

HEALTHCARE

# POLICY

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## Politiques de Santé

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

**Volume 14 ♦ Number 1**

**Improving Healthcare Providers' Interactions with Trans Patients:  
Recommendations to Promote Cultural Competence**

ELLA VERMEIR ET AL.

**Community-Based Reform Efforts: The Case of the Aging at Home Strategy**

ALLIE PECKHAM ET AL.

**State of the Evidence for Emergency Medical Services Care:  
The Evolution and Current Methodology of the Prehospital  
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**Stakeholder Views on Solutions to Improve Health System Performance**

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*Discussion and Debate ♦ Research Papers*

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

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

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

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

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

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

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## Measuring Progress in Access to Health Services

**W**HILE MANAGEMENT GURUS POINT OUT THAT THE ‘YOU CAN’T MANAGE WHAT you can’t measure’ dictum is not universally true, robust measurement of progress – or the lack thereof – can provide clarity, transparency and drive. In this spirit, federal, provincial and territorial governments recently endorsed a set of measures to support the 10-year investment agreement made in 2017 (Government of Canada 2018).

The 12 agreed measures were evenly split between indicators of access to mental health and addictions services and indicators of access to home and community care (Box 1). The Canadian Institute for Health Information (CIHI) is slated to begin annual reporting in 2019. (Note: The federal government and Quebec agreed to an asymmetrical arrangement. Likewise, given the then-recent election in Ontario, the province could not officially endorse the recommended measures.)

**BOX 1.** Recommended indicators of access agreed by federal, provincial and territorial governments (CIHI 2018)

Recommended indicators for access to mental health and addictions services:

- Wait times for community mental health services, referral/self-referral to services
- Early identification for early intervention, age 10–25
- Awareness and/or successful navigation of mental health and addictions services (self-reported)
- Rates of repeat emergency department and/or urgent care centre visits for a mental health or addiction issue
- Hospitalization rates for problematic substance use
- Rates of self-injury, including suicide

Recommended indicators for access to home and community care:

- Wait times for home care services, referral to services
- Alternate level of care length of stay for in-patients requiring home care services
- Home care services helped the recipient stay at home (self-reported)
- Caregiver distress
- (In)appropriate move to long-term care
- Death at home/not in hospital

These are not “do the best that you can with the data that you have” indicators. A few – such as time spent in alternative levels of care by hospitalized patients who need home care – are widely tracked today. But some require further definitional work (e.g., early identification for early mental health intervention in youth) and many imply new types of data collection and reporting, including patient-/client-reported measures.

In addition to setting out a pan-Canadian measurement agenda, the indicators imply a broad policy, practice and research program. For example, they invite questions about best practices for successful navigation of mental health and addiction services or for the provision

of home care services that help a recipient stay at home, both from the client's point of view. Understanding what works best for whom in what context will be an important enabler of improvement.

While there is much more to learn and to do, these are the types of questions that several authors address in this issue of the journal. From prehospital care and aging at home to the changing landscape of continuing care and specialty consultations, they provide insights on how care is delivered today and how it is evolving. Other articles focus on broader policy contexts, touching on a range of issues including geographical mobility of those who work in healthcare and how stakeholders view solutions to improve health system performance. As we look ahead via governments' shared priorities and on broader health system improvement questions, I encourage you to contribute your own insights to future issues of *Healthcare Policy/Politiques de Santé* as authors in this issue have done.

JENNIFER ZELMER, PHD

*Editor-in-Chief*

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## Mesure du progrès dans l'accès aux services de santé

**M**ÊME SI LES GOUROUS DE LA GESTION CLAMENT QUE LE DICTAT VOULANT qu'« on ne peut gérer ce qui ne peut se mesurer » ne soit pas une vérité universelle, de solides mesures du progrès – ou de son absence – peuvent favoriser la clarté, la transparence et la motivation. Dans cet ordre d'idées, les gouvernements fédéral, provinciaux et territoriaux ont récemment adopté un ensemble de mesures pour appuyer l'accord d'investissement sur 10 ans conclut en 2017 (gouvernement du Canada 2018).

