervention Programs: A Starting Point for Improvement

Sondage sur les pratiques d'équité en santé dans les programmes d'intervention précoce pour le traitement de la psychose : un point de départ pour l'amélioration



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Abstract

Equity has been identified as a core component of quality healthcare in Ontario. However, translating policy into practice can be challenging. This paper reports results from a province-wide survey of early psychosis intervention programs to assess the extent to which

equity has been incorporated into program delivery. All 56 programs (100%) completed the survey. Results found that while most programs perceive that they are meeting equity aims, they reported limited use of practices to support this aim, and few systematically collect information on performance. Strategies to improve equity in practice are discussed.

Résumé

L'équité a été désignée comme composante centrale de la qualité des services de santé en Ontario. Cependant, transposer les politiques en pratiques présente un défi. Cet article fait état des résultats d'un sondage provincial mené auprès des programmes d'intervention précoce dans le traitement de la psychose, et ce, afin d'évaluer dans quelle mesure l'équité fait partie de la mise en œuvre du programme. L'ensemble des 56 programmes (100 %) ont répondu au sondage. Les résultats montrent que bien que la plupart des programmes ont la perception qu'ils atteignent les cibles en matière d'équité, ils rapportent avoir peu recouru aux pratiques qui soutiennent cet objectif, et peu de programmes recueillent systématiquement des données sur le rendement. L'article discute des stratégies visant à améliorer la équité dans la pratique.



Background

Equity is an established priority and legal requirement of the Ontario healthcare system (e.g., Accessibility for Ontarians with Disabilities Act 2005; Excellent Care for All Act 2010; French Language Services Act 1990). Health equity is defined as the absence of disparities in the health outcomes of specific populations that are “not only unnecessary and avoidable, but in addition, are considered unfair and unjust” (Whitehead 1992: 433). A health equity strategy is intended to create opportunities for all individuals to experience good health, and reduce differences in the health outcomes of specific populations, for example, due to gender, sexual orientation, geography, ability, ethnicity or income. Importantly, a health equity approach is more than the absence of discrimination; it requires active steps be taken to counteract the existing disparities faced by vulnerable groups.

In recent years, positive steps have been taken in Ontario to put policy into practice. The Ministry of Health and Long-term Care (MOHLTC) developed the Health Equity Impact Assessment (HEIA), a tool that organizations can use to identify unintended impacts of policies and programs for marginalized populations and follow-up mitigation and monitoring strategies (MOHLTC 2013). Several Local Health Integration Networks (LHINs; regional health authorities) have implemented system-wide initiatives to expand and standardize socio-demographic data collection with the aim of improving health equity (e.g., Mississauga Halton LHIN 2016; Toronto Central LHIN and Mount Sinai Hospital 2016). Health Quality Ontario (HQO), a provincial agency that monitors the quality of healthcare, includes equity as one of six dimensions of quality care it monitors and reports annually as part of the Common Quality Agenda (Health Quality Ontario 2016a).

Despite these initiatives, health service providers have received limited direction on specific approaches to address health inequities in their programs. It remains mostly up to individual organizations to identify strategies to implement and set equity targets.

Early Psychosis Intervention (EPI) is one of a funded basket of services in the community mental health and addictions system in Ontario. EPI is an evidence-based model of care aimed at engaging young adults in treatment as soon as possible after their first episode of psychosis to minimize duration of untreated psychosis. The EPI model takes a holistic approach to treatment and, in addition to medication and therapy, focuses on active outreach, psychoeducation, re-engagement in education or work, physical health monitoring and family support (Bird et al. 2010).

Despite this emphasis on early engagement in care, research has shown that factors including race, ethnicity, gender, sexual orientation, income and immigration status are associated with compromised access to EPI programs, including negative pathways into care (i.e., access through justice or hospital) (Anderson et al. 2010; Bhui et al. 2003), higher dropout rates (Ouellet-Plamondon et al. 2015) and overall reduced help-seeking (Franz et al. 2010). Recognizing these issues, health equity is explicitly embedded in the Ontario EPI Program Standards (MOHLTC 2011). Standard 11, Barrier-Free Services, includes the expectation that individuals from all communities are able to access EPI services and that services are delivered in a manner sensitive to the backgrounds and experiences of different clients, considering language, customs, beliefs and other factors. The Standard lists strategies for programs to use to meet these aims; these pertain to both service quality (i.e., recruitment of diverse staff, use of interpreters, multilingual program materials, youth-friendly physical space) and access (i.e., self-referral, community early identification system).

After the EPI Program Standards were released, a committee was formed to support implementation. An initial task was a sector-wide key informant survey to learn about EPI program delivery in relation to the Standards. The present paper reports survey results for the Barrier-Free Standard, including the extent to which programs have incorporated health equity practices into service delivery, and available supports.

Method

Survey development

Two online surveys were developed as part of a larger project to obtain sector feedback on implementation of the EPI program Standards. Results from the first survey (Standards 1–6) are reported elsewhere (Durbin et al. 2016). The second survey on implementing Standards 7–13 asked about overall compliance, use of various implementation practices and availability of implementation supports. Survey development was supported by reviewing the literature and relevant policy documents, several iterations of feedback from Ontario EPI service providers on the clarity of survey questions and response options and on relevance of items to the Ontario system. The survey contained 85 questions in total.

Pertaining to the Barrier-Free Standard, there were 11 questions, both close-ended (Likert scale) and open-ended. Within these questions, programs were asked to rate: (1) overall compliance regarding the extent to which clients reflected the diversity of the local community and the extent to which the program was able to meet their treatment needs; (2) frequency of use of 14 strategies for incorporating a health equity approach into program delivery, with items based on Canadian and international equity policies and literature (e.g., Department of Health 2001; Registered Nurses' Association of Ontario 2007; Singh and Kunar 2010); (3) the extent to which additional supports were needed to promote the inclusion of 11 vulnerable groups, with groups based on the HEIA (MOHLTC 2013) and (4) the availability of administrative supports for this work (six items). In open-ended questions, respondents had the opportunity to elaborate on their responses and describe innovative practices.

Data collection

All 56 Ontario EPI programs were invited to complete the survey during February and March 2014. An invitation was sent to a contact person at each program, usually a manager or clinical lead, with follow-up e-mails and telephone calls to encourage completion.

Analysis

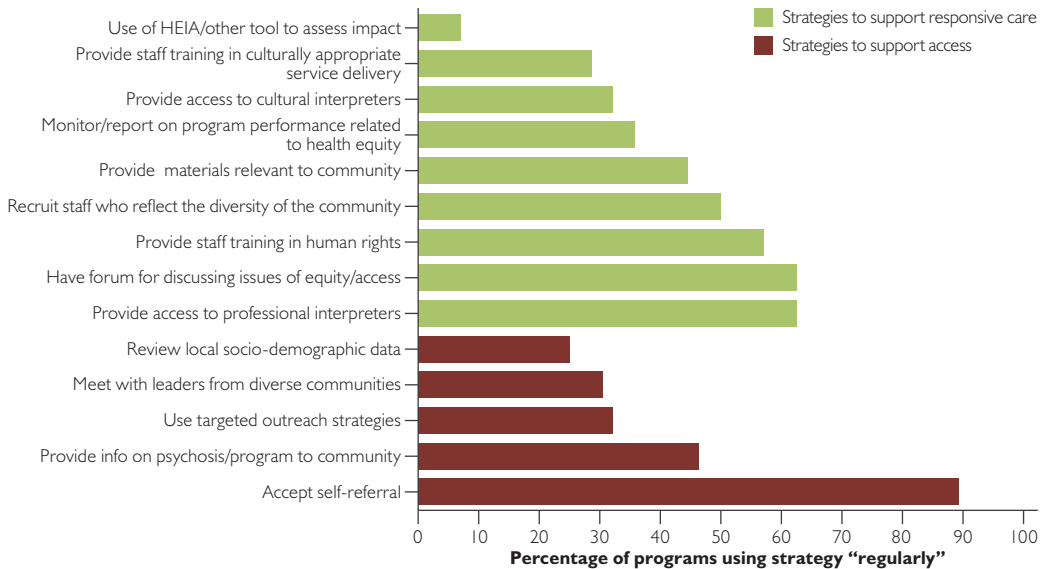
For the close-ended items, percentages were calculated of programs who indicated yes (vs. no), regularly (vs. not at all/rarely or sometimes) or a fair amount or great deal (vs. not at all/rarely or occasionally), as relevant. Results were calculated for the sample as a whole and then compared for small programs (two or fewer full-time equivalent [FTE] clinical staff) and large programs (greater than two clinical FTEs). Large programs typically serve urban catchment areas, whereas small programs serve rural or mixed urban/rural catchment areas (Durbin et al. 2016). Fisher's Exact tests were used to determine significance. Qualitative feedback from open-ended questions was summarized to distill key ideas.

Ethics approval for this study was obtained from the research team home institution.

Results

Fifty-six Ontario EPI programs participated in the survey, achieving a 100% response rate. Informant ratings of overall compliance with the Barrier-Free Standard were high, with the majority of programs (84%) reporting that they were able to meet the treatment needs of diverse clients a fair amount or great deal, and that the clients reflected the diversity of their local community. However, use of strategies to support equitable access and care was variable, with 10 of 14 assessed strategies used by fewer than half of programs (see Figure 1). Only one-third of programs reported regularly on their program performance related to health equity to their Board or LHIN; only 7% regularly used the HEIA or other equity assessment tools.

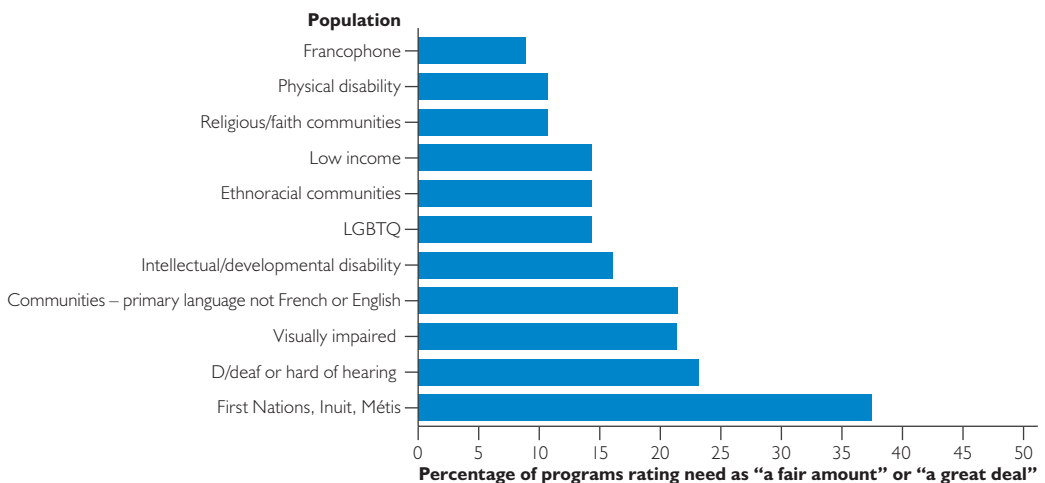
FIGURE 1. Program use of strategies to support barrier-free care (N = 56)



HEIA = Health Equity Impact Assessment. Percentage reporting "regularly" versus "occasionally" or "rarely/not at all".

Regarding access for marginalized groups, almost 40% of programs identified First Nations, Inuit and Métis and 21–23% identified linguistic minorities and persons who are D/deaf, hard of hearing or visually impaired as communities for whom additional support was needed to engage and appropriately meet their needs (Figure 2). Although fewer programs requested additional support to engage individuals with developmental disabilities, qualitative results found that some programs felt challenged to provide care for this population.

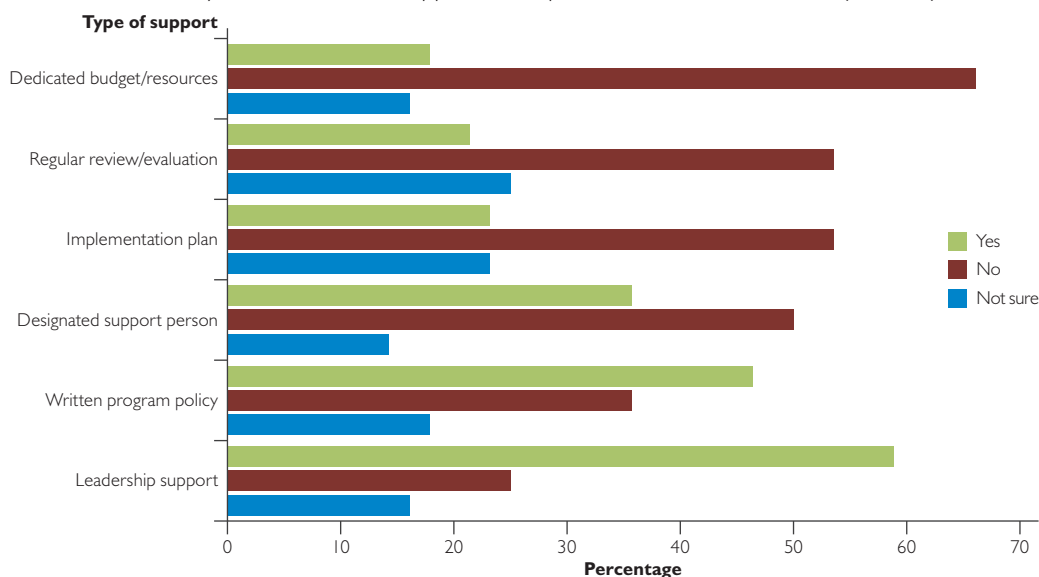
FIGURE 2. Program rating of need for additional support for inclusion of specific populations (N = 56)



LGBTQ = lesbian, gay, bisexual, transgender and queer. Percentage of programs reporting "a fair amount" or "a great deal" versus "not at all" or "somewhat".

Almost 60% of programs reported having leadership support to implement the Standard and almost half had a written policy. However, few programs reported having a designated support person (36%), an implementation plan (23%) or dedicated resources (18%), and few regularly evaluated their performance (21%) (Figure 3). A high number of respondents were uncertain whether or not supports were available. Qualitative responses provided more detail on implementation challenges including: limited resources to conduct outreach; insufficient staff training; difficulty recruiting staff reflective of the community and an inaccessible physical space.

FIGURE 3. Availability of administrative supports to implement barrier-free service (N = 56)



There were generally no significant differences between large ($n = 31$) and small ($n = 25$) programs (not shown). The only exceptions were that small programs were more likely to meet with leaders from diverse communities (48% vs. 16%; $p = 0.02$) and large programs were more likely to provide access to interpreters (77% vs. 44%; $p = 0.01$).

Overall, the qualitative responses revealed that while some programs are using innovative and creative strategies to incorporate equity approaches into their programs, others identified significant barriers. Additionally, some respondents stated that they were unfamiliar with the term “health equity” and others gave responses indicating a misunderstanding of the concept, for example: “We are not excluding anyone from our program at this time.” “Equity is not a concern in our small agency/small community. We do not discriminate against any minority group.”

Discussion

This study found that most programs believed they were providing equitable care; however, use of practices to support this aim was limited. To enhance access, most programs accepted

self-referrals but few reported regular use of other strategies (e.g., review of local socio-demographic data to identify underserved groups). To make care responsive, many programs offered access to language interpreters but few provided regular staff training on equity. Only one-third systematically monitored their performance and few used the HEIA or other tools to assess impact of program practices or changes on disadvantaged groups, though it is provincially recommended. The survey results suggest that despite the focus on equity at a policy level, there is a lack of understanding of health equity among some programs, low use of equity promoting strategies and a lack of resources and support for this work.

Our findings align with a broad literature showing the challenge of translating policy into practice and the need for active and sustained efforts to achieve practice change (Torrey et al. 2012; Wyatt et al. 2016). Our findings also echo other Ontario work. Public Health Ontario investigated the use of health equity tools and similarly found that the absence of resources and a shared understanding of equity were barriers to the uptake of the tools. They found that incorporating equity indicators into performance reporting was an important facilitator of success (Tyler et al. 2014). In their Health Equity Plan (2016b), HQO highlighted the need to build capacity for health equity through education and knowledge exchange, and the importance of ongoing generation of both provincial and local data to better understand what is needed.

Based on these findings, we suggest two strategies to support the dual aims of more equitable access and more equitable care in Ontario EPI programs that may be feasible to implement.

First, although most programs reported they were serving all members of their communities, few are systematically collecting and reviewing information to understand who is and who is not accessing services. EPI and other programs need a deliberate strategy for routinely collecting demographic data on their service population and comparing to community profiles. Effective collection and use of data for quality monitoring is a common challenge in community programs (Mental Health and Addictions Leadership Advisory Council 2015) and selecting a specific issue to address may be a good starting point. Socio-demographic equity indicators are starting to be monitored in provincial and regional reporting (e.g., Health Quality Ontario 2016a, LHIN service accountability agreements), so the data that programs collect can be used to meet broader accountability reporting, and also create an opportunity for comparing and learning from each other.

Efforts to track program access may be supported by work that has been done by the Toronto Central LHIN to define a minimum set of key socio-demographic variables, supported by eight standardized questions, for monitoring access to service (Toronto Public Health et al. 2013). Collecting these data is currently required in the 17 Toronto Central LHIN hospitals and the standardized questions are being recommended for inclusion in the Ontario Common Assessment of Need, a province-wide assessment tool in community mental health programs. Providing training to front-line staff on the aims of health equity, the value of this information and strategies for asking sensitive questions will be key (Toronto Public Health et al. 2013).

Second, programs may need additional direction, training and field coaching/supervision support on how to serve diverse groups. Regional bodies, such as the LHINs, and sector-specific networks, such as the Early Psychosis Intervention Ontario Network, can collaborate to identify needs and provide supports. These efforts also may identify policy gaps around mandates and admission criteria for serving more vulnerable groups. For example, in our survey, some EPI programs indicated a lack of clarity on their role in supporting young adults with developmental disabilities. Although programs recognized the importance of ensuring equitable treatment for this population, they were unclear on whether and how this could be achieved in EPI programs and what their role was in relation to other parts of the system (e.g., the social services sector). Policies at the regional or provincial level on how to include more complex populations would offer programs guidance and create consistency across the province. That said, there will still be a need for local adaptation given regional population differences and the unique needs and resources of local communities.

A key strength of this study is the high response rate, providing full provincial representation for this sector. However, the study did not include the perspective of clients and families, or the experience of those who have not been able to access services. Future work could examine clients' and families' perceptions on whether the assessed strategies could lead to reduced barriers to access, or what else might be helpful. Follow-up work could also explore factors that contribute to some organizations making equity a priority and devoting resources to it. It should be noted that the survey was confidential but not anonymous and it is possible that programs may have inflated their responses, suggesting that use of equity strategies in practice may be even lower than reported.

Although equity is a core component of the EPI Standards and has been clearly endorsed in Ontario healthcare policy, few programs have been able to implement specific and purposeful equity approaches in practice. Similar challenges may exist in other health services. A more active implementation approach at front-line program levels, that includes better information about who programs are serving and strategies to improve care for identified vulnerable populations, is necessary to achieve an equitable healthcare system.

Acknowledgements

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What Is Bending the Cost Curve? An Exploration of Possible Drivers and Unintended Consequences

Qu'est-ce qui fait fléchir la courbe des coûts? Exploration des incitateurs possibles et des effets non-intentionnels



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Abstract

Health expenditures in most OECD countries have increased at a slower rate since 2008/2009. Potential drivers of this bending of the cost curve include: (1) changes in pharmaceuticals and technology innovations; (2) healthcare reforms, and specifically those focusing on care for complex and high-user patients and (3) government expenditure controls resulting from general economic conditions. We use publicly available National Health Expenditure data from the Canadian Institute for Health Information to assess the merits of each of these drivers, with a focus on British Columbia. We find some evidence for the effects of changes in pharmaceuticals and technology, but the dominant effect is government spending controls, which are greatest for non-Medicare-covered services. These changes suggest potential unintended consequences on access and equity that should be understood before declaring victory for healthcare expenditure control.

Résumé

Dans la plupart des pays de l'OCDE, on observe un ralentissement du taux d'augmentation des dépenses de santé depuis 2008–2009. Les incitateurs potentiels de ce fléchissement de la courbe des coûts incluent : 1) les changements pharmaceutiques et les innovations technologiques; 2) les réformes des services de santé, particulièrement celles qui portent sur les soins pour les états de santé complexes et celles qui visent les grands utilisateurs de services; et 3) le contrôle des dépenses gouvernementales découlant de la conjoncture économique générale. Nous employons les données publiques disponibles sur les dépenses nationales de santé, de l'Institut canadien d'information sur la santé, afin d'évaluer la qualité de chacun de ces incitateurs, en mettant l'accent sur la Colombie-Britannique. Nous avons dégagé certaines données concernant les effets des changements pharmaceutiques et technologiques, mais l'effet dominant reste le contrôle sur les dépenses gouvernementales, lequel est plus important pour les services non couverts par l'assurance maladie. Ces changements laissent entrevoir d'éventuels effets non-intentionnels en matière d'accès et d'équité, lesquels devraient être mieux compris avant de déclarer victoire sur le contrôle des dépenses de santé.