Les 12 mesures convenues se répartissent également entre indicateurs pour la mesure de l'accès aux services de santé mentale et en toxicomanie et indicateurs pour la mesure de l'accès aux services à domicile et en milieu communautaire (voir l'encadré). L'Institut canadien d'information sur la santé (ICIS) est responsable de commencer la production de rapports annuels en ce sens à partir de 2019. (À noter : le gouvernement fédéral et le Québec ont convenu d'un accord asymétrique. Par ailleurs, en raison de la récente élection en Ontario, la province n'a pas encore adopté officiellement les mesures recommandées.)

**BOX 1.** Indicateurs recommandés tel que convenu entre les gouvernements fédéral, provinciaux et territoriaux (ICIS 2018)

Indicateurs recommandés pour la mesure de l'accès aux services en santé mentale et en toxicomanie :

- Temps d'attente pour des services communautaires en santé mentale, orientation ou auto-orientation
- Identification et intervention précoces chez les jeunes de 10 à 25 ans
- Niveau de connaissance et d'utilisation des services en santé mentale et en toxicomanie (données autodéclarées)
- Taux de visites répétées au service d'urgence ou dans un centre de soins d'urgence en raison d'un problème de santé mentale ou de toxicomanie
- Taux d'hospitalisations en raison de l'utilisation problématique de substances
- Taux de blessures auto-infligées, y compris de suicides

Indicateurs recommandés pour la mesure de l'accès aux services à domicile et en milieu communautaire :

- Temps d'attente pour des services à domicile, orientation
- Durée du séjour en niveau de soins alternatif pour les patients hospitalisés qui nécessitent des services à domicile
- Maintien à domicile du bénéficiaire grâce aux services à domicile (données autodéclarées)
- Détresse des aidants naturels
- Transition appropriée ou inappropriée en soins de longue durée
- Décès à la maison ou hors hôpital

Il n'y a pas d'indicateurs du genre « faire le mieux qu'on peut avec les données qu'on a ». Certains indicateurs sont largement documentés aujourd'hui, par exemple, la durée du séjour en niveau de soins alternatif pour les patients hospitalisés qui nécessitent des services à domicile. D'autres demanderont plus de précision dans leur définition (par exemple, l'identification et l'intervention précoces chez les jeunes) tandis que plusieurs d'entre eux

nécessiteront la cueillette et le traitement de nouveaux types de données, notamment quant aux données autodéclarées par les patients et la clientèle.

En plus de permettre l'instauration d'un programme de mesures pancanadien, les indicateurs impliquent la mise en place d'un vaste programme en matière de politiques, de pratique et de recherche. Par exemple, ils soulèvent des questions quant aux pratiques exemplaires dans l'utilisation des services en santé mentale et en toxicomanie ou pour le maintien à domicile des bénéficiaires grâce aux services à domicile, tous deux selon le point de vue du client. Mieux comprendre ce qui fonctionne pour telle personne dans tel contexte sera un atout indéniable pour l'amélioration.

Bien qu'il reste encore beaucoup à faire et à apprendre, voilà le genre de questions que plusieurs auteurs traitent dans le présent numéro. Que ce soient les soins préhospitaliers, le vieillissement à domicile, le paysage changeant des soins continuels ou les consultations auprès d'un spécialiste, tous ces articles proposent des pistes sur l'état actuel et l'évolution de la prestation des services. D'autres articles portent sur de plus vastes contextes politiques, dont la mobilité géographique des professionnels de la santé ou le point de vue des parties prenantes sur les solutions visant l'amélioration du rendement du système de santé. Alors qu'on s'apprête à voir l'avenir sous le prisme des priorités partagées entre les gouvernements et à la lumière des grandes questions visant l'amélioration des systèmes de santé, je vous invite à proposer vos propres pistes de réflexion pour d'éventuels numéros de *Politiques de Santé/Healthcare Policy*, comme l'ont fait les auteurs pour la présente publication.

JENNIFER ZELMER, PHD

*Rédactrice en chef*

### *Références*

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# Corrigendum

In Volume 13, Issue 4 of our journal, Emily Gard Marshall has been omitted from the list of authors of the following manuscript:

Breton, M., S.T. Wong, M.A. Smithman, K. Kreindler, J. Jbilou, J. Sutherland et al. 2018. "Centralized Waiting Lists for Unattached Patients in Primary Care: Learning from an Intervention Implemented in Seven Canadian Provinces." *Healthcare Policy* 13(4): 65–82. doi:10.12927/hcpol.2018.25493.

Emily Gard Marshall has been added to the authors list and the updated version of this manuscript has been posted online at <http://www.longwoods.com/content/25555>. The original version has been archived but is available to the reader on request.

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# Improving Healthcare Providers' Interactions with Trans Patients: Recommendations to Promote Cultural Competence

Améliorer l'interaction entre fournisseurs de soins de santé et patients trans : recommandations visant la compétence culturelle



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## Abstract

Research indicates that trans people face a number of barriers to healthcare, including challenges in finding healthcare providers (HCPs) who are knowledgeable about, and sensitive to, trans identity and health issues. These and other barriers contribute to this population's under-usage of healthcare services and, in turn, their poor overall health outcomes compared to the general population. This article provides research-informed recommendations to improve HCPs' cultural competence, which may increase trans individuals' utilization of healthcare and thus contribute to better health outcomes for this population.

## Résumé

Les recherches indiquent que les personnes trans font face à de nombreux obstacles quant aux soins de santé, notamment la difficulté à trouver des fournisseurs de soins de santé (FSS) qui sont familiers avec les questions de santé et d'identité trans. Ces obstacles contribuent, parmi d'autres, à une sous-utilisation des services de santé par les personnes trans, ce qui donne lieu à un état de santé plus faible dans ce sous-groupe par rapport à la population générale. Cet article présente des recommandations éclairées par la recherche afin d'améliorer la compétence culturelle des FSS, ce qui pourrait accroître le recours aux services de santé par les personnes trans et ainsi améliorer l'état de santé de cette population.

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## Introduction

Trans individuals are those whose gender identity does not match their sex assigned at birth. In this article, “trans” is used as an umbrella term for a full spectrum of non-cisgender identities, including transgender, gender non-conforming, and non-binary individuals.

Research shows that trans individuals often face barriers to healthcare, including finding healthcare providers (HCPs) they believe are knowledgeable about, and sensitive to, trans health issues such as mental health, trauma histories, and health concerns related to hormone replacement therapy (HRT) and gender-confirming surgeries (Dean et al. 2000; Sanchez et al. 2009). Not being able to find an HCP who is knowledgeable about, and sensitive to, trans issues is a contributing factor to the trans population's underutilization of healthcare services and may be partially responsible for the poor health outcomes prevalent in the trans population as compared to the general population (Dean et al. 2000; Grant et al. 2010; Vermeir et al. 2018).

The purpose of this article is to highlight some key recommendations for individual HCPs, healthcare organizations, and relevant educational institutions to improve HCPs' knowledge, attitudes, and behaviours with respect to trans patients. The recommendations are based on data collected through qualitative interviews with eight trans participants in Nova Scotia, Canada, which explored barriers to primary and emergency healthcare in terms of interpersonal relationships with HCPs, the physical environment, and the social environment. (See Vermeir et al. 2018 for details about the study methods and findings related to these barriers.) We recognize that eight individuals is a small number of participants upon which to base recommendations, however, the qualitative methodology provided robust, in-depth participant-focused exploration of the issues. The veracity of these findings is strengthened as a number of the recommendations concur with, or can be implied from, other studies. It is, of course, possible that different or additional recommendations may have arisen if there had been a larger number of participants in our study, but nevertheless the recommendations we present may play a significant role in improving HCPs' knowledge, attitudes, and behaviours. They may also be beneficial to HCPs

working in other environments beyond primary and emergency care, as well as non-HCP staff members.