THE HEALTHCARE COST CURVE BENT IN 2008/2009, WITH OVERALL EXPENDITURES increasing more slowly since then in most OECD countries, including Canada. Bending of the cost curve appears to be mainly the result of overall government spending controls rather than policy success within the health sector. Negative effects on equity and access are potential unintended consequences of this form of cost containment.

Healthcare expenditures are increasing in OECD countries including Canada, but the pace has slowed since 2008/2009 (OECD 2017). OECD data show an average annual growth in per capita health spending of 3.4% for 2005–2009 but only 0.5% for 2009–2013 (OECD 2015). There is extensive literature on healthcare expenditure trends (Chandra et al. 2013; CIHI 2013b; Cuckler et al. 2013; Cutler and Sahni 2013; Morgan and Astolfi 2014; Roehrig et al. 2012) which we do not re-produce here. Instead, this analysis focuses on the most recent period of slowed spending growth, and attempts to identify its causes and potential consequences, with a specific focus on British Columbia. In contrast to other analyses (Di Matteo and Busby 2016; McGrail and Evans 2014), we focus both on total spending, and private and public contributions to this total.

What Might Be Controlling Healthcare Expenditures?

One potential explanation is changes in pharmaceuticals and other technological innovations. In the pharmaceutical sector, a few expensive drugs came off patent, there have been fewer new blockbuster drugs and governments have focused on controlling drug costs. The combination of these developments may have at least temporarily disrupted increasing expenditure

on pharmaceuticals (Cutler and Sahni 2013; Morgan and Astolfi 2014). At the same time, advances in other health technologies have slowed and there continues to be a shift in care from in-patient to out-patient settings (Cutler and Sahni 2013).

A second possibility is that health reform efforts are working. Many recent health reforms are built around the “Triple Aim” of improving the experience of care, improving population health and controlling per capita expenditures on health (Berwick et al. 2008). In many jurisdictions, a commitment to the Triple Aim prompted reforms that focus on chronic disease management and/or modifying service delivery for high users of healthcare services (Delon and MacKinnon 2009; General Practice Services Committee 2015; MOHLTC 2012). Reforms involving better coordination of care for patients moving among healthcare providers and the introduction and improvement of disease management programs may decrease hospitalizations, improve the health status of patients and positively change their health behaviours (Brown et al. 2012; Lorig et al. 1999), all of which could lead to lower costs.

A third possibility is macroeconomic: the financial crisis in 2007–2009 forced governments to curtail public spending on healthcare. Some suggest this is the case, but the effects may be temporary in that once economies fully recover we will again see increases in healthcare expenditure growth (Cuckler et al. 2013; Cutler and Sahni 2013). In the absence of cost reductions coming from the health sector, governments may simply curtail spending in the areas that are most amenable to change in the short term. In Canada, this is likely to mean decreased spending in pharmaceuticals, other institutions and/or other health spending, as these are services outside the mandate of the *Canada Health Act* (Canada Health Act 1985), which covers only the hospital and physician sectors. A decrease in public spending on services not mandated by the *Canada Health Act* can be offset by increased private insurance coverage or by out-of-pocket spending, or can result in a decrease in access to and use of services. The effects of limited access may in some cases be offset by an increase in informal care, such as family members taking on the care of frail elders when residential beds are not available. This informal care is not monetized and thus not captured in healthcare expenditure calculations (Keating et al. 2014), though clearly it can have equity and financial implications.

The consistency in changes in country-level healthcare spending after 2008 may lead to the conclusion that the macroeconomic argument is most persuasive. However, the pharmaceutical and technology trends put forward equally cut across international borders as do ideas for healthcare reform (Morgan and Astolfi 2014). The Triple Aim in particular has had a broad international reach (The Commonwealth Fund 2013).

One potential way to disentangle the causes of cost-curve bending is to assess how changes in per capita spending on healthcare occur across age groups, across health sectors, and in terms of shares of public and private spending. If, for example, we observe a flattening of spending only on pharmaceuticals, we might conclude that the technology change effect is dominant. If instead we see flattening of public and an increase in private expenditures, we may conclude that government belt-tightening was dominant. This same could be true,

or perhaps health reform is working, if what we observe are changes in healthcare service use patterns across age groups.

All of these possibilities are examined here. We use Canada, and more specifically British Columbia (BC), as a case study, with the expectation that given the international similarity of overall trends, there will also be some similarity in its underlying causes.

What Data Can Be Used to Assess Trends?

The National Health Expenditure (NHEX) suite of data produced by the Canadian Institute for Health Information (CIHI) provides estimates of healthcare spending from 1975 forward (CIHI 2013a). Estimates of overall, public, private and sector-specific spending are available through 2016 (2015 and 2016 are forecasts), while public-sector age-specific trends are available through 2014. Spending on nursing homes and home care services is included in broader groupings; the former is the dominant part of “other institutions,” whereas the latter is the non-dominant part of “other health spending.” In 2016, hospitals, physicians, drugs, other institutions and other health spending accounted for 73% of total health expenditures in BC; it is those categories that are the focus here.

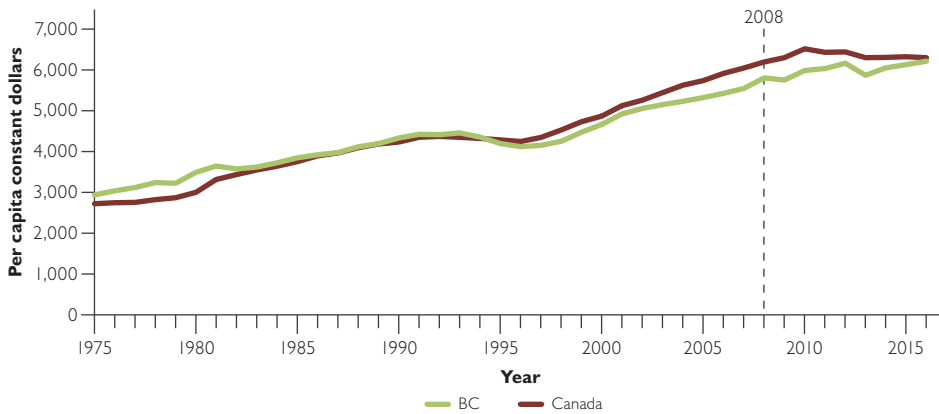
Current expenditures were converted to constant dollars using the implicit price index provided in an appendix to the NHEX data. This index is built based on public spending and so is imperfect as an adjuster, but consistently applied provides a reasonable approach to approximating constant dollars. We assess overall spending trends, public spending as a share of total, and both overall and age-specific trends for the five sub-sectors.

What Do the Data Show?

Overall spending in BC and in Canada follows the international trend, with increases slowing after 2008 (Figure 1). BC, home to about 12% of the Canadian population, shows a somewhat greater flattening of the curve, at least until 2016 (which are still projections). Figure 2 shows the percentage of the total and of each of the five sub-sectors paid for through public funding for BC. The share of total spending from public sources shifted very little from 1975 to 2016, starting and ending this period at 70%. There have, however, been some changes beneath this surface since 2008, including decreases in public coverage of drugs (34%–30%), other health spending (85%–70%) and other institutions (70%–56%). The latter in fact fell from a high of 88% in 2002.

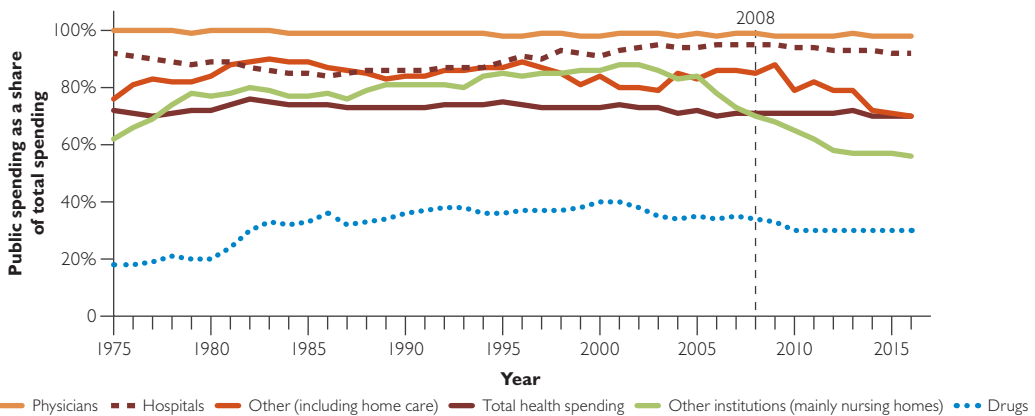
Total per capita spending (Figure 3) in constant dollars continues to increase for hospitals, albeit more slowly in the last few years, physician spending per person has been relatively flat since 2008, drugs have been a bit up and down and the other institutions and other categories are declining. Comparing public and private spending is more revealing about differences in these latter three sub-sectors. In the case of drugs, the declines are seen in both the private and public spending. In contrast, for both other institutions and other health spending, the declines in public spending have been offset, but not completely, by increases in private spending.

FIGURE 1. Constant dollar per capita total expenditure on healthcare, 1975–2016, Canada and BC



Source: CIHI NHEX 2016, Series A (Canada), D1 (BC) and Appendices.

FIGURE 2. Public spending as a share of total, overall and by sub-sector, BC, 1975–2016



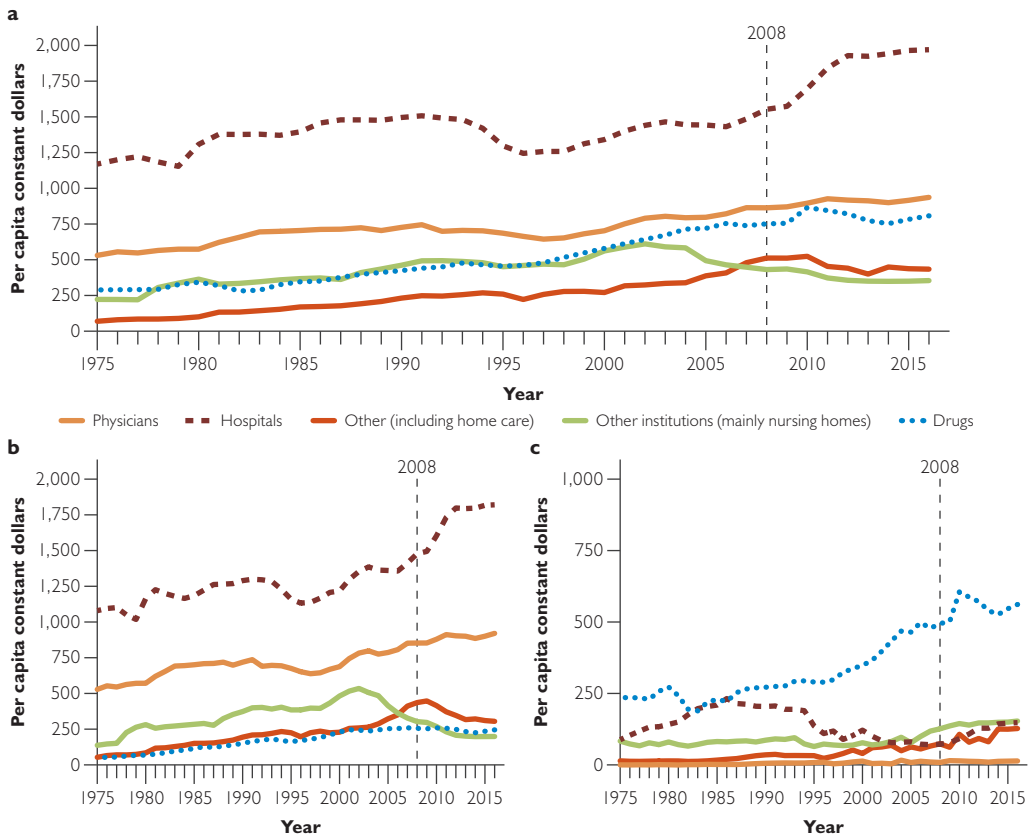
Note: Categories cover >80% of total spending. Source: Authors' calculations using CIHI NHEX, series D1 and D3.

A small proportion of people, largely older adults, have significant and complex needs, and as a result consume a high proportion of total care (Reid et al. 2003). For this reason, it is important to consider age-specific patterns of use, even though these are available only for the public portion of spending and not for the “other health spending” category.

Figure 4 shows age-specific use curves for public spending by sub-sector and overall for 1998 (first year of available information in all sub-sectors), 2008 (start of the “bend” in costs) and 2014 (last year of available information). As expected, expenditures generally rise with age, and between 2008 and 2014 overall per capita spending is relatively stable, with the largest changes seen for the youngest and oldest age groups (13.2% increase for the former, or 2.1% per year, and 12.0% decrease for the latter, or 1.9% per year). Hospital and physician services show the typical increases in spending over time, with the trends most pronounced for the older age groups. Other institutions (nursing homes) in contrast show a substantial

decline in public per capita spending over time; for example, the 80–84 age group had average per capita (constant dollar) spending in this sub-sector of \$4,700 in 1998, \$3,200 in 2008 and \$1,700 in 2014. Pharmaceutical spending per capita was stable between 2008 and 2013 for younger age groups, but there were substantial declines for those above 60.

FIGURE 3. Total (a), public (b) and private (c), constant dollar, per capita spending, BC, 1975–2015



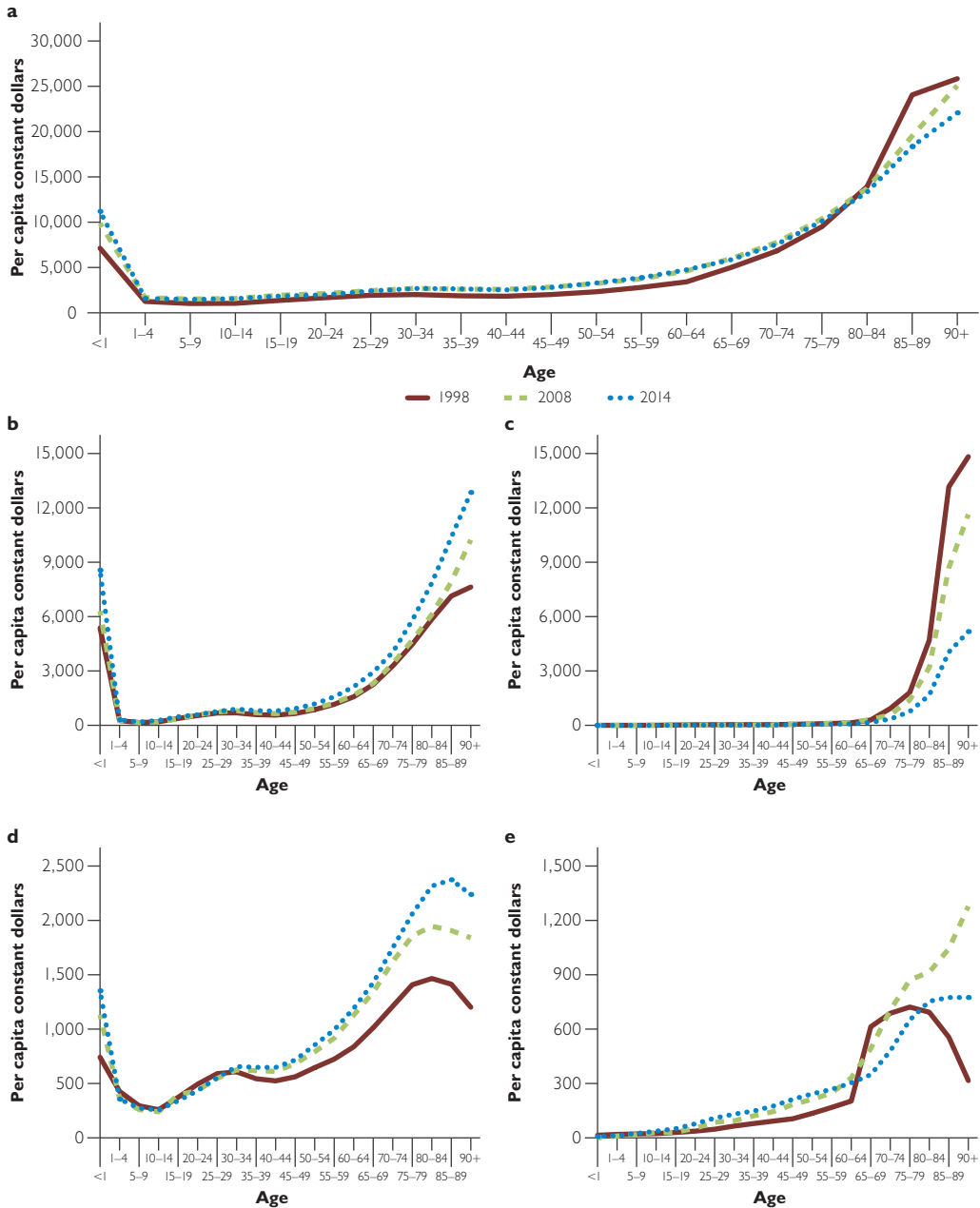
Source: Authors' calculations using CIHI NHEX, series D1, D2, D3 and Appendices.

What Are the Implications?

Healthcare costs have been increasing at slower rates in recent years, and this is not unique to BC or Canada. In BC, public and private expenditures are declining at an equal pace, as public spending as a share of total has not changed significantly since 1975. We proposed that there are three potential explanations for the bending of the cost curve in BC: changes in drugs and technology, effectiveness of targeted reform efforts and macroeconomic effects.

Since 2008, the public share for drugs, and more significantly, other spending (which includes home care) and other institutions (nursing homes) have all declined. This change in share was accompanied by overall declines in spending per capita for both public and private spending on drugs, but opposing public and private trends for the other two categories.

FIGURE 4. Age-specific, constant dollar, per capita public spending, BC, 1998, 2008 and 2014; total (a) and by sub-sector: hospitals (b), other institutions (mainly nursing homes) (c), physicians (d) and drugs (e)



Source: Authors' calculations, based on CIHI NHEx data, Series E and Appendices.

Public-sector age-specific trends show increasing spending across age groups for physician and hospital services, mixed age-specific spending since 2008 on drugs, but decreasing spending since 1998 for other institutions. The age-specific trend in drug expenditures in

combination with overall public and private trends suggests provincial cost controls and expensive drugs coming off patent were drivers of change (CIHI 2011). All of this suggests that changes in use and cost of drugs contributed to the ending of the cost curve, but that the story is more complex than that because of some cost-shifting as well.

The picture for the effects of targeted reform is more stark. The pronounced change both in lower total spending and lower share of public spending for other institutions and other health spending in part reflects a static supply of beds while the population is aging (Cohen et al. 2009), which will inevitably decrease cost per capita. The intent in BC was to offset the need for nursing homes with a public investment in Assisted Living and commitment to providing more care in the community, for example, through home care and home support (Cohen et al. 2005). However, the change in public share of expenditures and increases in private spending means there was also cost-shifting; the shrinking public nursing home sector was not fully offset by increased public spending in other areas. There is no private insurance in Canada for either home care or long-term care, so the shifts in those cases must have been from public to out-of-pocket spending. Further, the decrease in total spending implies a decline in access to care which will largely affect the most economically vulnerable older adults. Any compensatory care that is provided by family members or other informal caregivers is not captured in these financial data.

In other words, more controlled expenditures are not likely the result of better care for complex, high-use patients. If it were, we ought to see the results in reduced or at least more tightly controlled hospital and physician expenditures. Instead, those expenditures continue to increase while “savings” are achieved by shifting costs from public to private spending, and more specifically in the case of home care and nursing homes, from public to out-of-pocket spending by families.

This leaves macroeconomic effects as the most prominent driver of change, consistent with the analysis of government spending (i.e., public-only) trends reported elsewhere (Di Matteo and Busby 2016). As those authors point out, constraints imposed from outside the system can have effects, but these may not be sustained (or sustainable) over time. This will be an important challenge as provinces now face lower annual increases in transfers from the federal government (Galloway and Grant 2016; Government of Canada 2012).

There are some limitations to these analyses. Public health expenditures are reported by provincial Ministries of Health to CIHI, but private expenditures must be estimated. There are reasonable sources of estimates for drug spending, but estimates are more difficult for other institutions and the “home care” part of other health spending. It is possible estimates are not accurate over time, but if they are wrong, they are likely to be underestimated, and thus, if anything, the trends seen here are conservative.

More importantly, costs for Assisted Living and home support (as opposed to home care) are not included in the CIHI data used here. Public spending on these services among the elderly (where they are most heavily concentrated), however, increased by only \$50 million between 2008 and 2013 (BC Ministry of Health 2014). This increase was not quite enough to keep up with changing demographics, so including these expenditures would not materially alter the conclusions.

Finally, our analyses focus on Canada overall and BC specifically, not including other provinces. An initial assessment of the data suggested that while there are similarities across provinces, there are differences in trends too. Extending these analyses to other provinces would be instructive, but would also require in-depth knowledge of the healthcare context in each jurisdiction.

Where to from Here?

Healthcare systems everywhere have taken pride in bending the healthcare cost curve. These analyses suggest that in BC the macroeconomic hypothesis of tightening of spending is dominant, and that this tightening was selectively targeted at services that are outside the federal framework for public healthcare and can thus be treated as “discretionary.” This means we are shifting more costs to patients and their families. To the extent this means more informal care, the magnitude of this shift will be underestimated (perhaps substantially) in total health expenditures.