The purpose of the interviews with trans adults was to explore their perceptions of, and/or experiences with, primary and emergency healthcare, as well as their suggestions for needed changes that they believe would help to reduce barriers to access. All the participants in our study agreed to being referred to as “trans.” “HCPs” were defined as the various types of providers found in primary and emergency healthcare settings including physicians, nurses and technicians. Participants reported receiving various types of healthcare within these settings including mental healthcare and transition-related healthcare. Each participant used specific terms to describe their gender identity, but three identified with the pronouns “she/her,” three with “he/him” and two with “they/them.” The participants ranged in age from 18 to 44 years, had varying socio-economic statuses, and all identified as white or Caucasian. The qualitative research approach of our study was informed by social constructivism, queer theory, and an environmental framework. Framework analysis and the constant comparative method were used to guide the data analysis (Vermeir et al. 2018).

As we have previously reported, participants in our study raised concerns about HCPs' lack of knowledge regarding trans identity and health issues, as well as HCPs' poor attitudes and negative behaviours (Vermeir et al. 2018). These issues, and the recommendations stemming from them (that participants either specifically mentioned or that we have inferred from their comments), fall within the realm of cultural competence, although participants did not explicitly use this term. Cultural competence is defined as the ability of HCPs and organizations to effectively understand, communicate with, and deliver suitable healthcare services to diverse populations (Wilkinson 2014). Researchers have suggested that HCPs often lack the cultural competence necessary to provide appropriate healthcare for trans patients (Baker and Beagan 2014), which is likely a consequence, at least in part, of the little to no education that many HCPs receive on trans identity and health (Beagan et al. 2015; Moll et al. 2014). It may also be related to the societal stigma that exists with respect to trans people (Lombardi et al. 2002).

There have been noteworthy critiques of the term “cultural competence,” including that it is impossible to become competent in an experience that one has not actually lived (e.g., the experience of being a trans person) (Baker and Beagan 2014; Gregg and Saha 2006). However, there are components of cultural competence that are critical to providing informed and compassionate healthcare to members of diverse populations. Such components include having a sensitive understanding of how gender identity influences interactions with the healthcare system, as well as acknowledging the pervasive power differentials that exist between HCPs and patients, especially those from marginalized groups. We argue that these important components of cultural competence should be encouraged and supported through appropriate interventions. The recommendations provided in this article are intended to help improve cultural competence, and thus reduce some of the barriers to healthcare for trans patients. Some of the recommendations presented stem from barriers

which we have previously reported on (Vermeir et al. 2018); however, in this article, we take these issues and explicitly state them as actionable items that HCPs can implement. We also elaborate on a couple of recommendations that were only touched upon when discussing the barriers.

Equitable access to healthcare is a cornerstone of the Canadian healthcare system, and we argue that efforts must be made to ensure access to healthcare by reducing barriers. The recommendations provided in this article are intended to contribute to the reduction and/or elimination of some of the barriers experienced by the trans population (Vermeir et al. 2018). It is also important to attend to these recommendations given that the number of people who report identifying as trans is increasing likely due, at least in part, to heightened social acceptance (Flores et al. 2016; Reed et al. 2009), although we recognize that societal stigma does still exist. The growth of those reporting a trans identity underscores the increased need for HCPs to have the appropriate knowledge, attitudes, and behaviours when interacting with trans patients.

### **Knowledge: Recommendations for Improvement**

As we have previously reported, a number of participants spoke about HCPs' lack of knowledge regarding trans health, including that most participants had encountered an HCP who was unsure of the meaning of "transgender" (Vermeir et al. 2018). A number of our participants felt burdened by, what they perceived as, an "expectation" that they should educate their HCP about trans issues (Vermeir et al. 2018). Having to educate HCPs is a recurring issue for trans people accessing care (Williams and Freeman 2008; Xavier et al. 2007). As we have previously reported, participants recommended that HCPs should have some knowledge regarding trans identity and health, at least in terms of understanding the basic definitions and concepts, and should be willing to increase their knowledge when it is deficient (Vermeir et al. 2018). Some participants also specifically recommended that when an HCP is interacting with a trans patient, the HCP should be up front with their patient regarding their existing knowledge and prior experience with trans patients. If needed, they should increase their knowledge and show improvement over time if there are ongoing interactions with the patient. To do so, HCPs should not rely on their patients to educate them but should use reputable resources to ensure that what they learn is accurate (Vermeir et al. 2018). We recognize that searching for such resources may take some time, which can be challenging for HCPs who have busy clinical practices. However, it is critical that HCPs are using the appropriate resources. Healthcare organizations can help to lessen this task for individual HCPs by compiling and circulating a list of useful resources for HCPs to use as a starting point.

Participants in our study believed that improving HCP knowledge would not only benefit the HCP but would also allow for a positive relationship between HCPs and trans patients to develop over time, which may increase patients' utilization of healthcare services. Although it is critical that individual HCPs learn about the trans population, we believe that there is also a need for educational organizations and regulatory bodies to incorporate this

topic into their curriculums and continuing education opportunities to promote HCPs' cultural competence including an acknowledgement of the power differentials between HCPs and trans patients. We appreciate that there are many topics deserving of HCPs' and future-HCPs' time and that it may be challenging to incorporate more material into the curriculum. However, the high rates of trans people underutilizing and avoiding healthcare, coupled with the poor health of many in this population (Dean et al. 2000; Grant et al. 2010), underscores the urgency of education on the topic for those in the healthcare field. Historically, the opportunities for HCPs to receive trans-health training have been deficient (Beagan et al. 2015; Moll et al. 2014), but it is necessary that this improve in order to reduce the HCP knowledge barriers that hinder the trans population's access to care. As HCP knowledge increases, accessibility to basic healthcare services, as well as the comprehensive healthcare services that some trans patients require (including HRT prescribing and management), should improve and patients may feel more confident in the care they receive. For those who feel burdened by a sense of responsibility to educate their HCPs, the increased knowledge of HCPs will likely lessen this burden.

### Attitudes and Behaviours: Recommendations for Improvement

When discussing HCPs' attitudes and behaviours, participants stressed a number of what they referred to as "basic and easy" recommendations for improvement, including the need for HCPs to respect a person's chosen name and preferred pronouns regardless of whether these have been legally changed, and politely asking what a patient's preferred pronouns are, rather than assuming they know. Engaging in such practices would point to the HCPs' sensitivity to the population, which is a key component of cultural competence.

At the organizational level, intake forms in physicians' offices or clinics, for example, can be used to help gather information about names and pronouns, and many participants suggested having blank lines for individuals to write both their preferred and legal names, and their gender identity, as opposed to "male" and "female" boxes. Beagan and colleagues (2013) further suggest listing potential gender identities, such as "male, female, transgender, non-binary, etc.," following the blank line as this indicates explicit awareness of these identities. In a situation in which a gender, pronoun, or name mistake has been made, participants noted that an apology and a correction of the mistake are helpful for overcoming any negative reactions to the error. Making excuses for one's mistake may be frustrating and triggering for the patient and are to be avoided.

As we have previously reported, some participants in our study discussed their dislike of gendered terms within healthcare, such as "women's health" (Vermeir et al. 2018). In many cases, a trans man pursuing these services may be physically indistinguishable from a cisgender man. One participant discussed his experience asking for directions in a "women's healthcare" setting and remarked that he was met with surprise when HCPs realized he was the patient. He stated: "[they] didn't know that it was even a possibility [that] someone who looked like me [would be a patient]." Based on such experiences, participants recommended

that HCPs avoid using gendered terms, such as “women’s health,” so as to not exclude the non-women who access, or want to access, these services. They also stressed the importance of HCPs being aware that individuals with diverse gender identities are utilizing traditionally “gendered” services and that these individuals should not be isolated, called-out, or rudely questioned for appearing to be “out of place.” We understand that these changes may be difficult at first given that gendered care and language is ingrained within the healthcare system. However, as more HCPs work to make their language more inclusive, they contribute to a more accessible healthcare system for trans people.