If the macroeconomic hypothesis is dominant in other provinces and countries as well, the specific effects on healthcare systems may be different, but the ultimate effects on equity and access are likely to be similar. Moreover, if history is a guide, these externally imposed constraints may not hold, as technological innovation expands again and populations continue to age. The aspiration must be to control costs while maintaining or improving the quality of care and the population’s health (Berwick et al. 2008).

Bending the cost curve by transferring costs to older, sick people and their families has not been an explicit policy choice in BC. That these changes may occur through the unintended consequence of a number of other choices does not blunt the impact they have on those affected. While the cost curve may be bending in healthcare, attention to the equity and access implications are required before declaring victory.

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Personal Support Workers in Canada: The New Precariat?

Les préposés aux patients au Canada : un nouveau précariat?



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Abstract

There has been much recent discussion internationally about the emergence in modern society of a new class of workers – the precariat – with a common consciousness based on features such as low wages, insecurity, short-term jobs, minority status and restricted rights. This paper critically explores the extent to which the growing, large-scale group of personal support workers (PSWs) can be viewed as part of a new precariat in terms of their position in the healthcare labour market. Drawing on currently available empirical data, this issue is examined particularly with reference to PSWs in Canada – drawing out some of the implications for government health policy in this sphere.

Résumé

Les débats internationaux récents évoquent souvent l'émergence, dans les sociétés modernes, d'une nouvelle classe de travailleurs – le précariat – dont les caractéristiques communes sont

des bas salaires, l'insécurité, des emplois temporaires, un statut minoritaire et des droits limités. Cet article explore, de façon critique, dans quelle mesure l'important groupe grandissant de préposés aux patients (PAP) peut être considéré comme un nouveau précarier en raison de sa place sur le marché du travail de la santé. Au moyen des données empiriques actuellement disponibles, l'article examine la question relativement aux PAP au Canada et fait ressortir certaines répercussions pertinentes pour les politiques de santé gouvernementales dans ce domaine.

The Precariat and Personal Support Work: An International Agenda

A new class has recently been argued to have emerged internationally in neo-liberal societies with the increasing privatization of the welfare state and developing New Public Management (Dent et al. 2004) – the “precariat.” The precariat includes “a multitude of insecure people, living bits-and-pieces lives, in and out of short-term jobs, without a narrative of occupational development ...” (Standing 2011: 14). The precariat is defined as an emerging class of workers and, as such, builds on, but is different from, precarious employment *per se*. Although both include many of the same principles (e.g., job insecurity and low wages) (Vosko 2006), they differ, as the precariat is defined as a collective group with a potential class consciousness and not simply as having similar precarious job characteristics. Precarious employment has therefore been common throughout history, whereas the new precariat class of workers is argued to have emerged following the rise of neo-liberalism in the 1970s (Standing 2011).

The recently defined precariat class includes a wide array of workers, in contrast to the contemporary proletariat of Marxist philosophy, as it does not have stable and predictable working conditions. To be sure, both classes lack ownership of the means of production, but the precariat does not have the same security as the proletariat in the labour market – with, among other things, laws regulating employers, greater upward social mobility, recognizable standards of workplace safety, stronger income streams and more workplace representation (Standing 2011). Part of the purpose of this identification is to consider whether such workers may become class conscious and politically active – in a similar way that the proletariat was felt to be a radical force in the nineteenth and twentieth centuries by Marxists – because of unfavourable work circumstances in national and international contexts. However, another key driver of the analysis has been to underline the precariousness of work widely carried out in modern societies, particularly with its gender and ethnic dimensions (Johnson 2015). Whatever the reasons for such precariousness and its potential political ramifications, there are clear implications for the health of the workers themselves and community well-being – locally, regionally, nationally and globally.

What has rarely been discussed explicitly in the literature (with the fleeting exception of Savage et al. 2013) is whether personal support workers (PSWs) in healthcare are a new and central element of the precariat. This is important because they now form the largest part

of the healthcare workforce in neo-liberal societies, outnumbering professional groups such as nurses and doctors (see, for instance, Saks and Allsop 2007). Although this is debated, PSWs can be defined by three key features: they provide front-line support for clients and their carers in clinical, community or domiciliary healthcare settings; do not hold qualifications accredited by professional bodies and are not formally regulated by statutory bodies (Manthorpe and Martineau 2008). A large array of occupational titles represents PSW work, from “healthcare aides” to “nursing attendants” – where title varies across region and sector. PSWs have a broad scope of practice which lies between informal care by family and friends and formal medically oriented care in hospitals. In addition to such tasks, as Korczyk (2004) outlines, PSW work is often characterized by features like low wages, job insecurity, and short-term employment in many countries including Australia, Canada, Denmark, France, the Netherlands and the US. Internationally too, most PSWs are older women, and minority status is typically higher for PSWs than for other occupational groups within the same countries. Given their central role in healthcare delivery and service integration, they are therefore pivotal globally to well-being – not least in relation to the growing ageing population, which increasingly has multiple chronic conditions (United Nations Population Fund 2012). In this paper, we explore the extent to which PSWs are part of the precariat – a new concept in this literature – by presenting common characteristics of PSWs in the labour market, and examining the degree to which they align with features of the precariat using secondary sources as evidence. Having defined the precariat and its relationship to PSWs in modern societies, we now refer at greater length to PSWs in the US and UK, before addressing the example of PSWs in Canada.

In this regard, PSWs possess several of the characteristics covered by the analytical concept of the precariat. To illustrate this, in the US, Polson (2013) argues that home healthcare is a complex and ill-regulated area subject to the fraying of the welfare state, privatization and the externalization of costs to individual families. She claims the consequence has been the growth of a low-waged workforce between the formal and informal economy, operating in conditions akin to a precariat. This has only been partially addressed by government in that, with union support, there has been a drive towards a living wage and rationalization of the industry in places such as New York City. Such moves have, at least in the short term, assisted the largely female and ethnic minority workforce suffering from multiple dimensions of precariousness that has left it vulnerable in the recession – namely, labour market insecurity, lack of regulatory protection, lack of control of the labour process and low income (Black 2012).

Governments have also taken a greater interest in PSWs in the UK, where similar patterns are evident. Here, the independent review by Cavendish (2013) highlights not just concerns about public safety with a workforce with a relatively limited level of education, but also the lack of a progressive career – where low-paid employees are undertaking excessively long shifts and travel and other backfill costs are often not covered by employers. However, the ascription of the precariat to PSWs as a descriptor is not straightforward,

in part because the PSW labour force has fewer common organizational structures allowing for uniformity in comparison to other healthcare workers, and some elements of it are better positioned than others, especially where labour substitution for employees of a higher standing is involved (McKee et al. 2006). A study of the regulation of PSWs undertaken for the UK Departments of Health by Saks et al. (2000) found that there were over three hundred different types of PSWs. At the top end of the scale, some workers, such as operating department practitioners, were in the process of professionalization. But if care is needed in seeing PSWs as a cohesive group of workers with the ability to mobilize as a class nationally and internationally, especially because they are currently largely politically unorganized, what of PSWs in Canada?

Personal Support Workers and the Precariat in Canada

These characteristics of the precariat internationally have been reflected in Canada, which has faced similar pressures to other neo-liberal countries with the rise of an ageing population – accentuating the increased proportion of users with chronic conditions and the associated shifts of healthcare from hospitals and other institutions to the home and community (HCC 2012). These larger shifts have led to increased dependence on PSWs (Fujisawa and Colombo 2009), who undertake a whole range of tasks from bathing, dressing, lifting and toileting to more clinically related roles, including reminding patients about medication and providing rehabilitation therapy. Although the definite number of PSWs working in Canada is as yet unknown, partly as a result of disorganization within this workforce, a nationwide study using 2001 data reported an estimate of 30,000 PSWs working in home care (HCSSC 2003). Health Canada's latest estimation in Ontario alone was of some 100,000 PSWs (HPRAC 2006) – suggesting that there may now be over a million such workers in Canada as a whole. Projections of PSW demand across Canadian provinces and territories indicate that the number is growing further, with greater anticipated future increases (Bloom et al. 2012; HCSSC 2003). Indeed, one province estimates that PSW hours in the home care sector will almost double by 2037 (Government of Manitoba 2016).

Canadian PSW literature to date has largely focused on specific provinces and/or is often restricted to the home and community care sector. Knowledge gained from this literature suggests that Canadian PSWs are primarily older women, with lower education levels in comparison to other paid front-line healthcare workers (HCSSC 2003), and higher proportions of visible minority and immigrant status in comparison to the general working population (Lum et al. 2010). All of these are also common features of PSWs elsewhere (Fujisawa and Colombo 2009; Korczyk 2004), as well as the precariat more generally (Standing 2011). The relatively low education levels most likely relate to the lack of mandatory standardized training and educational qualifications for PSWs across Canada in contrast to other paid healthcare providers, although varying PSW requirements exist in healthcare settings by province, region, sector and employer. This lack of consistent educational requirement and associated low education levels in comparison to other paid front-line

healthcare providers contributes to the low human capital, market value and status of PSWs. However, the quality of education in Canada does not alone contribute to low PSW status, as key issues related to PSW status and market value remain even where there are robust PSW educational programs (Kelly 2017). The structure of Canada's neo-liberal healthcare system, with its related power dynamics in terms of occupational hierarchies and differences by sector, may play a major role in perpetuating the low status of PSWs (Lilly 2008). The gendered and ethnic nature of PSW work likely also contributes to the low human capital, market value and status of PSWs.

Commonalities between PSWs and typical precariat characteristics also exist in terms of workplace-related variables. PSWs are thought to regularly transition between this labour force and other work roles, low wages are commonplace and hours are mainly casual, contract-based or part-time (Zeytinoglu et al. 2009). Past research varies in the reported proportions of PSWs with full-time, part-time or casual status. Nonetheless, there are often high levels of part-time (52% of an Ontario sample [Zeytinoglu et al. 2014]) and casual (46% of a British Columbia, Ontario and Nova Scotia sample [Sims-Gould et al. 2010]) employment. PSW unionization varies by location – for instance, the proportions of PSWs in Canada's home care sector that were unionized ranged from 7.69% to 100% by province (Sims-Gould et al. 2010). Unions provide workers with a greater sense of unity, generally higher pay and job security (Long 1993) – thus, PSWs working without unionization are expected to be disadvantaged. The low upward mobility and high degree of unpaid labour for PSWs is commented on throughout the literature (Nugent 2007). Low wages are a common feature of PSW work, where pay tends to be focused around, and sometimes below, a living wage – with the lowest rates generally found in the home and community care sector (Lilly 2008) and the highest in Western provinces (Church et al. 2004; Parent et al. 2001). Across Canada, an average of \$12.60 per hour was reported for PSWs working in home care in 2001; registered nurses received approximately double in the same year and sector (HCSSC 2003). Given low average wages, inconsistent unionization, non-guaranteed hours of work and the casual or part-time nature of PSW work, as in many other neo-liberal societies, a great number of PSWs in Canada can be considered part of the precariat. However, variations in wages, part-time or casual status and other elements of the picture indicate that blanket statements cannot be made; variance in the extent to which PSWs technically can be seen to belong to the precariat differs according to the spectrum of workplace characteristics, individual socio-demographic characteristics and location in terms of province and sector. But despite this range of features, past research indicates that general PSW workplace and other characteristics align this workforce with the precariat.

These findings about the generally precarious features of PSW activities are reinforced by other Canadian-based literature where there is added evidence of the potential consequences of precarious work. For instance, aspects of the existence of PSWs in Ontario such as part-time or casual hours, job insecurity, fear of job losses, heavy workloads and low workplace support have been found to contribute to high stress and/or lower

job satisfaction (Denton et al. 2002). Furthermore, there is evidence for a link between job insecurity and musculoskeletal disorders (Zeytinoglu et al. 2015), implying that the precarious nature of PSW work is not only associated with psychological repercussions related to stress, but physical consequences too. PSWs generally have low health scores across all types of health measures, with PSWs in Canada reporting musculoskeletal injuries as the most common health issue (Alamgir et al. 2007; Ngan et al. 2010). The precariousness of the PSW labour market may also result in a backlash for employers and those receiving care. Zeytinoglu and colleagues (2009) show that in a sample of PSWs from Ontario home care, casual hours along with perceived employment and labour market insecurity are associated with higher turnover intention – with untoward implications for employers and users, not least in continuity of care.

Clearly, past Canadian literature that highlights aspects of socio-demography and employment for PSWs suggests precarity is a predominant feature of their situation. The potential dangers to PSWs – and, by extension, PSW employers and those receiving PSW care – have also been indicated. Many of the factors discussed in this section, including low full-time employment opportunities, poor opportunities for advancement, high job and employment insecurity and high levels of injury at work, associate PSWs with the previously given definition of the precariat including a lack of security related to the labour market, employment, skill reproduction, income and representation. Given rising reliance on PSWs and mounting evidence that suggests a precarious PSW labour force, more research is needed in Canada on such related issues as the stability of employment for PSWs and the labour supply outcomes for PSWs. Further research in these areas should also shed light on how far precarity itself is a new phenomenon in this sector of the labour market.

Conclusion: Policy Implications

This said, it should be stressed that in Canada there appears little sign of the development of a class-conscious group of PSWs in face of the widespread characteristics of precarity that many of these workers seem to share. This can be illustrated with reference to Ontario, where – while there has been some anger by workers at their precarious standing – there has been relatively limited sign up to the more politicized unions and associations for PSWs (Zlomislic 2016). Although Canadian workers overall tend not to be politically conscious, PSWs would benefit from becoming so considering their relatively low position in the labour market. This current general lack of politicization of PSWs is perhaps understandable given that – despite the size of the PSW workforce – resources and political power are limited for workers of generally low social, political and economic standing, in addition to their differentiation by role and sector. Defining PSWs as part of the precariat can have multiple implications. A positive implication for PSWs is that they may improve their situation in belonging to a larger group with shared disparities by becoming politically active and class conscious (Standing 2011). Although more research is necessary into the subjective perceptions of PSWs, one negative consequence could be that the development of a self-image

of themselves as part of the precariat may reinforce their low status, until or unless there is a successful political movement to enhance their position.

The long-run sustainability of the Canadian health system also points to the need to improve the precarious conditions of many PSWs. There are several advantages to this from a policy viewpoint in healthcare. One of these is to make the PSW role sufficiently attractive to ensure that there is an adequate supply of suitable quality PSWs on the labour market to meet the rising demand for such workers – in a situation where there have already been reported shortages (Canadian Home Care Association 2008). Selective evidence-based attention to this group through government policy and other initiatives could also aid retention and improve the quality of this workforce, reducing risks to public health and safety. This is of course in addition to attending to the basic human rights of particularly disenfranchised PSWs in the precariat to combat social exclusion in Canada's fundamentally egalitarian and meritocratic society. Self-employment, part-time and casual employment, illicit working and other workplace features common to PSWs' precarious position impact their rights in a manner akin to that of the wider precariat – who are viewed as having a limited range of civil, cultural, social, economic and political rights (Standing 2011).

In this light, it should not be surprising that in Canada the government and the private sector have begun taking actions to counter the effects identified here of the newly identified precarity of PSWs in the provinces and territories. In Ontario, in fact, the Ministry has made several attempts to enhance the position of PSWs – not least through systematic wage increases for PSWs and increased investment in training through an envisaged standardized curriculum. This in turn brings financial advantage to PSWs in the market, even if a register of PSWs in Ontario has recently been closed down – despite enrolling approximately one-third of the relevant labour force (Zlomislac 2016). Other measures based on evidence that have been proposed for providers of services include task shifting for PSWs to make the role more interesting (Zeytinoglu et al. 2014). Such endeavours underline the importance of determining the precarious nature of the position of PSWs through proactive data gathering and analysis and finding the most appropriate ways to combat this from a policy viewpoint – whether through creating more systematic and relevant educational opportunities or other means. With limited financial resources and ever-expanding healthcare costs internationally, it is vital that governments and other players address the conspicuously disadvantaged position of many PSWs – a key element of the precarity of a workforce that is critical to future well-being in Canada and beyond.

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What's Involved with Wanting to Be Involved? Comparing Expectations for Public Engagement in Health Policy across Research and Care Contexts

Que signifie « vouloir participer »? Comparaison
des attentes en matière d'engagement public pour les
politiques de santé dans les contextes de la recherche
et des services de santé



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Abstract

Objectives: We explored public preferences for involvement in health policy decisions, across the contexts of medical research and healthcare.

Approach: We e-surveyed a sample of Canadians, categorizing respondents by preferences for decision control: (1) more authority; (2) more input; (3) status quo. Two generalized ordered logistic regressions assessed influences on preferences.

Results: The participation rate was 94%; 1,102 completed responses met quality criteria. The dominant preference was for more input (average = 52.0%), followed by status quo (average = 24.9%) and more authority (average = 21.1%), though preferences for more control were higher in healthcare (57.2%) than medical research (46.8%). Preferences for greater control were associated with constructs related to reduced trust in healthcare systems.

Conclusion: The public expects health policy to account for public views, but not base decisions primarily on these views. More involvement was expected in healthcare than medical research policy. As opportunities for public involvement in health research grow, we anticipate increased desired involvement.

Résumé

Objectifs : Nous avons étudié les préférences de la population quant à la participation aux décisions en matière de politiques de santé dans le contexte de la recherche médicale et dans celui des services de santé.

Démarche : Nous avons effectué un sondage en ligne auprès d'un échantillon de Canadiens, en classant les répondants selon leurs préférences quant au contrôle sur les décisions : (i) plus d'autorité; (ii) plus de suggestions ("input"); (iii) statu quo. Deux analyses de régression logistique généralisée ordonnée ont permis d'évaluer les influences sur les préférences.

Résultats : Le taux de participation était de 94 %; 1 102 questionnaires remplis répondaient aux critères de qualité. La préférence dominante était plus de suggestions (moyenne = 52,0 %), suivi du statu quo (moyenne = 24,9 %) et de plus d'autorité (moyenne = 21,1 %), quoi que les préférences relativement à plus de contrôle étaient plus élevées pour les services de santé (57,2 %) que pour la recherche médicale (46,8 %). Les préférences pour un plus grand contrôle étaient associées à des constructs liés à une baisse de la confiance envers les systèmes de santé.

Conclusion : La population s'attend à ce que les politiques de santé reflètent ses points de vue, mais pas à ce que les décisions se fondent principalement sur ces points de vue. On s'attend à une plus grande implication dans les services de santé que dans les politiques pour la recherche médicale. Alors qu'il y a davantage d'occasions pour la participation de la population dans la recherche sur la santé, nous nous attendons à ce qu'il y ait un plus grand désir de participation.

Introduction

In the last several decades, there has been growing political interest in involving the public in health policy decision-making (Mitton et al. 2009). Many initiatives address public engagement in healthcare, including in resource allocation decision-making (e.g., health technology assessment; Gagnon et al. 2011; Menon and Stafinski 2011), or service design and quality improvement (Barello et al. 2012; CFHI 2011, 2014). As well, a largely distinct body of work explores engagement in the context of health research, including in setting priorities for the allocation of research funds, conducting research, and analyzing and disseminating its findings (Boote et al. 2002, 2010; Domecq et al. 2014; Elberse et al. 2011; O'Donnell and Entwistle 2004). In both the healthcare and health research contexts, the emphasis of recent work is on engaging patients (and informal caregivers), to take advantage of patients' particular expertise and ensure accountability to patients as users of healthcare services and research-based knowledge. Less recent work explores engagement with the general or lay public, who are prospective service users as well as citizens with a broad interest in public investments in generating knowledge or services for the community as a whole. The engagement of the general public in policy development related to health research and healthcare is important for reasons of democratic accountability and legitimacy, given the influence of such policy on the future of health knowledge and health systems.

In Canada, policy efforts related to public involvement have been directed more towards healthcare than health research. On the healthcare side, calls for increased public engagement from various government commissions and public institutions are long-standing (e.g., the Clair Commission [2000], the Fyke report [2001], the Health of Canadians report [Kirby and LeBreton 2002], the Mazankowski report [2001] and the Romanow report [2002]) and engagement activities have proliferated (e.g., citizens' juries, deliberative polling; Abelson et al. 1995, 2003; Maxwell et al. 2003; Menon and Stafinski 2008). Historically, less has been done to engage the public in health research policy – a point highlighted in the 2011 external review of the Canadian Institutes of Health Research (CIHR 2011a). However, the introduction of Canada's Strategy for Patient-Oriented Research by CIHR has created momentum for change in health research policy, though this is not directed at the lay public; rather, it is specific to patient engagement (CIHR 2011b). Moreover, while this work encourages the engagement of patients with the research process, it does not highlight the role of patients or the public in setting priorities in health research.

To date, the bulk of the research on public engagement in healthcare and health research policy has focused on describing these activities (Abelson et al. 1995; Burgess et al. 2008; Godard et al. 2007; Gooberman-Hill et al. 2008; Maxwell et al. 2003; Menon and Stafinski 2008; Oliver et al. 2004) and on determining the effectiveness of different methods of engagement (Abelson et al. 2003; Dolan et al. 1999; Rowe et al. 2005). Some work has also examined whether or not the public wants to be involved in health policy decision-making and the core determinants of these preferences, such as trust. In the healthcare context, this literature shows that, in general, the public expresses interest in being involved in

decision-making (Abelson et al. 1995; Bowling 1996; Broqvist and Garpenby 2015; Dolan et al. 1999; McKie et al. 2008; Richardson et al. 1992; Wiseman et al. 2003). Less has been done regarding the public's desired role in health research policy. One study found that only 40% agreed that "citizens should assume a more important role in decisions on science and technology" (Luján and Todt 2007) but another found that 69% of people believe that "scientists should listen more to what ordinary people think" (Castell et al. 2014).