Many trans people encounter HCPs who ask inappropriate questions regarding their trans identity or bodies, or questions that are irrelevant to their care. Unnecessary inquiry into such details can be humiliating (Hussey 2008; Vermeir et al. 2018). Participants recommended that HCPs remember that a patient’s purpose is not to satisfy one’s interest, and that even if a question is relevant to one’s care, it must be asked with sensitivity and appropriateness. As noted above, such sensitivity is key to cultural competence, and cannot be overstated.

Trans people experience disproportionately high rates of harassment and violence (Doan 2010), which can have a traumatic impact on them and cause them to avoid or feel reluctant to pursue healthcare, particularly healthcare involving physical examinations (Grant et al. 2010). Notably, research shows that trans women who have biologically male sex organs often avoid prostate and testicular examinations, and trans men who have biologically female sex organs often avoid mammograms and pelvic exams (Baker and Beagan 2014; Williams and Freeman 2008). As previously noted, a few participants in our study felt that they had endured inappropriate physical examinations, and at least one participant stated that they avoid physical examinations altogether (Vermeir et al. 2018). Trans patients must be made to feel comfortable when undergoing physical examinations to ensure that they will access the necessary health screenings. Participants proposed a number of recommendations that can increase patients’ comfort. Firstly, they suggested that HCPs ask the individual if there are certain terms they prefer for their sex organs. Next, they should provide a thorough explanation of the importance of the procedure and detail what is going to happen throughout. They also recommended that HCPs receive patient consent before touching them in a new location and ensure that patients feel welcome and comfortable to ask questions. Some participants highlighted the importance of patients being adequately draped throughout the examination so as to protect their privacy. One participant, in particular, shared how they had a chest and pelvic exam without adequate draping. They felt as though the HCP was “curious” about their body and that they “just wanted to have a science experiment.” Changing practices to increase patients’ comfort may require altering the way in which one has “always done things,” but small changes can play an important role.

Some participants discussed instances where accommodations had been made for them, which increased their comfort and shows the importance of simple changes. For example, a few participants pursuing gynecological care were offered the opportunity to sit in a private room as opposed to sitting in the common waiting room, which was viewed positively. Another participant waiting for an X-ray was told that they could stay in their clothes while they waited instead of changing in a gendered changing room and then waiting in a common space while wearing a revealing hospital gown. These examples suggest that there are various accommodations that HCPs can offer to reduce patients' anxieties and demonstrate to patients that they are understanding and sensitive to their needs. Of course, these accommodations should be offered to patients and not required. For example, trans patients might appreciate having the choice to sit in a private waiting room, but being told to sit separately from other patients might be viewed as discriminatory. It is also important to ensure that these accommodations are offered in a thoughtful way, because, for example, doing so publicly could potentially "out" the patient.

Our research suggests that trans individuals appreciate when their HCPs are supportive, compassionate and understanding. Studies have found that as an HCP's knowledge of, and experience with, trans patients increases, there is also an improvement in their attitudes and perceptions of trans people (Kelley et al. 2008). Thus, we encourage HCPs, healthcare organizations, and educational institutions to take the time to learn about trans identity and health issues and implement steps to demonstrate their knowledge and sensitivity.

### Conclusion

Trans individuals experience several kinds of barriers to healthcare including negative interactions with HCPs. In this article, we have provided a number of explicit and detailed recommendations to help improve these interactions, with a focus on increasing HCPs' cultural competence in regard to trans patients. There are, as we note, many benefits to implementing educational interventions such as increasing HCPs' knowledge including their understanding of the power inequities experienced by trans patients. However, it is recognized that changing attitudes and behaviours is not always easy or straightforward, and that ongoing education and supports may be necessary. We suggest that although it is imperative for individual HCPs to take the initiative to improve their interactions with trans patients, it is equally necessary for educational institutions and healthcare organizations to encourage better interactions and actively promote the cultural competence of HCPs.