There are many different forms of engagement or involvement, from consultation without decision authority, to co-production or partnership, ensuring public authority with respect to decision-making (Arnstein 1969; Bovaird 2007). Yet despite the broad range of possibilities, only a small body of work explores how the public wants to be involved in health research and healthcare policy. Where it has been considered, the extent of the public's desired involvement in healthcare decision-making varies, with a distinction based on how much control the public wants to have in the decision-making process (Bowling 1996; Dolan et al. 1999; Richardson et al. 1992; Wiseman et al. 2003). Often, the public would prefer to play a consulting role, rather than being responsible for making final decisions (Castle and Culver 2006; Litva et al. 2002, 2009; Shrimpton et al. 2008). In the research context, some work has explored the factors involved in wanting to have a role in these decisions. For example, Knight and Barnett (2010) found that higher political efficacy, defined as "people's belief that they can make demands of governing systems and get adequate responses from these systems," is associated with preferences that experts make decisions about science governance. There is also a literature examining engagement exercises as a strategy for building public trust, though there is some debate about its effectiveness (Molster et al. 2013; Petts 2008; Wynne 2006). Thus, it remains unclear whether trust is an important influence on preferences for involvement in health policy.

Given the limited Canadian data available on public opinion regarding public engagement in healthcare and health research policy, the objective of this study was to explore preferences and identify factors that may influence desired involvement in health policy decisions among the Canadian "lay public." Specifically, we sought to compare public preferences for public involvement across healthcare and health research, with a particular focus on medical research. We also sought to explore the factors associated with the public's preferred level of involvement.

Methods

Sample and data collection

In January 2013, we administered a bilingual (French, English) survey to a representative sample of Canadians through an Internet panel provided by Survey Sampling International (SSI), which hosts online panels to support market and academic research. Eligible panelists were sent an e-mail inviting them to participate in the survey by following a link to the survey page. Those willing to participate who met targets for a nationally representative sample by age, gender and region of residence, consistent with 2011 Statistics Canada data, were eligible to complete the questionnaire. To recognize time invested, SSI provided incentives to panelists who completed relevant sections of the questionnaire (respondents were able to select rewards points, prize draws or cash).

Questionnaire design

We probed attitudes towards the role of the public in healthcare and medical research policy within a survey study on newborn screening, which included specific items about population screening in newborns (Miller et al. 2015), and research opportunities with leftover blood samples generated through newborn screening (Hayeems et al. 2016), as well as general items regarding healthcare and research policy. Items in the research context used the terminology “medical research” to align with the biomedical nature of some of the items (e.g., references to blood samples and curing disease). The survey also included a training module to familiarize respondents with newborn screening concepts and the types of trade-offs inherent in this type of health policy issue (e.g., identifying infants with disease/false positive results). The items reported in this study were set apart in two sections of a large, 10-section survey, where they were framed as addressing other issues in newborn screening, healthcare and medical research in general. The survey questionnaire was developed by a multidisciplinary team based on a review of the literature (European Commission 2005; Gaskell et al. 2005, 2011; Johri et al. 2009; Kim et al. 2001; Pardo and Calvo 2002; Schwartz et al. 2004; Straten et al. 2002; Willison et al. 2008) pretested through face-to-face cognitive interviews (over three rounds; $n = 16$) and piloted with members of the internet panel ($n = 87$) to assess comprehension, face and content validity. The study was approved by the University of Toronto Health Sciences Research Ethics Board.

Measures

The items that are the focus of this paper were adapted from standardized items used to assess public understanding of science, alongside selected bespoke items. Specifically, we included three sets of items exploring public preferences for involvement in science decision-making modified to be specific to “healthcare programs” or “medical research,” as well as other items assessing trust in healthcare and medical research systems.

The first of the three-item sets assessed preferences for taking account of the public’s views, seeking opinions on the following statement: “To direct [healthcare programs/medical research] in the right way, it would be better to take more account of what the public thinks, in other words people like you and me” (von Roten 2004). These items were assessed using five-point Likerts, from strongly agree through strongly disagree.

The second set assessed preferences related to making decisions contrasting public and expert opinion. Respondents selected whether “Decisions about [healthcare programs/medical research] should be based primarily ...” “... On the advice of experts” or “... On the general public’s views” (European Commission 2005). Finally, the third item set assessed beliefs about the types of knowledge that should be used in health policy decisions, asking whether “Decisions about [healthcare programs/medical research] should be based primarily ...” “... on scientific evidence about the risks and benefits involved” or “... on the moral and ethical issues involved” (European Commission 2005).

Other attitude items were assessed with five-point Likerts, from strongly agree through strongly disagree. Three items assessed trust in healthcare systems (i.e., role in funding [Potter et al. 2012], and assuring quality [Straten et al. 2002]) and three items assessed trust in medical

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research systems (i.e., the conduct of researchers [adapted from Pardo and Calvo 2002], the curative potential of its outcomes [adapted from Pardo and Calvo 2002], and protection for participants [*de novo*]). See Table 1 for additional items of solicited demographic information about participants.

TABLE 1. Attitudes towards public involvement in healthcare programs and medical research

| Questionnaire items | Total (N = 1,102) | |
|--|-------------------|------|
| | n | % |
| <i>Public expectation for input</i> | | |
| To direct healthcare programs in the right way, it would be better to take more account of what the public thinks, in other words people like you and me | | |
| Strongly agree | 401 | 36.4 |
| Agree | 492 | 44.6 |
| Neutral | 158 | 14.3 |
| Disagree | 43 | 3.9 |
| Strongly disagree | 8 | 0.7 |
| To direct medical research in the right way, it would be better to take more account of what the public thinks, in other words people like you and me | | |
| Strongly agree | 236 | 21.4 |
| Agree | 482 | 43.7 |
| Neutral | 281 | 25.5 |
| Disagree | 81 | 7.4 |
| Strongly disagree | 22 | 2.0 |
| <i>Public expectation for decision authority</i> | | |
| Decisions about healthcare programs should be based primarily ... | | |
| On the general public's views | 289 | 26.2 |
| On the advice of experts' views | 813 | 73.8 |
| Decisions about medical research should be based primarily ... | | |
| On the general public's views | 220 | 20.0 |
| On the advice of experts' views | 882 | 80.0 |
| <i>Trust in healthcare systems</i> | | |
| If the government has funded a health test or procedure, it is probably a worthwhile test to have | | |
| Strongly agree | 404 | 36.7 |
| Agree | 462 | 41.9 |
| Neutral | 186 | 16.9 |
| Disagree | 41 | 3.7 |
| Strongly disagree | 9 | 0.8 |

TABLE 1. Continued

| Questionnaire items | Total (N = 1,102) | |
|---|-------------------|------|
| | n | % |
| The government wouldn't fund a health test or procedure if they were not sure of its benefits | | |
| Strongly agree | 164 | 14.9 |
| Agree | 378 | 34.3 |
| Neutral | 343 | 31.1 |
| Disagree | 162 | 14.7 |
| Strongly disagree | 55 | 5.0 |
| The government will ensure a high-quality health system | | |
| Strongly agree | 205 | 18.6 |
| Agree | 378 | 34.3 |
| Neutral | 348 | 31.6 |
| Disagree | 133 | 12.1 |
| Strongly disagree | 38 | 3.4 |
| <i>Trust in medical research systems</i> | | |
| Medical research will help to cure illnesses such as AIDS, cancer | | |
| Strongly agree | 525 | 47.6 |
| Agree | 431 | 39.1 |
| Neutral | 119 | 10.8 |
| Disagree | 20 | 1.8 |
| Strongly disagree | 7 | 0.6 |
| Most medical researchers want to work on things that will make life better for the average person | | |
| Strongly agree | 423 | 38.4 |
| Agree | 495 | 44.9 |
| Neutral | 143 | 13.0 |
| Disagree | 29 | 2.6 |
| Strongly disagree | 12 | 1.1 |
| The privacy and confidentiality of people who participate in medical research will be protected | | |
| Strongly agree | 429 | 38.9 |
| Agree | 462 | 41.9 |
| Neutral | 176 | 16.0 |
| Disagree | 24 | 2.2 |
| Strongly disagree | 11 | 1.0 |

Data analysis

Following survey administration, we removed respondents who sped (i.e., below minimum times per section) or “straight-lined” (i.e., providing answers to blocked items along only one column) to ensure data quality.

We dichotomized the items that assessed preferences for taking account of the public’s views into agree (strongly agree or agree) or not (neutral, disagree or strongly disagree) as a measure of public expectation for input. We used items that assessed preferences for relying on public or expert opinion in making decisions as a measure of public expectation for decision authority (more or status quo). Next, we used cross-tabs to categorize respondents with respect to their preferences for public involvement in health policy decisions across three main decision types: respondents who preferred (1) more authority (more input with decision authority); (2) more input (more input without decision authority) or (3) status quo (status quo input without decision authority; see Table 2). We recognize that a fourth category (status quo input with decision authority) might exist as a result of genuine if somewhat illogical preference, or because of respondent error or inattention, but anticipated that it would be residual in size.

TABLE 2. Preferences for type of public involvement

| Questionnaire items | Total (N = 1,102) | |
|--|-------------------|------|
| | n | % |
| <i>Preferences for public involvement: Healthcare programs</i> | | |
| More authority: More input with decision authority | 263 | 23.9 |
| More input: More input without decision authority | 630 | 57.2 |
| Status quo: Status quo input without decision authority | 183 | 16.6 |
| <i>Preferences for public involvement: Medical research</i> | | |
| More authority: More input with decision authority | 202 | 18.3 |
| More input: More input without decision authority | 516 | 46.8 |
| Status quo: Status quo input without decision authority | 366 | 33.2 |

Note: Categories produced using cross-tabs of input and authority items (Table 1).

We conceived of the three main categories of preferences for public involvement as an ordered dependent variable, ranging from lowest preferred involvement (status quo) to highest preferred involvement (more authority). We ran two separate generalized ordered logistic regressions to examine factors associated with preferences for public involvement in healthcare programs and medical research, respectively. Generalized ordered logistic regressions provide a parsimonious but relatively non-restrictive approach to analyzing ordered categorical dependent variables. Using a process similar to a backward stepwise regression, the analysis identifies the most parsimonious model. Partial proportional odds ordered logit estimates identify the nature of the relationship between independent and

dependent variables, whether these are uniform (i.e., ordered) or differing across different values of the dependent variable (Williams 2006). Two-sided p-values of <0.05 indicated statistical significance. Independent variables were entered into the models at the same time. Data were managed and analyzed using Stata (version 10.1, StataCorp LP., Station College, Texas).

We generated two composite measures for (1) trust in healthcare systems (three items) and (2) trust in medical research systems (three items), using principal components factor analysis with orthogonal rotation. Two eigenvalues reached relevance with three variables loading on each. For each composite measure, we generated means and standard deviations, and used Cronbach’s alpha to assess consistency.

The composite measures were included as independent variables for both models. We also included the item set measuring beliefs about the types of knowledge that should be used in health policy decisions (healthcare or medical research) in each model, and other demographic covariates (see Table 3 for included covariates). Composite measures were analyzed as interval data; individual items were analyzed as three-part categorical variables; demographic variables were measured and analyzed as categorical variables, except for age, which was measured and analyzed as a continuous variable.

TABLE 3. Independent variables entered in regressions

| Questionnaire items | Total (N = 1,102) | |
|--|-------------------|------|
| | n | % |
| <i>Age</i> | | |
| 18–83 (entered as continuous variable) | 1,102 | 100 |
| Mean age | | 45.9 |
| <i>Gender</i> | | |
| Male | 516 | 46.8 |
| Female | 586 | 53.2 |
| <i>Region</i> | | |
| East | 84 | 7.6 |
| Quebec | 256 | 23.2 |
| Ontario | 420 | 38.1 |
| West | 342 | 31.0 |
| <i>Income</i> | | |
| Less than \$40,000 | 358 | 32.5 |
| \$40,000–79,000 | 375 | 34.0 |
| \$80,000+ | 287 | 26.0 |
| Prefer not to say* | 82 | 7.4 |

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| Questionnaire items | Total (N = 1,102) | |
|---|-------------------|---------------|
| | n | % |
| <i>Education</i> | | |
| High school or less | 347 | 31.5 |
| College/CEGEP | 400 | 36.3 |
| University+ | 343 | 31.1 |
| Other* | 12 | 1.1 |
| <i>Trust in healthcare systems</i> | | |
| Trust in government stewardship of health care (0–12 scale) Alpha: 0.63; standard deviation: 2.2 | 1,102 | 8.0 (mean) |
| <i>Trust in medical research systems</i> | | |
| Belief that medical research will bring benefit and can be trusted (0–12 scale) Alpha: 0.70; standard deviation: 1.9 | 1,102 | 9.6 (mean) |
| <i>Information relevant to decision-making</i> | | |
| Healthcare programs | 0 | 0 |
| Decisions ... should be based primarily on the moral and ethical issues involved | 198 | 18.0 |
| Decisions ... should be based primarily on scientific evidence about the risks and benefits involved | 904 | 82.0 |
| <i>Medical research</i> | | |
| Decisions ... should be based primarily on the moral and ethical issues involved | 213 | 19.3 |
| Decisions ... should be based primarily on scientific evidence about the risks and benefits involved | 889 | 80.7 |

*Omitted from regression.

Results

Survey respondents

The survey participation rate was 94% (2,345/2,499; ratio of unique visitors who agreed to participate/unique first survey page visitors); of these, 1,102 completed responses met quality criteria for a 47% completion rate (ratio finished relevant sections – those excluded for quality reasons [speeding, straight-lining]/agreed to participate). This is typical of Internet surveys that target samples representing the population on key demographic criteria (Johri et al. 2009; Miller et al. 2013; Schlesinger et al. 2012). By design, our sample was representative of the Canadian population by age, gender and region. However, our sample was better educated and had a more narrowly distributed income than Canadian averages ($p < 0.001$; Statistics Canada 2011a, 2011b).

Preferences for public involvement in health policy

On the issue of preferences for public input, a majority of respondents agreed (or strongly agreed) that “it would be better to take more account of what the public thinks” in directing

healthcare programs (81.0%); a significantly smaller majority agreed to the need to take more account of public views for medical research (65.1%; $p < 0.01$). On the issue of decision authority, a majority of respondents preferred to base decisions primarily on the views of experts for healthcare programs (73.8%), while a significantly larger majority preferred to rely on experts for medical research (80.0%; $p < 0.01$; Table 1).

Preferences for type of public involvement

When categorized with respect to preferences for type of involvement in healthcare programs, the majority of respondents preferred the intermediate degree of involvement (i.e., more input, 57.2%); the next most preferred was the highest degree of involvement (i.e., more authority, 23.9%), while the lowest level of involvement was least preferred (i.e., status quo, 16.6%; Table 2).

A slightly different pattern of preferences for involvement emerged for health research. The intermediate degree of involvement was still most preferred, but with fewer respondents (i.e., more input, 46.8%). The next most favoured was the least involvement (status quo, 33.2%), while the highest degree of involvement was least preferred (i.e., more authority, 18.3%; Table 2).

As expected, a fourth residual category of responses was present in both healthcare and medical research contexts. In the former, 2.4% of respondents preferred status quo input with decision authority, and in the latter, this residual category was smaller still at 1.6%. This category was not included in either regression model.

Trust in healthcare and medical research systems

The composite measure of trust in healthcare systems had a mean of 8.0 (out of 12) and standard deviation of 2.2. The composite measure of trust in medical research systems was higher with a mean of 9.6 (out of 12) and standard deviation of 1.9.

Factors associated with preferences for more public involvement

HEALTHCARE PROGRAMS

We explored factors associated with a preference for more public involvement in decision-making regarding healthcare programs (Table 4). Several of the independent variables included in the model were associated with preferences for more public involvement in an ordered fashion, from lowest preferred involvement (status quo) to highest preferred involvement (more authority). Specifically, women were significantly more likely than men to want more public involvement ($p < 0.01$), as were those with less formal education compared to those completing university degrees (high school $p < 0.001$; college/CEGEP $p < 0.05$). As well, those with higher levels of trust in healthcare systems were more likely to want *less* public involvement than those with less trust ($p < 0.05$). However, we also identified several non-ordered relationships (see Table 4).

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TABLE 4. Factors associated with preferences for more public involvement in health policy (generalized ordered logistic regressions)

| Variables | Healthcare programs | | Medical research | |
|--|--|--|--|--|
| | Status quo versus (more input OR more authority) | (Status quo OR more input) versus more authority | Status quo versus (more input OR more authority) | (Status quo OR more input) versus more authority |
| <i>Demographics</i> | | | | |
| Age | -0.00 (0.00) | -0.00 (0.00) | -0.01 (0.00) | -0.01 (0.00) |
| Female | 0.42 (0.14)** | 0.42 (0.14)** | 0.03 (0.13) | 0.03 (0.13) |
| <i>Region (reference: Quebec)</i> | | | | |
| East | -0.03 (0.28) | -0.03 (0.28) | 0.44 (0.26) | 0.44 (0.26) |
| Ontario | 0.01 (0.18) | 0.01 (0.18) | 0.38 (0.16)* | 0.38 (0.16)* |
| West | -0.52 (0.21)^ | -0.08 (0.21) | 0.02 (0.17) | 0.02 (0.17) |
| <i>Income (reference: \$80,000+)</i> | | | | |
| \$40,000–79,000 | 0.07 (0.18) | 0.07 (0.18) | -0.00 (0.17) | -0.00 (0.17) |
| Less than \$40,000 | 0.09 (0.17) | 0.09 (0.17) | -0.13 (0.15) | -0.13 (0.15) |
| <i>Education (reference: University+)</i> | | | | |
| College/CEGEP | 0.39 (0.17)* | 0.39 (0.17)* | 0.46 (0.15)** | 0.46 (0.15)** |
| High school or less | 0.82 (0.18)*** | 0.82 (0.18)*** | 0.61 (0.16)*** | 0.61 (0.16)*** |
| <i>Trust in healthcare systems</i> | | | | |
| Trust in government stewardship of healthcare | -0.07 (0.03)* | -0.07 (0.03)* | 0.02 (0.03) | -0.09 (0.04)^ |
| <i>Trust in medical research systems</i> | | | | |
| Belief that medical research will bring benefit and can be trusted | 0.19 (0.05)^ | -0.18 (0.04)^ | 0.04 (0.04) | -0.12 (0.05)^ |
| <i>Information relevant to decision-making</i> | | | | |
| Moral versus scientific: healthcare | -0.44 (0.26) | -1.02 (0.19)^ | | |
| Moral versus scientific: medical research | | | -1.24 (0.17)*** | -1.24 (0.17)*** |
| Peudo-R ² | 0.08 | 0.08 | 0.06 | 0.06 |
| N | 988 | 988 | 997 | 997 |

Coefficients are partial proportional odds ordered logit estimates. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$. ^ non-ordered relationship, $p < 0.05$.

MEDICAL RESEARCH

We ran a comparable model exploring factors associated with a preference for more public involvement in decision-making regarding medical research, which showed a broadly similar pattern of relationships. As was seen in the healthcare programs model, several independent variables were associated with preferences for more public involvement in an ordered fashion.

One of these relationships parallels that seen in our healthcare programs model. Specifically, those with less formal education were significantly more likely than those with a university degree to want more public involvement (high school $p < 0.001$; college/CEGEP $p < 0.01$). We also found that those who preferred that decisions about medical research be based primarily on scientific evidence preferred less public involvement than those who preferred that decisions be based primarily on the moral and ethical issues involved ($p < 0.001$). In addition, we identified a positive association between Ontario residence relative to Quebec residence in preferences for more public involvement ($p < 0.05$). As above, we also identified several non-ordered relationships (see Table 4).

Discussion

We explored public expectations for public involvement in health policy decisions, comparing preferences across contexts (research, healthcare). Our findings indicated a strong belief in the need to take more account of what the public thinks, but less commitment to the belief that decisions should be based primarily on these views. This is in line with previous findings that identify a preference for having input into decisions rather than control over decision-making (Castle and Culver 2006; Litva et al. 2002, 2009; Shrimpton et al. 2008). However, there were notable differences in public preferences for engagement in medical research as compared to healthcare, with reduced expectations for public involvement in the context of medical research and greater reliance on expert advice for decision-making in this context.

These differences in public preferences between medical research and healthcare may reflect a reduced sense of ownership of the research enterprise relative to healthcare. Healthcare in Canada is a highly visible public activity, and consistently a top policy priority for members of the public (Canadian Opinion Research Archive n.d.). It may also be that there is a lack of awareness in Canada of the central role of public funding in research and of the possibility for, or value of, public engagement in this context. While there has been much attempt in Canada and elsewhere to engage the public in healthcare policy decisions, significantly less attention has been given to the role of the public in health research policy in Canada. Recently, the Strategy for Patient Oriented Research of Canada's national health research agency has brought attention to the potential for public engagement in health research, though the strategy focuses principally on patient engagement in the research process, rather than public engagement in research priority setting or policy more broadly (CIHR 2011b).

Our study also corroborates a limited literature on factors associated with preferences for public involvement with findings that suggest that the less empowered seek greater access to engagement activities. Knight and Barnett (2010) have argued that higher political efficacy, that is, the confidence that one's demands of governing systems will be adequately addressed, is associated with preferences that experts make decisions about science governance. Our models suggest some similar relationships, with preferences for expert judgment associated with reduced expectations of public involvement in medical research, and trust in health systems associated with reduced expectations of public involvement in healthcare. In a parallel vein, our results suggest that those with less education are more likely to want more

public involvement in both medical research and healthcare, and that women are more likely to want more public involvement in healthcare. These findings align with those of a 2014 Public Attitudes to Science Survey, which has shown that women and the less affluent are more likely to think that scientists should listen more to the public (Castell et al. 2014).

Several limitations must be acknowledged. First, the items examined in this paper were embedded within a survey on newborn population screening and research, and while we aimed to obtain views that were not specific to newborn screening, it is impossible to know how the context may have impacted responses. However, we believe that embedding reflection on the public role in decision-making into the context of a survey that asks challenging questions and discusses explicitly the need for trade-offs in these types of decisions also provided added value to our data. These are exactly the types of difficult decisions that necessitate public input and therefore having primed respondents to think about some of the challenges involved in a specific health policy context does not seem inappropriate.

Additional limitations include that key terms used to describe our policy contexts, “healthcare programs” and “medical research,” were not defined. Thus, while the survey as a whole did provide illustrative insight, it is possible that respondents interpreted these terms differently than we intended. Similarly, we did not elaborate the mechanism by which the public would be involved in health policy decisions; thus, interpretations here could have varied as well. Further, survey participants differed slightly from the general population on some demographic characteristics, and as members of a standing panel of individuals willing to voice their opinions on various issues, may not reflect the general population. And while panel surveys provide an opportunity to engage with a large number of individuals, Internet panelists may not have been fully engaged with our online questionnaire. Finally, the several non-ordered relationships in our models limit our ability to draw inferences from these data.

Despite these limitations, this study offers insight into public expectations of public involvement across two health policy domains: healthcare and medical research. In showing that the public expects health policy to take account of public views, but not base decisions primarily on these views, this study corroborates other work. In showing that more involvement was expected in healthcare than research policy, we offer important comparative insight. It may be that the identified difference is due to greater faith in scientific or professional expertise in the medical research context than the healthcare context. Or it may be that the limited public engagement that has occurred within medical research in Canada has fostered inattention and public disinterest. If opportunities for public involvement in medical research grow, expectations for public involvement may increase proportionally. Given the potential value of increased engagement with the general or lay public – prospective service and knowledge users and arbiters of public investments and social commitments – such an outcome is greatly desired.

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A Review and Comparative Analysis of Information Targeted to the General Public on the Websites of Breast Screening Programs in Canada

Revue et analyse comparative de l'information à l'intention du grand public sur les sites Web des programmes de dépistage du cancer du sein au Canada



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Abstract

Organized breast screening programs in Canada recommend that women, usually 50–74 years of age, are screened regularly with mammography to reduce their risk of breast cancer death. There is increasing evidence that estimates of mortality reduction are overestimated and harms under-reported. This article will report on a review of the websites of 12 breast screening programs in Canada. The primary goal is to determine what information is provided to enable women to make an informed decision about mammography and whether

choice is emphasized. All publicly available English language information was extracted from the 12 websites by two independent reviewers, using a data extraction sheet. Information extracted included eligible age, screening interval and potential benefits and harms. This review is relevant to policy makers and breast screening program staff so they can determine what additional or alternative information is required on their websites to enable women to make informed decisions.

Résumé

Les programmes de dépistage du cancer du sein au Canada recommandent que les femmes, habituellement de 50 à 74 ans, procèdent régulièrement à une mammographie pour réduire les risques de mortalité liés au cancer du sein. De plus en plus de données font voir une surévaluation des estimations de réduction de la mortalité ainsi qu'une sous-déclaration des effets non désirés. Cet article fait état d'une revue des sites Web de 12 programmes de dépistage du cancer du sein au Canada. L'objectif principal est, d'une part, de déterminer quelle information est fournie aux femmes afin de leur permettre de prendre une décision éclairée au sujet de la mammographie et, d'autre part, de voir si on met l'accent sur la possibilité de faire un choix. Toutes les informations en anglais disponibles au public ont été extraites des 12 sites Web par deux examinateurs indépendants, au moyen d'une feuille d'extraction des données. L'information extraite comprenait l'âge d'admissibilité, l'intervalle entre les dépistages ainsi que les avantages et effets non désirés potentiels. Cette revue est pertinente pour les responsables de politiques et pour le personnel des programmes de dépistage du cancer du sein, afin qu'ils puissent déterminer quelle information supplémentaire ou complémentaire est nécessaire sur les sites Web pour permettre aux femmes de prendre des décisions éclairées.

BREAST CANCER REMAINS A SIGNIFICANT HEALTH RISK FOR WOMEN. IN 2016, THE Canadian Cancer Society estimated that breast cancer will remain the most commonly diagnosed new cancer among women, accounting for 25.8% of all new diagnoses or 25,700 estimated new cases. Breast cancer is the second leading cause of death by cancer among women, at 13.2% (CCSACCS 2016).

Mammography screening is the only early detection method currently recommended to reduce breast cancer morbidity and mortality. The Canadian Task Force on Preventive Health Care (2017) recommends that women aged 50–74 years have mammography screening every two to three years. However, it is a weak recommendation based on the GRADE approach, meaning that clinicians should assist women to make an informed decision about whether or not to have screening, which may be supported by decision aids. It does not recommend that women aged 40–49 be routinely screened with mammography (weak recommendation). These recommendations are currently under reconsideration.

The US Preventive Services Task Force (USPSTF 2017) recommends that women aged 50–74 years have mammography screening every two years. It states that it is an individual decision for women younger than 50 years based on their assessment of benefits and risks. For women of all ages, neither organization recommends clinical breast examination or breast self-examination.

Breast screening programs were first established in Canada in 1988 based on the reports of randomized trials that mammography screening reduces breast cancer mortality up to 35% (Shapiro et al. 1971; Tabar et al. 1985). Recent reports from a Cochrane Collaboration systematic review (Gøtzsche and Jørgensen 2013) and the Canadian National Breast Screening Study (Miller et al. 2014) found no reliable evidence of benefit but did find evidence of harm. The authors of these reports have contributed to the academic debate regarding the future of population-based mammography screening as they recommended that countries offering organized mammography screening reconsider this policy. Changing policy regarding population-based mammography screening – including discontinuation – is a difficult and controversial action for governments to take given decades of targeted promotion to maximize recruitment. Until there is clearer evidence regarding the effectiveness of mammography screening, it is imperative that women receive balanced information regarding potential benefits and harms so they can make an informed decision about participating (Gøtzsche et al. 2009; Gøtzsche and Jørgensen 2011; Gummertsbach et al. 2010; Jørgensen et al. 2009).

Evidence Regarding Harms and Benefits

The evidence suggests several harms associated with population-based mammography screening: diagnostic workup for false positive findings; overdiagnosis; unnecessary treatment; radiation-induced breast cancer and death; and psychological distress. Up to 60% of women will have a false positive finding after 10 mammography screens (Hubbard et al. 2011), which can lead to serious psychological distress – including the belief they are at increased risk for breast cancer – sometimes persisting for three years (Brodersen and Siersma 2013). Overdiagnosis refers to the diagnosis of breast cancers through screening that would not have become clinically detectable or caused harm to the woman in her lifetime, including ductal carcinoma in situ (DCIS). Revised estimates of overdiagnosis from the Canadian breast screening trial are estimated to be 55% and 16% for women 40–49 and 50–59, respectively, 20 years after screening cessation – including both invasive tumours and DCIS (Baines et al. 2016). Overdiagnosed women receive unnecessary cancer treatment including lumpectomy, mastectomy, radiation and hormonal therapy and may believe they are living with a potentially lethal disease. A recent modelling study commissioned by the USPSTF estimated that biannual digital mammography screening – and subsequent diagnostic mammography – of 100,000 average-risk women aged 50–74 years would cause 27 breast cancers and four deaths (Miglioretti et al. 2016). A further harm is the number of false negative results – or missed cancers. The National

Cancer Institute (2017) estimates that up to 46% of women with an invasive breast cancer will have a negative mammogram, giving these women a false sense of security and a delayed diagnosis.

In addition to a lack of evidence of breast cancer mortality reduction or all-cause mortality reduction, there is limited evidence on the effectiveness of population-based mammography screening in reducing the incidence of advanced breast cancer (Autier et al. 2011) or decreasing the rates of mastectomy (Douek and Baum 2003). It is believed that reduced breast cancer mortality observed in many countries is mainly due to improved treatment and awareness of women and not mammography screening (Gøtzsche and Jørgensen 2013).

There are 12 breast screening programs across Canada that offer mammography screening to women 40–75 years of age. It is estimated that 55% of average-risk eligible women in Canada, aged 50–69, have had a screening mammogram (CIHI 2017).

The purpose of this review and comparative analysis is to determine what information is available on the websites of breast screening programs in Canada to enable women to make informed decisions about whether to participate in mammography screening and if choice is emphasized.

Methods

Approach

A review of the website content of provincial and territorial breast screening programs across Canada was performed to document the information directed to the general public. Written English language information presented on all web pages, brochures, fact sheets, letters and direct links to external sources for evidence were eligible for review. Only information pertaining to women at average risk for breast cancer was reviewed. Ethical approval was not required for this document review as no patient information was involved.

Selection criteria

The selection criteria included all provincial and territorial websites in Canada that provided information on their breast screening programs by jurisdiction. Websites that presented on cancer screening in general (e.g., Canadian Cancer Society or Cancerview) were not eligible for inclusion. Information not included in the review was that targeted to women at higher risk for breast cancer, risk factors for breast cancer, lifestyle advice to reduce risk, program performance reports, information directed to healthcare professionals and the Public Health Agency of Canada (PHAC) decision aid for breast cancer screening by mammography (PHAC 2009), which is referenced as a link on some websites.

Data extraction

A data extraction form was designed to document all relevant information from the websites. Two reviewers (J.P. and A.M.) independently conducted the data abstraction for all eligible websites using a pre-specified extraction form. Relevant information extracted were eligibility

age without referral, screening interval and potential benefits (including breast cancer mortality and all-cause mortality relative risk reduction, less aggressive treatment options) and harms (including false positive and false negative rates, overdiagnosis, unnecessary treatment, radiation risk and psychological distress). It was also noted if a link was provided to the PHAC's decision aid on breast screening (PHAC 2009). Any discrepancies were resolved through discussion until consensus was reached. A third reviewer (A.K.) also reviewed the results in the data extraction table and provided feedback, when necessary.

Descriptive analysis

The content on the websites for the breast screening programs were summarized narratively. Subsequently, the results were interpreted and compared to identify the underlying patterns from the information available on the jurisdictional websites.

Results

The information summarized below is based on the web content identified in all jurisdictions across Canada, except for Nunavut (where there is no program). Box 1 provides the web address for each breast screening program at the time of the review. Details related to the information provided on the websites by province and territory are outlined in Appendix 1 (available at: www.longwoods.com/content/25322).

BOX 1. Links to the websites of 12 breast screening programs in Canada

- **Alberta** – <http://screeningforlife.ca/breast-cancer-at-a-glance/>
- **British Columbia** – <http://www.bccancer.bc.ca/screening/breast>
- **Manitoba** – <http://www.getcheckedmanitoba.ca/breastcheck.html>
- **Newfoundland and Labrador** – <http://www.easternhealth.ca/WebInWeb.aspx?d=3&id=1091&p=1078>
- **New Brunswick** – <http://www2.gnb.ca/content/gnb/en/departments/health/NewBrunswickCancerNetwork/content/NewBrunswickBreastCancerScreeningProgram.html>
- **Northwest Territories** – <http://breasthealthnwt.ca/>
- **Nova Scotia** – <https://breastscreening.nshealth.ca/>
- **Ontario** – <https://www.cancercare.on.ca/pcs/screening/breastscreening/OBSP>
- **Prince Edward Island** – <http://www.healthpei.ca/breastscreening>
- **Quebec** – <http://sante.gouv.qc.ca/en/programmes-et-mesures-daide/programme-quebecois-de-depistage-du-cancer-du-sein-pqdc/>
- **Saskatchewan** – <http://www.saskcancer.ca/Default.aspx?DN=3f3b564f-a7d1-4bee-bb80-0ec8f2b6b5d4>
- **Yukon** – <https://yukonhospitals.ca/whitehorse-general-hospital/mammographie>

Age of eligibility without referral

The most common eligibility age for mammography screening without a referral is 50–74 years (NWT, AB, ON, NB and NL), while two provinces stop screening at age 69 (SK, QC). Manitoba begins screening at age 50 but does not state the upper age limit. Several jurisdictions begin screening at age 40 (YK, BC, PEI and NS); among these programs, neither Yukon nor Nova Scotia specify the upper age limit.

Screening interval

Most jurisdictions ($n = 8$) recommend a two-year screening interval for mammography (BC, AB, SK, MB, ON, QC, NB and NS) while two recommend every two to three years (YK and

NWT) and one recommends every one to two years (NL). Some jurisdictions recommend annual screening for women 40–49 years of age (YK and NS). Three jurisdictions do not specify a screening interval for women aged 70 and older (NS) or 75 and older (YK and MB).

Relative risk reduction

Most websites state that screening mammography results in reduced breast cancer mortality. The estimates vary including 15%–25% (BC), 20%–30% (MB) and 25%–35% (NWT). The Quebec website cites seven deaths are prevented among 1,000 women who have a mammogram every two years for 20 years and that the goal of their screening program is to reduce breast cancer mortality by 25%. Six websites make a general statement that screening mammography can reduce the risk of death (ON, NB and NL), improve the chance of a cure (NS) or long-term survival (NWT and PEI). Ontario further states that a 42% breast cancer mortality reduction among women 50–74 years of age between 1990 and 2012 is likely due to a combination of mammography screening and improved treatment. No website specifically cites all-cause mortality reduction with mammography screening.

Claims less aggressive treatment

Nine jurisdictions state that screening mammography can result in earlier detection (YK, NWT, BC, AB, ON, QC, NB, PEI and NS) and eight jurisdictions state it can result in less invasive treatment (NWT and MB) including the possibility of no chemotherapy (QC), more effective treatment (YK and AB) and more treatment options (NWT, BC and ON).

False positive rate/recall rate

Cited rates of recall varied including 5% (MB), 7% (AB), 5%–10% (NL) and 10% (NWT and QC). The British Columbia website cites two different recall rates: 7% and 10%. The Yukon site states that digital mammography reduces the rate of “call-back” appointments. Different rates of breast cancer diagnosis are reported among women recalled including 10% (AB and SK) and 5% (NWT and QC). Two provinces give two different cancer diagnosis rates among women recalled: 5% and 10% (BC) and 10% and 20% (MB). Both Ontario and Newfoundland and Labrador websites state that “most” recalled women have a normal result on diagnostic workup. The Quebec site states that almost half of women screened for 20 years will have at least one additional examination.

False negative rate

Eight jurisdictions (NWT, BC, AB, SK, MB, ON, QC and NL) discussed the risk of a false negative result associated with screening mammography. Rates varied from 5% to 10% (NL), 10% (AB), 10% for women aged 50 and older (BC), 10%–20% (NWT), 20% (MB), 25% for women in their 40s (BC) and 27% among 1,000 women screened for 20 years (QC). Two websites generally state that a small number of breast cancers are not seen on mammography (SK) or that screening may miss some breast cancers (ON).

Additionally, the Ontario website states that interval cancers can occur between screens and the Quebec site states breast cancer can occur after a mammogram (i.e., as a missed or interval cancer).

Overdiagnosis

Overdiagnosis is described in various ways by seven websites. Quebec gave the best estimate of occurrence in their program at 13%. Four websites state that breast cancers may be found that may never have become symptomatic, caused harm or affected health (BC, AB, ON and QC). Three websites state that a woman may never have been diagnosed without screening (AB, MB and QC) or that screening could detect a very slow growing or benign tumour (AB and QC). The Manitoba website simply states that overdiagnosis can occur. In addition, the Nova Scotia website states that organized breast screening programs can minimize the unwanted effects of screening but these effects are not described. Five websites state that overtreatment or unnecessary treatment can occur (NWT, AB, MB, ON and QC). The Quebec website is the only one that provides additional information including the potential for frequent medical appointments and the side effects of unnecessary treatment. Also, two websites advise women that their quality of life or lifespan may not increase with mammography screening (AB and MB), two state that breast cancer may not be curable (MB and ON) and two that some women will still die of breast cancer (MB and QC). Quebec states that 17% of 1,000 women screened every two years for 20 years will die of breast cancer even though it was detected by screening. There is no mention of overdiagnosis on five websites (YK, SK, NB, PEI and NL).

Radiation risk

Seven jurisdictions state that women are exposed to a low dose (YK, NWT, SK and ON) or very low dose of radiation from mammography screening (BC, MB and NL). Two more websites state the benefits of mammography screening outweigh the risks associated with radiation (BC and ON). The British Columbia website states it has never been proven that radiation exposure from a mammogram has caused even one case of breast cancer.

Psychological distress

Seven websites discuss anxiety, worry and stress associated with screening – one in relation to waiting for results of the screen (MB), five in relation to being recalled for further tests (NWT, BC, AB, MB and QC) and one in relation to the experience of being overdiagnosed (QC). The Alberta website states that worry can last long after test results are known.

Directed to PHAC decision aid

Five jurisdictions include a link to the PHAC decision aid for breast cancer screening by mammography (PHAC 2009; YK, SK, MB, PEI and NS). Alternatively, the British Columbia website provides a link to the BC Cancer Agency breast screening decision aid (BC Cancer Agency n.d.).

Choice emphasized

Three websites explicitly make a general statement that it is a woman's choice to have mammography screening (NWT, SK and QC); in addition, the Yukon website states it is a choice for women 40–49 years of age. The Quebec website advises women to learn about the advantages, disadvantages and limitations to make an informed choice. Three websites give mixed messages regarding choice. The British Columbia website states that the benefits clearly outweigh the limitations for women 50–69 years of age (but advise women in their 40s to talk to their healthcare provider). The Ontario website states that women should talk to a healthcare provider regarding benefits and harms, and can opt out of the program at any time, while also stating that getting a mammogram is the best way to protect health. The Newfoundland and Labrador website states that women should be informed about benefits and harms and if deciding to participate in screening – to have regular screening mammograms. The choice of eligible women to take part in a provincial or territorial screening program was not explicitly mentioned on five websites (AB, MB, NB, PEI and NS).

Discussion

Breast screening programs in Canada have a legal and ethical duty to inform women of all potential benefits and harms of mammography screening so they can make an informed decision. This is particularly critical for organized programs which recommend mammography screening for all women in their targeted age group. All breast screening program material targeted to women should contain balanced information regarding potential benefits and harms in plain language that can be easily understood. In addition, all program material should emphasize a woman's right to choose whether to be screened and that the choice to not be screened by mammography is a reasonable one.

The purpose of this review was to determine what information is provided on the websites of 12 breast screening programs in Canada to enable women to make an informed decision about mammography screening and whether choice is emphasized. An informed decision regarding mammography screening is enabled if information regarding the potential benefits and harms is accessible to the public. For this to be the case, a breast screening program website would have to provide up-to-date information regarding potential benefits (e.g., reduced mortality, less aggressive treatment) and potential harms (e.g., false positives, false negatives, overdiagnosis and unnecessary treatment, radiation risks and psychological distress). This review of the websites of 12 breast screening programs in Canada determined that none provide comprehensive balanced information to support women to make an informed decision.

This review found that the information available and level of detail provided to the public varied by jurisdiction. As discussed in the results, the websites of six programs did not give specific information regarding breast cancer mortality reduction, and estimates varied among the jurisdictions that did. None of the websites reported on all-cause mortality reduction which the Cochrane Collaboration stated was a better predictor of benefit than breast

cancer mortality reduction. Further, the websites of six programs did not specifically cite their rates of false positives and false negatives. Women should be informed about the most serious risk of mammography screening – overdiagnosis and accompanying unnecessary treatment. Quebec’s website gave an explicit estimate of the risk of overdiagnosis although the websites of Alberta and Manitoba (in addition to Quebec) provided good descriptions of what overdiagnosis is and that it occurs. Radiation associated with mammography screening was generally described as low or very low, when it was described at all. The information on the radiation risks associated with mammography screening, therefore, was limited. The British Columbia website even stated there has never been a confirmed case of breast cancer caused by the radiation exposure of mammography. One website cited the psychological distress associated with screening itself; most described anxiety as normal if a screening result was positive. The Alberta website cited that “worry” may last long after the test results are known, and none of the websites discussed the significant stress associated with overdiagnosis and unnecessary treatment. Six websites directed women to a decision aid but the link to that of the PHAC was broken on several websites during the review phase of our study, and it appears to be archived on the PHAC website. Three websites explicitly stated that it is a woman’s choice to be screened by mammography.

The decision aids to which women are referred on six program websites do not provide balanced information to contribute to their informed consent regarding mammography screening. Information in the PHAC decision aid (PHAC 2009) needs to be updated to reflect increasing evidence that the benefit of mammography screening is lower than once thought and specific information needs to be provided regarding the risks of overdiagnosis and unnecessary treatment, and these factors should be explicitly discussed in the decision aid score card. The decision aid on the British Columbia website (BC Cancer Agency n.d.) collects information from women regarding their age, family history and screening history and provides a personalized estimate that a screening mammogram will find a breast cancer, cause a false positive result and lead to a biopsy for a false positive result. However, it states that mammography reduces breast cancer mortality by 25%, and there is no information regarding overdiagnosis.

The findings of this review are consistent with other reviews of breast screening promotional materials that have been described as emphasizing benefits and minimizing harms (Gøtzsche et al. 2009; Gøtzsche and Jørgensen 2011; Gummertsbach et al. 2010; Jørgensen and Gøtzsche 2006) and being very biased in favour of participation (Jørgensen et al. 2009). The goal of all informational materials should be focused on enabling informed consent, not increasing participation rates. Accessible and balanced information on all breast screening promotional materials will support women’s ethical and legal right to informed consent.

A limitation of this study is that the websites of breast screening programs in Canada are updated regularly, so it is not possible to confirm the results of this particular review. This risk was mitigated by having three reviewers involved in this review, and they agreed on the findings. The findings reported here are from a review conducted April 12–19, 2017.

A future direction for research is a review of invitations, recall letters and consent forms to determine what information is provided to women to enable informed consent. Moreover, it would be very useful to assess the understanding of women who engage in mammography screening regarding the potential benefits and harms.

In summary, breast screening programs have a legal and ethical responsibility to provide accessible information to eligible women regarding the potential benefits and harms of mammography screening in all program and promotional materials, including on their websites and in their consent forms. Women should be informed – in plain language – of the increasing evidence that organized breast screening is less effective than once thought. Screening personnel administering the consent forms should confirm women’s comprehension of the information presented before securing consent. It is critical that women are able to make an informed decision about participating in mammography screening.

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Prior Authorization and Canadian Public Utilization of Direct-Acting Oral Anticoagulants

Autorisation préalable et utilisation publique au Canada des anticoagulants oraux directs



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Prior Authorization and Canadian Public Utilization of Direct-Acting Oral Anticoagulants

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Abstract

Purpose: Provincial public drug formularies in Canada have different mechanisms for reimbursement of direct-acting oral anticoagulants (DOACs). We investigate how these differences influence DOAC utilization and expenditure across the country.

Methods: We conducted a population-based, cross-sectional study of all out-patient prescriptions for OACs dispensed to public beneficiaries between January 1, 2010, and June 30, 2015. We calculated quarterly rates of OAC use and expenditures stratified by OAC type and province.

Results: The greatest increase in quarterly rates of DOAC utilization occurred in provinces with more liberal mechanism of drug coverage: Ontario by 462%, Alberta by 425% and Quebec by 1,924%. This translated to increased expenditure on overall OAC by 270%, 204% and 390%, respectively. In contrast, provinces with more stringent mechanisms had low rates of DOAC utilization and expenditure.

Conclusions: DOAC utilization and expenditure is considerably different across Canada, associated with provincial difference in reimbursement mechanism.

Résumé

Objet : Les formulaires pharmaceutiques provinciaux au Canada prévoient divers mécanismes pour le remboursement des anticoagulants oraux directs (AOD). Nous avons étudié comment ces différences influent sur l'utilisation des AOD et sur les dépenses, dans l'ensemble du pays.

Méthode : Nous avons mené une étude transversale auprès de tous les patients externes auxquels était prescrit un anticoagulant oral entre le 1^{er} janvier 2010 et le 30 juin 2015. Nous avons calculé les taux trimestriels d'utilisation d'anticoagulant oral et des dépenses, ventilés selon le type de coagulant et la province.

Résultats : La plus forte croissance des taux trimestriels d'utilisation des AOD a eu lieu dans les provinces où le mécanisme de remboursement pour les médicaments est le plus libéral : Ontario, 462 %; Alberta, 425 %; et Québec, 1 924 %. À cela correspond également une hausse des dépenses pour l'ensemble des anticoagulants oraux, soit respectivement de 270 %, 204 % et 390 %. À l'opposé, les taux d'utilisation des AOD et les dépenses sont plus bas dans les provinces où les mécanismes de remboursement sont plus contraignants.

Conclusions : L'utilisation des AOD et les dépenses diffèrent sensiblement dans l'ensemble du Canada, en fonction des différences dans les mécanismes de remboursement des provinces.

Introduction

Direct-acting oral anticoagulants (DOACs) (rivaroxaban, dabigatran and apixaban) were introduced in Canada in 2008 for prophylaxis of venous thromboembolism after elective hip or knee replacement surgery (CADTH 2008). Prior to the introduction of DOACs, the only OAC was warfarin. Since DOAC introduction, there has been a cited shift in prescribing away from warfarin towards DOACs across Canada (Weitz et al. 2015). Compared to traditional anticoagulation management (i.e., warfarin, heparin), DOACs have been shown to be at least non-inferior for prevention of stroke or systemic embolism in patients with non-valvular atrial fibrillation (Connolly et al. 2009; Granger et al. 2011; Patel et al. 2011), as well as for treatment of deep vein thrombosis or pulmonary embolism (Agnelli et al. 2013; The EINSTEIN Investigators 2010; The EINSTEIN-PE Investigators 2012). They have also been shown to be superior for prophylaxis of deep vein thrombosis following hip or knee replacement surgeries (Eriksson et al. 2008; Lassen et al. 2010). In addition, they have fewer drug–drug or drug–food interactions and can be given in fixed doses without routine coagulation monitoring. DOACs have been mostly utilized by specialists in Canada under the influence of various practice guidelines (Camm et al. 2012; Verma et al. 2014; Weitz et al. 2015).

The cost-effectiveness of DOACs compared to warfarin has been found to be highly sensitive to patient characteristics, such as average time in therapeutic range (TTR), CHADS2 score and age (Coyle et al. 2013). CHADS2 score is commonly used to stratify ischemic stroke risk in patients with nonvalvular atrial fibrillation (Macle et al. 2014). It is cumulative based on six clinical features including congestive heart failure, hypertension, age ≥ 65 years, diabetes mellitus (1 point each), prior stroke or transient ischemic attack (2 points). DOACs have only been shown to be cost-effective compared to warfarin in certain atrial fibrillation populations based on international normalized ratio (INR) time in TTR below 64% (Connolly et al. 2009; Granger et al. 2011; Patel et al. 2011; Trusler 2015). Given the large price difference in the combined drug and lab monitoring costs (BC PharmaCare Special Authority 2013, 2016, 2017), reimbursement of DOACs is limited to patients meeting eligibility criteria. These criteria are fairly uniform across provinces. For example, among patients with non-valvular atrial fibrillation but without severe renal impairment, all provinces reimburse DOACs for patients who have tried warfarin for a minimum of two months but cannot reach the desired INR target, as well as for those with contraindications to warfarin and those with limited access to regular INR testing.

However, provincial public drug formularies differ considerably in the mechanism used to enforce these criteria (Table S1 in Appendix 1; available at: www.longwoods.com/content/25321). For instance, the special authority policy in British Columbia requires prescribers faxing or mailing a special authority request outlining each patient's eligibility for DOACs to provincial PharmaCare, which ultimately determines whether the patient meets the criteria for drug coverage (BC PharmaCare Special Authority 2013, 2016, 2017). Thus, patients cannot access DOACs until they receive approval from PharmaCare following

individual clinical review. In contrast, the Ontario Drug Benefit Program's Limited Use process requires only that prescribers confirm the indication and conditions for use by adding a specific "Reason for Use" code to the prescription (Ontario Drug Benefit Formulary/Comparative Drug Index 2016). These codes grant patients immediate access to DOACs without direct involvement of the provincial government.

Little is known about how these different approaches to DOAC accessibility influence utilization and expenditures related to these drugs. We explored how differential mechanism of DOAC coverage influenced the utilization and expenditure on DOACs on public drug formularies across Canada.

Methods

We conducted a population-based, cross-sectional study of all out-patient prescriptions for OACs dispensed to individuals covered by public drug programs in Canada between January 1, 2010, and June 30, 2015. The composition of provincial beneficiaries varies across Canada, as provincial governments independently provide public drug coverage for seniors, social assistance recipients and medically necessary hospital and physician services with varying eligibility and patient cost-sharing arrangements (Daw and Morgan 2012).

To interpret the results of public claims more accurately, we also separately conducted analysis of all privately funded new OAC (NOAC) prescriptions across Canada within the same time frame, including individuals covered by private insurance or by paying cash.

Data source for prescription claims

We obtained prescription data from IMS Geographic Prescription Monitor (GPM12), which contains data from a representative panel of approximately 65% of Canadian pharmacies. Total numbers of prescriptions and units dispensed, as well as associated costs, are projected monthly using geospatial methods based on the number of pharmacies in a given region, the size of the pharmacies and the distance between IMS-captured and uncaptured pharmacies. The projections are representative of provincial and national sales volumes. Data were available for Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland, Nova Scotia, Ontario, Prince Edward Island, Quebec and Saskatchewan, and were stratified by type of OAC, payer type (public, private or NIHB) and province.

Data source for public beneficiaries

The National Prescription Drug Utilization Information System (NPDUIS), developed by the Canadian Institute for Health Information, and the Ontario Drug Benefit (ODB) database were used to obtain estimates of the number of individuals eligible for provincial drug coverage in Alberta, British Columbia, Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland & Labrador and Ontario between 2000 and 2014. Eligible individuals were defined as those dispensed at least one prescription for any drug in each calendar year. Because NPDUIS does not capture prescription

data for Quebec, we obtained estimates of eligible beneficiaries from aggregated data in the annual reports of each public drug program (Annual Management Report 2014). In all provinces, the number of individuals eligible for public drug coverage in 2015 was estimated based on linear extrapolation from previous years.

Data analysis

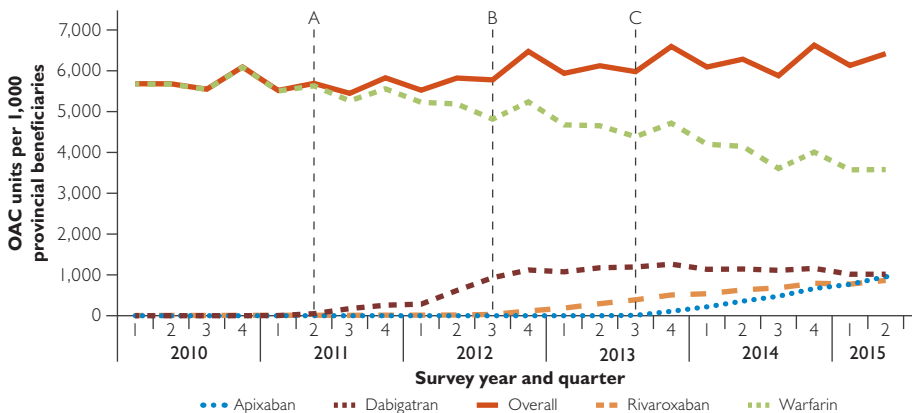
Rates of OAC use and expenditures were calculated quarterly for each province. For publicly funded prescriptions (i.e., public claims only), they were expressed as the number of units dispensed per 1,000 public beneficiaries and the total cost per 1,000 public beneficiaries. For privately funded prescriptions (i.e., private insurance claims or cash claims), the rates were expressed as the number of NOAC units dispensed per 1,000 provincial population. Quarterly estimates of provincial population were obtained from Stats Canada.

Results

Rates of publicly funded DOACs utilization at national level

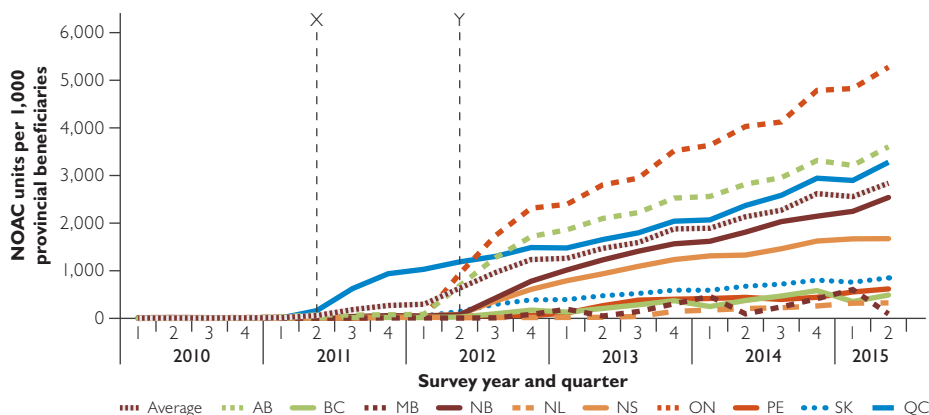
Over the 5-year study period, more than 1 billion OAC tablets or capsules were dispensed in Canada, and the overall quarterly rate of OAC dispensing remained relatively stable at approximately 6,000 units per 1,000 provincial beneficiaries (Figure 1). Nationally, the rate of publicly funded warfarin dispensing decreased by 36.9% from 5,677 to 3,580 units per 1,000 provincial beneficiaries over the study period, which aligned with the addition of each DOAC to public drug formularies in Canada (Weitz et al. 2015). By the second quarter of 2015, the rates of use of dabigatran, apixaban and rivaroxaban were similar (1,016, 957 and 865 units per 1,000 provincial beneficiaries, respectively; Figure 1).

FIGURE 1. Trends in publicly funded OAC dispensing in Canada (2010–2015)



OAC = oral anticoagulant. Note: A = First listing of dabigatran for stroke prevention in Quebec (April 2011), B = First listing of rivaroxaban for stroke prevention in Ontario (July 2012), C = First listing of apixaban for stroke prevention in Ontario (August 2013).

FIGURE 2. Trends in uptake of publicly funded NOACs by province (2010–2015)



NOAC = new oral anticoagulant. Note: X = Listing of dabigatran for stroke prevention in Quebec (April 2011), Y = Listing of dabigatran for stroke prevention in Ontario (April 2012), Alberta (May 2012), New Brunswick (June 2012) and Nova Scotia (June 2012).

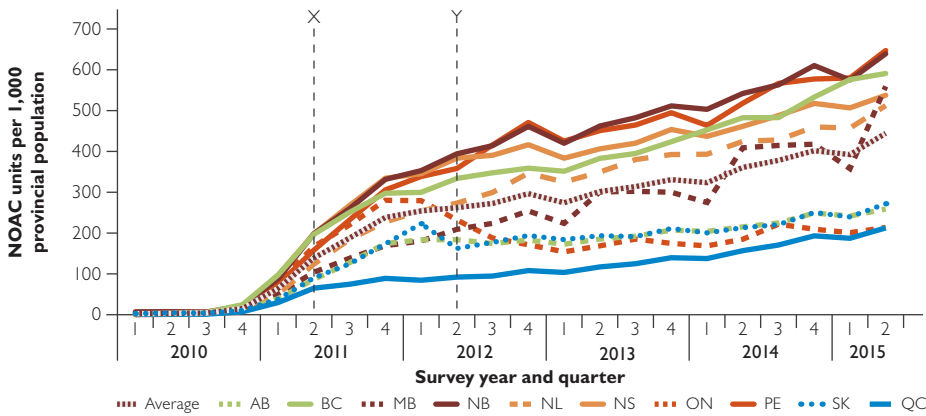
Interprovincial comparison of publicly funded DOACs utilization

While the overall rate of OAC dispensing has remained stable, the rate of warfarin dispensing has declined while the rate of DOAC dispensing has increased in each province (Figure 2 and Appendix 1). However, there is considerable interprovincial variation in DOAC uptake such that the provinces with more liberal mechanism of DOAC reimbursement criteria have much higher uptake of DOACs. These provinces include Ontario (5,275 units per 1,000 provincial beneficiaries), Alberta (3,604 units per 1,000 provincial beneficiaries) and Quebec (3,279 units per 1,000 provincial beneficiaries), where the rate of DOAC utilization was above the national average (2,839 units per 1,000 provincial beneficiaries). In all of the remaining provinces with more stringent mechanism, the rate of publicly funded DOAC use was low, ranging from 93 units (Manitoba) to 850 units (Saskatchewan) per 1,000 provincial beneficiaries in Q2 2015.

Interprovincial comparison of privately funded DOACs utilization

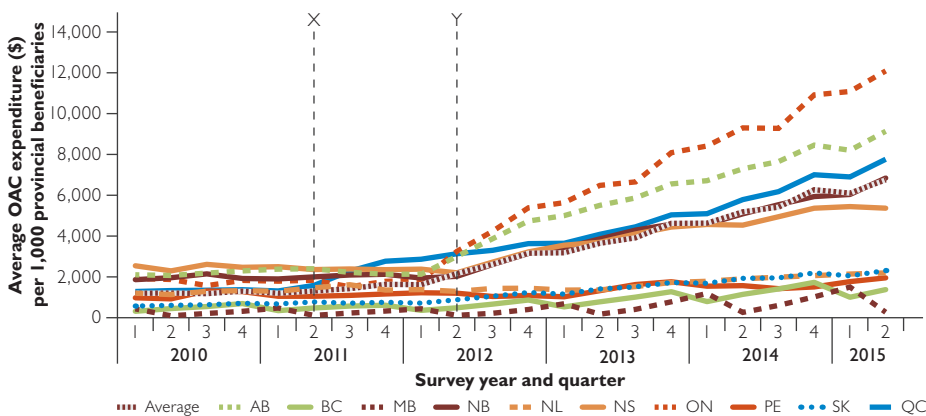
Privately funded DOACs uptake was in contrast to publicly funded DOACs uptake across Canada (Figure 3). Provinces with more liberal mechanism of public reimbursement had lower privately funded DOACs uptake. These provinces include Ontario (214 units per 1,000 provincial population), Alberta (259 units per 1,000 provincial population) and Quebec (212 units per 1,000 provincial population), where the rate of privately funded DOAC utilization was below the national average (444 units per 1,000 provincial population). In the remaining provinces with more stringent mechanism, the rate of privately funded DOAC use was higher, ranging from 272 units (Saskatchewan) to 647 units (Prince Edward Island) per 1,000 provincial population in Q2 2015.

FIGURE 3. Trends in uptake of privately funded NOACs by province (2010–2015)



NOAC = new oral anticoagulant. Note: X = Listing of dabigatran for stroke prevention in Quebec (April 2011). Y = Listing of dabigatran for stroke prevention in Ontario (April 2012), Alberta (May 2012), New Brunswick (June 2012) and Nova Scotia (June 2012).

FIGURE 4. Trends in average expenditure of publicly funded OAC by province (2010–2015)



OAC = oral anticoagulant. Note: X = Listing of dabigatran for stroke prevention in Quebec (April 2011). Y = Listing of dabigatran for stroke prevention in Ontario (April 2012), Alberta (May 2012), New Brunswick (June 2012) and Nova Scotia (June 2012).

Interprovincial comparison of publicly funded OACs expenditure

Rising DOAC utilization on public drug plans has translated to increasing provincial expenditure on OACs as a drug class such that the provinces with less stringent mechanism of DOAC reimbursement have considerably higher expenditure (Figure 4). Since provincial listing of DOACs for stroke prevention in April 2011 (Weitz et al. 2015), provincial expenditures on OACs increased ranging from 23% in Manitoba (from \$218 to \$267 per 1,000 provincial beneficiaries each quarter), where mechanism of DOAC reimbursement is more stringent, to 390% in Quebec (from \$1,583 to \$7,764 per 1,000 provincial beneficiaries each quarter), where mechanism is less stringent.

Furthermore, while DOACs account for 41% (86 million units of 209 million units) of all OACs dispensed across Canada, they account for 88% (\$180 million of \$204 million)

of OAC expenditure between July 2014 and June 2015 (Figure S3 in Appendix 1). This is particularly striking in Ontario and Quebec where DOAC reimbursement is less stringent, such that DOAC represented approximately 50% (47 million units of 97 million units and 25 million units of 53 million units, respectively) of OAC prescription volumes, but accounted for 90% (\$97 million of \$106 million and \$53 million of \$60 million, respectively) of OAC expenditures.

Discussion

In this population-based study spanning 5 years, we found varying patterns of DOAC utilization across Canada since their addition to provincial formularies in 2011, along with considerable interprovincial differences in public expenditures on OACs across Canada. Despite this, the overall population-adjusted rates of OAC utilization have been relatively stable across Canada during our study period, suggesting that these rising expenditures are not due to market expansion (Steinberg et al. 2013), but replacement of warfarin with DOACs.

Interprovincial differences in DOAC utilization were related to the differences in mechanism of provincial reimbursement. Publicly funded DOACs' uptake and associated expenditure were much higher in provinces with more liberal mechanism of reimbursement, such as Ontario, Alberta and Quebec, whereas privately funded DOACs' uptake remained much lower in these provinces. Specifically, Ontario and Quebec have the most liberal mechanism in Canada, where prescribers access DOACs for their patients by using special codes on the prescriptions allowing pharmacies to directly bill for DOACs. Consequently, DOACs make up almost half of all OAC volume in these provinces. Alberta has slightly more controlled DOAC access compared to Ontario and Quebec, involving screening of patients' past medication history by computer systems before reimbursing DOACs. Nevertheless, the ability for patients meeting the clinical criteria to immediately access DOACs following this review – as well as the fact that pharmacists can override the results of the computer screening – may have led to the high rate of DOAC uptake seen in this province. The five provinces with strict mechanism in which policies restrict access to DOACs until the completion of a clinical review for eligibility (British Columbia, Manitoba, Saskatchewan, Newfoundland & Labrador and Prince Edward Island) all had similarly low rates of DOAC uptake, suggesting that clinicians in provinces where prior authorization is not required may be interpreting eligibility criteria more broadly than intended.

Our results are consistent with published findings in other jurisdictions. In Denmark where public coverage of prescription costs is universally implemented (Vrangbæk 2008), utilization of warfarin was reduced by approximately 60% with increasing uptake of DOACs for stroke prevention from 2011 to 2013 after the introduction of DOACs to the market (Olesen et al. 2015). In the US, the proportion of ambulatory physician visits involving dabigatran prescriptions among OACs increased from 3.1% to 18.9% within a year following its FDA approval. This translated to an increase in dabigatran direct expenditure from \$16 million

to \$166 million, exceeding direct expenditure on warfarin (\$144 million) on the US market (Kirley et al. 2012). In Canada, we found similar trends towards increasing uptake of publicly funded DOACs, and we were able to further demonstrate differential uptakes across Canadian provinces depending on the level of provincial enforcement for reimbursement criteria.

Several limitations of our study merit emphasis. First, we were unable to ascertain indications for anticoagulant therapy, and therefore could not address whether DOACs were being used according to clinical criteria in each province. Second, it is possible differences in the eligibility criteria and structure of benefits between provinces leads to differences in demographic and comorbidity status of individuals receiving publicly funded DOACs which could influence our findings. Because we did not have any individual-level information that allowed us to specifically analyze these differences, we were unable to determine the impact that these differences may have had on our findings. Third, our data were only available at the unit (i.e., tablet or capsule) level, and we could not conduct patient-level analyses to infer clinical appropriateness or clinical outcomes of DOAC use. Fourth, we cannot address drivers that potentially influence interprovincial difference in uptake of DOACs, such as interprovincial difference in promotion or sale activities or adoption by prescribers, especially in provinces with more liberal mechanism of reimbursement. Finally, we did not have any data for the Territories, so we could not provide any insight on DOAC utilization in those regions of Canada. However, these regions represent a small proportion (approximately 0.33%) of the total population of Canada (Statistics Canada 2015).

Conclusions

Since 2011, there have been increasingly divergent trends in DOAC utilization and related expenditures across Canada, likely reflecting interprovincial differences in mechanism of clinical criteria for these drugs. Future studies should examine characteristics and clinical outcomes of patients using DOACs in those provinces with liberal mechanism of reimbursement to determine the extent to which uptake aligns with intended clinical criteria for coverage (Xu et al. 2016). This is of importance to both policy makers and clinicians because these clinical criteria are generally designed to facilitate use of DOACs to populations in whom they have been shown to be both safe and cost-effective (Wells et al. 2012).

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Evaluating the Implementation of The Champlain BASE™ eConsult Service in a New Region of Ontario, Canada: A Cross-Sectional Study

Évaluation de la mise en œuvre du service de consultation
en ligne The Champlain BASE™ dans une nouvelle région
de l'Ontario, Canada : une étude transversale



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Abstract

Objective: To replicate an existing electronic consultation (eConsult) service in a new jurisdiction to test its generalizability.

Methods: We conducted a cross-sectional study of all eConsults submitted by providers in the region of Mississauga Halton, Ontario, between January 5, 2015, and May 31, 2016.

We compared our results to those from the original pilot in Eastern Ontario. The RE-AIM model served as our study framework.

Results: Providers submitted 594 patient cases to 46 different specialty groups during the study period. Specialists responded in a median of 1.1 days, with 75% of cases answered within four days. Providers rated the service as having high or very high value for themselves and their patients in 92% of cases. The service yielded a net program cost of \$10,321.56.

Conclusion: Our findings resembled those of the initial implementation, though with a faster rate of uptake and lower cost because of the avoidance of start-up and administrative costs.

Résumé

Objectif : Reproduire la mise en place d'un service de consultation en ligne existant dans une nouvelle région et en évaluer la généralisabilité.

Méthode : Nous avons mené une étude transversale de toutes les consultations en ligne effectuées par les fournisseurs dans la région de Mississauga Halton, en Ontario, entre le 5 janvier 2015 et le 31 mai 2016. Nous avons comparé nos résultats à ceux du projet pilote initial dans l'Est ontarien. Le modèle RE-AIM a servi de cadre de travail pour notre étude.

Résultats : Les fournisseurs ont présenté 594 cas à 46 groupes de diverses spécialités au cours de la période à l'étude. Le temps médian de réponse des spécialistes est de 1,1 jour, et 75 % des cas ont reçu une réponse en moins de quatre jours. Les fournisseurs ont accordé aux services les cotes « grande utilité » et « très grande utilité » pour eux-mêmes et leurs patients dans 92 % des cas. Le coût net du programme généré par le service s'élève à 10 321,56 \$.

Conclusion : Nos résultats ressemblent à ceux observés lors de la mise en œuvre initiale, quoiqu'avec un taux d'adhésion plus rapide et des coûts moindres en raison d'une diminution des frais de lancement et des frais administratifs.

Background

Scaling up healthcare innovations can be challenging. Many programs fail to realize their potential in “real world” settings as the evidence supporting their effectiveness often does not account for local contexts, which can be crucial to successful replication. This is especially true of eHealth solutions, which are often created without a nuanced understanding of the problems they seek to address (Ammenwerth et al. 2006). Neglecting these factors can result in costly failures. This was seen in the UK, where the National Health Service invested in an initiative providing physicians with a suite of health information technologies. Despite an investment of billions of dollars, 98% of the purported benefits of many programs have not been achieved (National Audit Office 2013). Similar failures have been reported in other health systems (Johnson 2010) including Canada's (Liddy et al. 2015b).

Since 2008, our team has been addressing the issue of excessive wait times for accessing specialist care, which is a significant problem facing many healthcare systems worldwide, including

Canada's (CIHI 2017; Globerman et al. 2015; Viberg et al. 2014). A report by the Fraser institute found that patients wait a median of 18.3 weeks between being referred to a specialist and receiving treatment, an increase of 97% from 1993. Median wait times vary widely by region, from 13.6 weeks in Saskatchewan to 43.1 weeks in Prince Edward Island (Barua 2015). These waits exceed the duration deemed reasonable by many clinicians and have serious real-world consequences, resulting in worse health outcomes, proliferation of chronic disease, burdensome costs from missed work and higher mortality rates (Barua 2015; Barua et al. 2014).

To this end, we launched the Champlain BASE™ (Building Access to Specialists through eConsultation) eConsult service in the Champlain Local Health Integration Network (LHIN), a health region situated in the easternmost part of Ontario. The eConsult service is a secure web-based platform that facilitates communication between primary care providers (PCPs) and specialists. PCPs submit a patient-specific question to one of 95 different specialty groups and receive a reply within one week. Two-thirds of cases are resolved without the patient requiring a face-to-face specialist visit. The eConsult service's effectiveness at reducing wait times, high levels of patient and provider satisfaction, and ability to lower costs for care have been described in previous studies using a range of methods, including cross-sectional analyses of usage data and close-out survey responses, thematic analyses and costing evaluations (Keely et al. 2013; Liddy et al. 2013a, 2013b, 2015a, 2016, 2017a).

Having successfully implemented the eConsult service in our health region, our team has begun exploring its implementation in new jurisdictions across Canada. However, prior to a broad expansion to new provinces and territories, it was necessary to explore and verify the service's generalizability on a smaller scale. We thus sought to replicate the eConsult service in the Mississauga Halton LHIN, another Ontario health region situated in the province's southwest.

In this study, we examined the process of implementing eConsult in Mississauga Halton and evaluated its adoption rates, utilization and impact using the RE-AIM model developed by Glasgow and colleagues (1999). By exploring the implementation process in a new jurisdiction, we identified the critical success factors needed to support the successful adoption of eConsult services.

Methods

Setting

The Mississauga Halton LHIN is one of Ontario's 14 health regions. Located to the southwest of Toronto, it covers approximately 900 square kilometres and is home to over 1.2 million residents (Mississauga-Halton LHIN 2016). Two hospital corporations spanning six sites provide many of the specialty services to people living throughout the region.

Intervention/eConsult service model

The Champlain BASE™ eConsult service was designed by clinicians as a solution to excessive wait times for specialist care, based on the specific needs determined by patients and their PCPs (Keely et al. 2013; Liddy et al. 2013a, 2013b). The eConsult service was built on an

existing web-based platform supported by the Champlain LHIN and hosted within the secure infrastructure of the Winchester District Memorial Hospital, ensuring adherence to provincial privacy policies. Cases begin when the PCP (a family physician or nurse practitioner) sends a question to a selected specialty. Specialists are notified by e-mail and respond to the question within one week with advice for care, a recommendation for referral or a request for more information. PCPs ultimately decide how to apply the specialist's suggestion and when the case can be deemed complete. Upon closing the case, PCPs complete a brief survey assessing the outcome and value of the service. Specialists are generally compensated on a pro-rated hourly basis (Liddy et al. 2013a, 2013b), although some are salaried and do not receive any additional compensation. Funding for the physician compensation is provided through the provincial Ministry of Health. PCPs are not remunerated directly from the service, though family physicians in Ontario are eligible for compensation based on an e-Consult billing code (JCL Medical Systems 2016).

Organization of specialty services

At the time of this study, a comprehensive, multispecialty eConsult service with access to 67 different specialty groups from within the Champlain LHIN was made available to participants from Mississauga Halton. One of the study's goals was to leverage specialists in one jurisdiction to help address the needs of PCPs in another, while simultaneously building a local base of specialists. Specialists from the Mississauga Halton LHIN were added to the service based on requests from the PCPs as well as the specialists' interest and availability. For some specialty groups, the service included specialists located in both the Champlain and Mississauga Halton LHINs. In a few cases, specialty groups in Mississauga Halton not previously available in the Champlain LHIN were formed and began serving the broader community (geriatrics, general surgery and cancer screening).

PCP recruitment

PCPs were recruited into the study via the Ontario Provincial eConsult Initiative developed in partnership between several provincial organizations, including Ontario MD, the Ontario Ministry of Health and Long-Term Care (MOHLTC), the Ontario Telemedicine Network and the Mississauga Halton and Champlain LHINs (Keller 2015). The initiative's goal was to provide access to three different online eConsult technology platforms, one of which was the Champlain BASE™ eConsult service. Mississauga Halton chose to receive the Champlain BASE™ model of care. The official date of the provincial initiative was January 5, 2015, although a small number of users ($n = 13$) registered for our service prior to the provincial launch, as a result of physician engagement activities during a ramp-up phase. The majority of users were engaged and registered during the first year of the provincial initiative through the Mississauga Halton Primary Care Advisor (PCA) team. PCAs are individuals who promote LHIN-wide programs and initiatives to support the advancement of primary care engagement across all service providers (Burden 2016). In the context of the present study, the recruitment typically consisted of PCAs visiting and/or communicating with the

local primary care clinics on various topics, including eConsult, and connecting the eConsult support team with interested PCPs for further instructions and orientation to the service.

Evaluation framework

For this study, we evaluated all cases completed by PCPs in Mississauga Halton between January 5, 2015, and May 31, 2016. We used the RE-AIM framework created by Glasgow et al. (1999) to evaluate the service's implementation. The RE-AIM framework proposes that the translatability and public health impact of an initiative is best evaluated by examining its: (1) reach into the target population; (2) effectiveness or efficacy; (3) adoption by target settings, institutions and staff; (4) implementation, including its consistency and costs of delivery; and (5) maintenance of intervention effects in individuals and settings over time. To assess these dimensions, we examined the data routinely collected by the system. PCPs' responses to the mandatory close-out survey were used to determine (1) whether using eConsult resulted in PCPs choosing a new course of action for treatment and (2) whether a face-to-face consultation was originally contemplated and/or ultimately recommended. We compared our results to those obtained during the pilot phase of the service in the Champlain LHIN (Keely et al. 2013). Given that eConsult is a health system-level innovation, we chose to examine its effectiveness/efficacy on four key dimensions of care outlined by the Quadruple Aim framework developed by Bodenheimer and Sinsky: population health, patient experience, provider experience and cost (Bodenheimer and Sinsky 2014). Since assessing eConsult's impact on population health outcomes in the early pilot stages was not possible due to low case volumes, we focused on quality of care outcomes related to the attainment of timely and appropriate healthcare, which by the Institute of Medicine definitions reflect the degree to which healthcare services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge (Institute of Medicine [US] 2001). Our key outcomes included the timeliness of access to specialist expertise and the effect on PCPs' course of action, including the need for face-to-face visits.

Table 1 provides definitions for the five RE-AIM dimensions and lists the questions we used to guide our assessment of eConsult's implementation in Mississauga Halton.

Results

Reach

The eConsult service demonstrated greater reach during its implementation in the Mississauga Halton LHIN than it did in the Champlain LHIN during an equivalent period. PCPs in the Mississauga Halton LHIN completed 594 eConsults during the study period compared to 451 in the Champlain LHIN (Figure 1a). The monthly volume of cases also grew more rapidly in the Mississauga Halton LHIN than they had in the Champlain LHIN (Figure 1b). When expressed as population rates, PCPs completed 0.36 eConsults per 1,000 people in the Mississauga Halton LHIN during the first year of implementation compared to 0.16 eConsults per 1,000 people in the Champlain LHIN (Statistics Canada 2011).

TABLE 1. A description of the five dimensions of care outlined by the RE-AIM framework

| RE-AIM dimension | Definition | Questions specific to eConsult evaluation |
|---|---|--|
| Reach into the target population | The absolute number, proportion and representativeness of individuals who are willing to participate in a given initiative, intervention or program. | What was the absolute number and proportion of patients reached and served via eConsult service? Which patients were reached in terms of the breadth of specialties accessed through the eConsult service? |
| Effectiveness or efficacy | The impact of an intervention on important outcomes, including potential negative effects, quality of life and economic outcomes. | What was the impact of eConsult on the key areas to care quality: population health, patient experience, provider experience and cost? |
| Adoption by target settings, institutions and staff | The absolute number, proportion, and representativeness of settings and intervention agents (people who deliver the program) who are willing to initiate a program. | What was the uptake of the eConsult service (absolute number, regional proportion, monthly growth over time) among the PCP population in MH LHIN? What was the uptake/participation among the specialists/specialty groups from the MH LHIN? |
| Implementation consistency, costs and adaptations made during delivery | The consistency and fidelity to the program protocol, the costs and adaptations made during delivery. | What was the fidelity to the essential steps (Liddy et al. 2013b) (including establishing partnerships, addressing privacy issues, physician engagement and payment) previously described as necessary for replication of eConsult platform in other health regions? |
| Maintenance of intervention effects in individuals and settings over time | The extent to which a program or policy becomes institutionalized or part of the routine organizational practices and policies. | What is the ongoing usage of eConsult? What were the reinforcing factors required to maintain the eConsult service? |

MH LHIN = Mississauga Halton Local Health Integration Network; PCP = primary care provider.

The breadth of specialties accessed by patients from the Mississauga Halton LHIN is shown in Figure 2. The most commonly accessed specialties were dermatology (18% of cases), obstetrics/gynecology (OBS/GYN) (9%), hematology (7%), endocrinology (7%) and cardiology (6%).

Effectiveness

We used the Quadruple Aim model as a lens to view the different elements of effectiveness (Bodenheimer and Sinsky 2014).

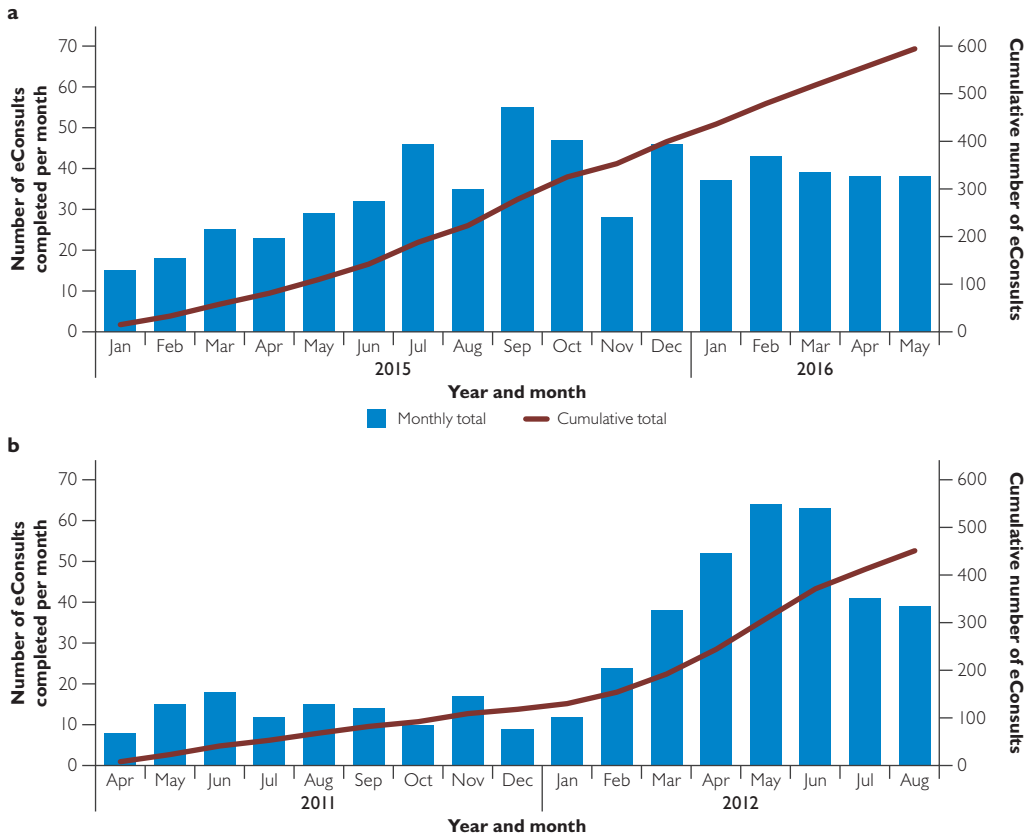
POPULATION HEALTH

Specialists provided an initial response to PCP questions in a median of 1.1 days, with 75% of eConsults answered within 4.2 days. In 5% of cases (29/594), the specialists took longer to respond than the prescribed 7-day response period. PCPs closed eConsult cases (e.g., received and read response and answered close-out survey) in a median of 5.3 days, with 75% of cases completed within 13.2 days.

PCPs received advice on a new or additional course of action in 51% of cases, and confirmed their original course of action in 44% (Figure 3). Only 3% of responses were deemed not to be useful. In 40% of cases, a referral was originally contemplated but ultimately avoided. In 32% of cases, a referral was not originally contemplated and was still not needed. Overall, 72% of all completed cases did not require a face-to-face visit.

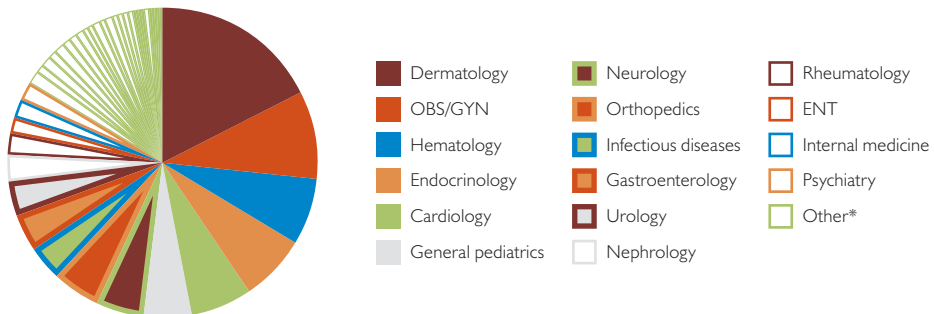
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FIGURE 1. eConsult case volume – Number of cases completed per month and cumulative total in MH LHIN (a) and Champlain LHIN (b)



LHIN = Local Health Integration Network; MH = Mississauga Halton.

FIGURE 2. Specialty distribution: eConsult cases submitted to all specialties

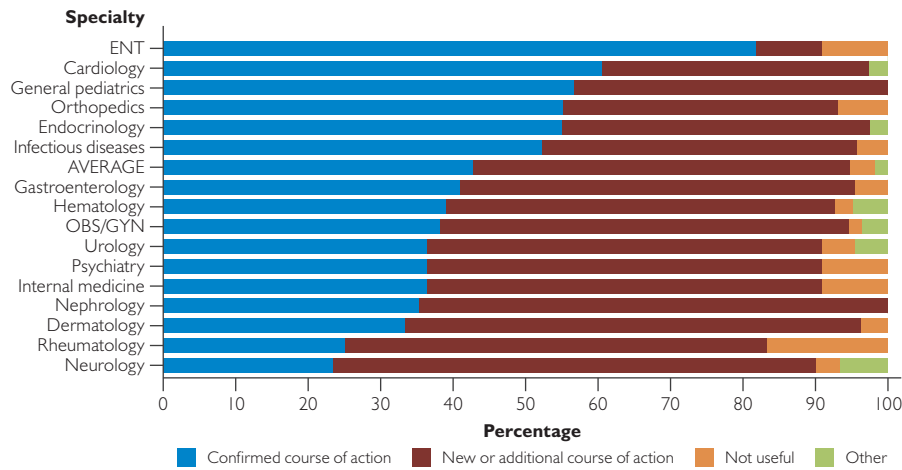


ENT = ear, nose and throat; OBS/GYN = obstetrics and gynecology. *30 different specialties for a total of 16.3% of all cases submitted.

These numbers varied across specialty groups. For dermatology, urology, nephrology, and cardiology, over 50% of the cases would have required a face-to-face consultation if eConsult was not available (Figure 4). In 18% of cases, a referral was originally contemplated and was still needed, but the PCP perceived that eConsult would lead to a more

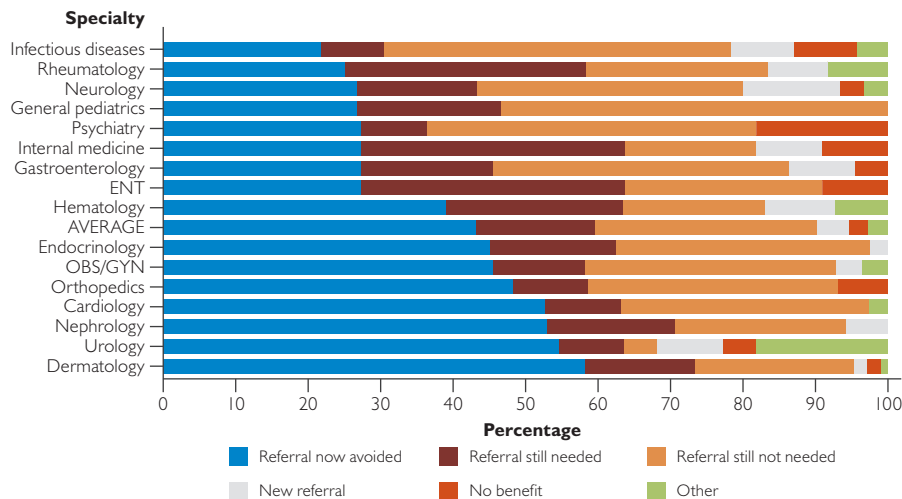
effective specialist visit. In 5% of cases, a referral was not originally contemplated, but eConsult process resulted in a referral being initiated (Figure 4). The latter is an example of an unintended consequence of the service with a potential impact on improved patient safety, as delayed referrals can have significant consequences (Liddy et al. 2016, 2017a). This finding was also observed in the Champlain LHIN, albeit to a slightly lower extent (3% of cases). Overall, these results were very similar to those obtained in Champlain LHIN (Keely et al. 2013).

FIGURE 3. Impact of eConsult on the course of action by the PCP by specialty service (for specialty groups with 10 or more completed cases; N = 497)



ENT = ear, nose and throat; PCP = primary care provider; OBS/GYN = obstetrics and gynecology.

FIGURE 4. Impact of eConsult on need for face-to-face referral by specialty service (for specialty groups with 10 or more completed cases; N = 497)



ENT = ear, nose and throat; OBS/GYN = obstetrics and gynecology.

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PATIENT AND PROVIDER EXPERIENCE

The close-out survey includes a question to PCPs on their perceived value of the service for their patients, which we used as a proxy measure of patient satisfaction. On a five-point Likert scale, PCPs rated the eConsult service's value to their patients as four or five (indicating good or excellent) in 92% of cases. Using the same scale, PCPs likewise rated the service's value for themselves as four or five in 92% of cases. In the free-text portion of the survey, PCPs frequently cited the speed of responses, quality of advice, capacity for improving patient care and educational opportunities as its chief benefits. These results mirror those obtained in Champlain LHIN (Keely et al., 2013).

COST

The delivery costs of the eConsult service in the Mississauga Halton LHIN during the study period amounted to \$7,616.33 (Table 2). These included user set-up and registration, user support and variable administration costs. Consultation-specific costs included \$27,283.33 for specialist remuneration and \$113.85 in assignment costs. The costs of referrals initiated as a result of the eConsult amounted to \$3,811.00. The total costs of eConsult service came to \$38,824.51, not including the fixed administration costs, which are incurred regardless of the Mississauga Halton LHIN eConsults. A total of 237 specialist visits were avoided due to eConsult, resulting in savings of \$28,502.95. The net program costs were \$10,321.56.

TABLE 2. Total costs and total savings of using eConsult by Mississauga Halton LHIN PCPs during the study period

| Item | Value (\$) |
|------------------------------------|------------------|
| Costs | |
| <i>Delivery costs</i> | 7,616.33 |
| User set-up/registration/training | 5,002.36 |
| Support | 2,568.43 |
| Administration | 45.54 |
| <i>Consultation-specific costs</i> | 27,397.18 |
| Specialist remuneration | 27,283.33 |
| Assignment | 113.85 |
| <i>Added referrals</i> | 3,811.00 |
| Total | 38,824.51 |
| Savings | |
| <i>Avoided referrals</i> | 28,502.95 |
| Total | 28,502.95 |
| Net costs | 10,321.56 |

Using these costs, we calculated the average cost per eConsult for each specialty that received over 10 cases during the study period (Table 3). Across all of these specialty groups, each eConsult case cost an average of \$47.38.

TABLE 3. Average specialist self-reported times to complete eConsult and average remuneration costs by specialty (for specialty groups with 10 or more completed cases; $N = 497$)

| Specialty | <i>n</i> | Average time to complete (minutes) | Average specialist cost per eConsult (\$) |
|---------------------------------|----------|------------------------------------|---|
| Dermatology | 105 | 14.29 | 47.62 |
| Obstetrics and gynecology | 55 | 13.00 | 43.33 |
| Hematology | 41 | 13.78 | 45.93 |
| Endocrinology | 40 | 11.38 | 37.92 |
| Cardiology | 38 | 11.84 | 39.47 |
| General pediatrics | 30 | 12.00 | 40.00 |
| Neurology | 30 | 10.50 | 35.00 |
| Orthopedics | 29 | 19.83 | 66.09 |
| Infectious diseases | 23 | 13.91 | 46.38 |
| Gastroenterology | 22 | 17.95 | 59.85 |
| Urology | 22 | 15.68 | 52.27 |
| Nephrology | 17 | 18.24 | 60.78 |
| Rheumatology | 12 | 14.58 | 48.61 |
| Ear, nose and throat specialist | 11 | 10.45 | 34.85 |
| Internal medicine | 11 | 14.09 | 46.97 |
| Psychiatry | 11 | 15.91 | 53.03 |

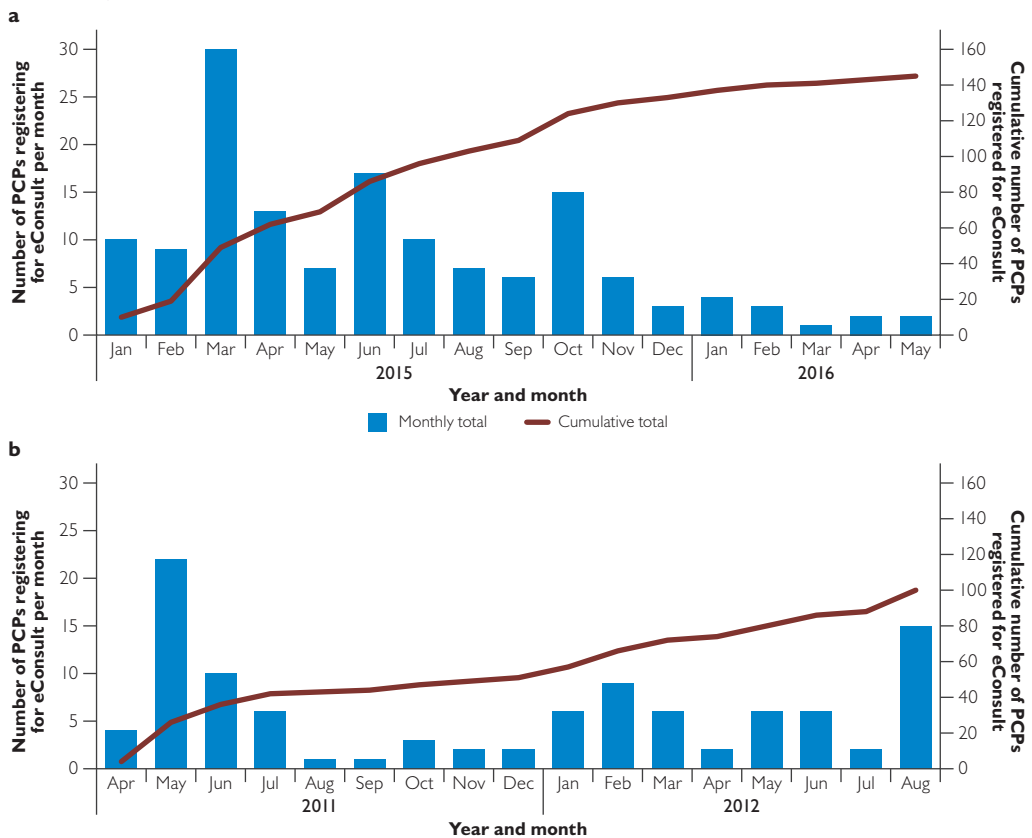
Adoption

In the Mississauga Halton LHIN, 133 family doctors and 12 nurse practitioners registered for the eConsult service over the course of the study, representing 13.2% of all family physicians (Gall 2015) and 11% of nurse practitioners (College of Nurses of Ontario 2015) practicing in the region (Figure 5a). The monthly growth rate was more robust than the one observed during the initial pilot phase of the service in the Champlain LHIN (Figure 5b), ultimately leading to greater number of PCPs reached over a time period of the same duration (145 vs. 103). Of the PCPs who registered with the service, 47% ($n = 68$) submitted at least one eConsult (with a median of four cases). This result is similar to the Champlain LHIN pilot data, where 48% of the PCPs who registered for the service were found to complete at least one eConsult (with a median of five cases) (Keely et al. 2013).

On a setting level, eConsult was adopted by individual PCPs from 78 clinics in 10 cities/towns across the Mississauga Halton LHIN. The majority of clinics were located in Mississauga (53%), followed by Oakville (14%), Georgetown (13%), Milton (10%) and

Etobicoke (4%). Other cities represented by individual clinics included Acton, Brampton, Burlington, Toronto and Woodbridge. All clinics were urban or suburban. Sixty-one (78%) were group physician practices, of which seven were Family Health Teams. There were also individual clinics belonging to the following models: Community Health Centre, Community Care Access Centre, Family Health Organization, Family Health Group and Family Medicine Teaching Unit. Sixty-nine clinics (89%) used electronic medical records.

FIGURE 5. PCP engagement – Number of new PCPs per month and cumulative total in MH LHIN (a) and Champlain LHIN (b)



LHIN = Local Health Integration Network; MH = Mississauga Halton; PCP = primary care provider.

During the study period, 15 specialists working in the Mississauga Halton LHIN registered with the eConsult service, one of whom withdrew due to a heavy workload. The remaining 14 specialists represented 13 specialty groups, which were gradually established over the study period. A similar number of specialty groups ($n = 16$) were established in the Champlain LHIN during the equivalent time period (Keely et al. 2013).

Three groups represented by Mississauga Halton specialists (geriatrics, general surgery and cancer screening) constituted new specialty groups previously not available via the eConsult service. This is an example of reciprocal leveraging of specialty expertise between

jurisdictions to meet specific needs and gaps in specialty care. All Mississauga Halton specialists made themselves available to answer queries from PCPs outside of their LHIN. In cases where a particular specialty group already existed in the Champlain BASE™ service, the Mississauga Halton LHIN specialists were available to answer local eConsult cases for Mississauga Halton as well as cover for the other specialists from Champlain LHIN as necessary (e.g., during vacations).

Implementation

When planning implementation in Mississauga Halton, we consulted the 10 steps that we established in a previous paper based on our experiences in the Champlain LHIN: (1) identify your partners, (2) choose your platform, (3) start as a pilot project, (4) design your product, (5) ensure patient privacy, (6) think through the process, (7) foster relationships with your participants, (8) be prepared to provide physician payment, (9) provide feedback and (10) plan the transition from pilot to permanency (Liddy et al. 2013b). Many of these steps (e.g., choosing a platform, designing a product, ensuring patient privacy) required little additional work, as we were able to build on our existing eConsult platform. Others (e.g., identifying partners, planning for transition from pilot to permanency) required consideration to adjust to this new context.

The eConsult service was implemented in the Mississauga Halton LHIN under the context of a focused LHIN-wide and MOHLTC-led provincial eConsult initiative. This enabled greater support associated with planning, launching and maintaining an eConsult platform (e.g., Primary Care Advisor staffing and assistance in the recruitment of users) and helped to keep the focus on innovation and continued development of the service based on regional needs. The key adaptation was the fact that as a region, the Mississauga Halton LHIN was not required to set up its own platform but could instead leverage the existing service available in the Champlain LHIN. This adaptation came with several advantages, including immediate access to a wide group of specialty groups (67 at the start and 86 by the end of the study period) and avoidance of the start-up costs and certain fixed administration costs necessary to support the service. Finally, since the Champlain and Mississauga Halton LHINs are located in Ontario, provincial policies related to privacy requirements, sources and levels of payment for users of the service and rules regarding interjurisdictional collaboration that could potentially impact the service's ability to support the provision of care were the same in both jurisdictions.

Maintenance

The Ontario MOHLTC continues to support the eConsult service in Mississauga Halton, while the provincial adoption of eConsult is being planned with the partners involved in this provincial initiative. The province has specifically identified greater access to specialist care as a main objective in recent health planning with the Patients First Act emphasizing the need to improve access and continuity of care (MOHLTC 2016). Operations, governance,

sustainable payment models and quality assurance are key aspects that are under discussion. These actions demonstrate an understanding of the importance of wait times as a determinant of care outcomes, and speak to ongoing support for eConsult. In the meantime, the service continues to grow, and the data we collect directly from users (PCPs and specialists) reflect its consistently high levels of efficacy and satisfaction (Liddy et al. 2015a; Keely et al. 2015). Recent efforts at expansion include partnership with the Canadian Foundation for Healthcare Improvement, who selected Champlain BASE™ as one of two innovative services to implement among 10 improvement teams across Canada (CFHI 2017). Furthermore, the Government of Ontario has announced a plan to expand the eConsult service across Ontario and allocated \$10 million in their 2017 budget for this and other innovations targeting wait times for specialist care (Government of Ontario 2017).

Discussion

We have successfully implemented the Champlain BASE™ eConsult service in another health region in Ontario, thus demonstrating the model's generalizability. Using the RE-AIM framework, we compared specific aspects of the implementation process between the two regions. Compared to the original site, implementation in the Mississauga Halton LHIN demonstrated more rapid adoption by PCPs and a greater reach as reflected by monthly eConsult case volumes. Enrolment reached an initial peak in the Mississauga Halton LHIN at month nine (September 2015), whereas the Champlain LHIN exhibited a similar trend later in the process, during months 14–15 (May and June, 2012). This most likely reflects the different recruitment approaches in both regions, with a focused LHIN-wide and MOHLTC-led provincial eConsult initiative in the Mississauga Halton LHIN versus a slower and more organic implementation in the Champlain LHIN initially supported only by limited research funding. The early service also provided access to a smaller menu of specialty services during its initial implementation, which could contribute to the smaller number of cases processed. In both LHINs, 40% cases had PCPs originally contemplating referrals, but ultimately avoiding them based on specialists' advice. Participating PCPs considered the service to have high value for themselves and their patients in nearly all cases—an important finding, given that provider experience has been shown to have a substantial impact on adoption of new technologies (Bodenheimer and Sinsky 2014). While PCPs in the Mississauga Halton LHIN had access to specialists in the Champlain LHIN, specialists from within the region ultimately joined the service as well. This uptake demonstrates that although it is beneficial to leverage specialists from the local region, doing so is not required for a successful service. The potential system level impact is significant with eConsult not only from an improved patient access perspective where specialist advice is available in days instead of months of waiting, but also from an efficiency and cost savings lens (Wasfy et al. 2016; Liddy et al. 2016, 2017a). In terms of cost-effectiveness, the service was shown to cost a weighted average of \$47.35 per case across specialty groups, versus \$133.60 per case for traditional referrals. Additional savings were evident when accounting for societal costs, such

as patient travel, lost wages/productivity associated with face-to-face specialist visits, avoided tests and potential improved health outcomes associated with shorter wait times (Liddy et al. 2016, 2017a). Recent work has also shown that cost savings per case of \$1,100.93 for patients from remote communities when considering indirect costs such as travel and time off work saved with an avoided face-to-face visit because of eConsult access (Liddy et al. 2017b).

An extensive body of literature stemming from the seminal work by Rogers and colleagues has identified the following five attributes as critical to facilitating adoption of innovations: relative advantage, low complexity, compatibility, observability and trialability (Rogers 2003). Innovations that have a clear, unambiguous advantage in either impact or cost-effectiveness are more easily adopted and implemented. The starting point for our eConsult service was (and remains) the tremendous problem of excessive wait times and the associated burden that falls onto the PCP, which the traditional model of referral-consultation often fails to address. Synchronous telemedicine systems (e.g., video conferencing) can link providers in real time, but face a number of challenges in terms of infrastructure requirements and scheduling. Video conferencing services require high-speed broadband connectivity in order to function, limiting their effectiveness in many rural communities (where internet access remains limited even today), despite the fact that these communities are often most in need of improved access to care (Linkous et al. 2012). By embracing a low-complexity solution, eConsult greatly reduces the minimum technology required for use—requiring minimal bandwidth and running on any device with an internet browser—and removes the challenges associated with coordinating PCPs and specialists to meet remotely. Furthermore, innovations that are compatible with the intended users' values, norms and perceived needs are more readily adopted. The eConsult service demonstrates this compatibility, as evidenced by interviews with providers (Liddy et al. 2015a; Keely et al. 2015). For instance, a survey of participating specialists found that 94% believe eConsult improves their communication with PCPs (Keely et al. 2015), whereas a review of PCP survey comments revealed high satisfaction with eConsult's impact on access, care quality and continuity of care (Liddy et al. 2015a). Lastly, the eConsult service's benefits have a high degree of observability, meaning they can be quickly and easily perceived by adopters. As PCPs who use eConsult are directly involved with the cases they submit, they are immediately aware of response times and whether a referral they had originally planned to make could now be avoided based on the advice they received from the specialist—an outcome that occurs in over 40% of cases (Keely et al. 2013). This high level of observability is reflected in the close-out surveys, which have repeatedly shown that PCPs rank eConsult as having high/very high value in over 90% of cases (Keely et al. 2013; Liddy et al. 2015a)

In addition to the attributes identified by Rogers, Greenhalgh et al. (2004) argued that a receptive context facilitates adoption of innovations. The MOHLTC-led provincial eConsult initiative played a significant role in setting a receptive structural and organizational context for adoption of the eConsult service in the Mississauga Halton LHIN. Furthermore, other

studies have emphasized that the ease with which technological innovations integrate into existing workflows plays a key role in determining their success (Bates et al. 2003; Gagnon et al. 2009). The eConsult service was designed to accommodate different workflows and can be adopted by new users with only a minimal amount of training.

We have previously identified the following 10 essential steps for replication of eConsult in a new region: partners, platform, piloting, product, privacy, process, participants, payment, providing feedback and planning for sustainability (Liddy et al. 2013b). We successfully aligned with local priorities through collaborative partnerships with regional stakeholders, and obtained support for local staffing through MOHLTC and a strong focus on physician end-user engagement throughout the process. We capitalized on existing technology infrastructure by using platforms hosted jointly by the Champlain LHIN and Winchester District Memorial Hospital, while leveraging a multitude of specialty services from the Champlain LHIN and integrating new local ones from the Mississauga Halton LHIN.

Limitations

The Mississauga Halton and Champlain LHINs are both in Ontario, which limits generalizability to within the province. The sample of providers from the Mississauga Halton LHIN was small and the policy context was the same in both regions, limiting implications for replication in other Canadian provinces or territories. The Ontario Provincial eConsult Initiative supported the service's implementation, but also allowed participants to choose other competing eConsult alternatives. It is not known if the population of users who picked Champlain BASE™ over the other eConsult options available through the provincial initiative differed from the rest of the population. Costing data were limited to case costs handled directly by the service and did not include in-kind services or costs shouldered by our partner organizations (e.g., PCAdvisors/marketing), and are thus not intended as a comprehensive list of costs associated with replicating an established service.

Conclusion

The Champlain BASE™ eConsult service was successfully replicated in the Mississauga Halton LHIN, demonstrating its generalizability. The specialist response times, referral avoidance, PCP satisfaction and costs associated with implementation were largely comparable to those seen in the Champlain LHIN during the service's initial rollout. We demonstrated that specialists could be effectively leveraged across jurisdictions to help address regional gaps in care, while supporting the development of a local base of specialists. The successful implementation was enabled by cultivating a receptive context and establishing key partnerships, building a service grounded in patient needs that offered an improvement over current referral processes, and leveraging a low cost simple technology solution.

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