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# Using an Integrated Knowledge Translation (IKT) Approach to Enable Policy Change for Electronic Consultations in Canada

Utilisation de l'application des connaissances intégrée  
(ACI) afin de faciliter un changement politique pour  
la consultation électronique au Canada



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## **Abstract**

This paper explores our efforts to support the expansion of a regional electronic consultation (eConsult) service on a national level by addressing potential policy barriers. We used an integrated knowledge translation (IKT) strategy based on five key activities leading to a National eConsult Policy Think Tank meeting: (1) identifying potential policy enablers and barriers; (2) engaging national and provincial/territorial partners; (3) including patient voices; (4) undertaking co-design and planning; and (5) adopting a solution-based approach. We successfully leveraged a diverse set of stakeholders in strategic discussions, culminating in actionable suggestions for next steps, which will serve to inform a national implementation strategy.

## **Résumé**

Cet article étudie les efforts déployés pour soutenir l'application à l'échelle nationale d'un service régional de consultation électronique (eConsultation), et ce, en abordant d'éventuels obstacles d'ordre politique. Nous avons employé une stratégie d'ACI fondée sur cinq activités clés qui ont nourri les discussions d'un groupe de réflexion national sur l'eConsultation : (1) repérer les obstacles et facteurs favorables d'ordre politique, (2) mobiliser les partenaires nationaux, provinciaux et territoriaux, (3) inclure le point de vue des patients, (4) s'engager dans la conception et la planification et (5) adopter une démarche axée sur les solutions. Nous avons réussi à impliquer un ensemble diversifié de partenaires dans les discussions stratégiques, ce qui a mené à la formulation de suggestions pratiques pour les prochaines étapes, lesquelles serviront à éclairer la stratégie de mise en œuvre nationale.

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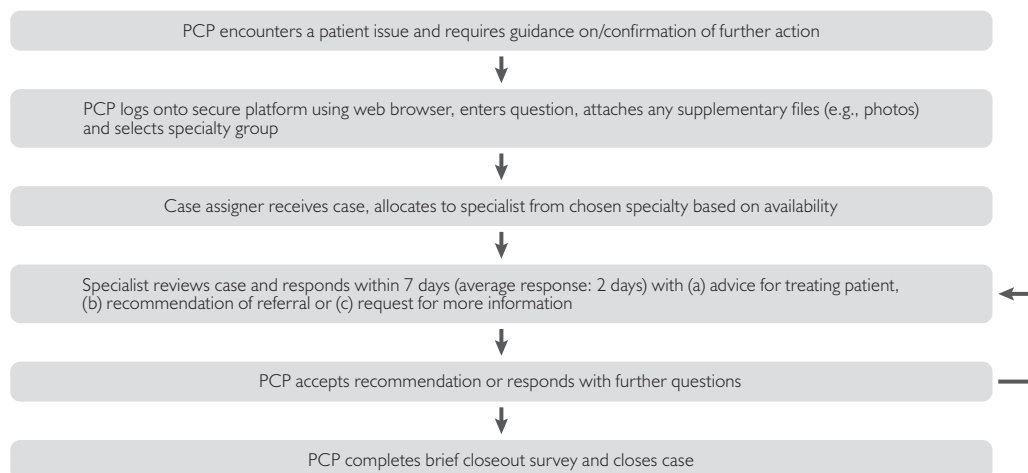
## **Introduction**

Canada has been described as the land of perpetual pilot projects (Bégin et al. 2009; Naylor et al. 2015). Despite significant investments (Naylor et al. 2015), many pilots are unable to expand beyond a local level, causing valuable knowledge to remain siloed and unable to improve

healthcare on a broader scale. An advisory panel convened by the Canadian government has attributed this trend to the lack of any dedicated funding or mechanism to drive systemic innovation, and the fragmented nature of the system itself, with separate budgets and accountabilities for different provider groups and sectors (Naylor et al. 2015). In addition, the broader research community often fails to actively engage in knowledge translation beyond traditional passive dissemination through journal publications. Consequently, policy issues are often cited as insurmountable barriers for scale-up and spread of healthcare innovations, particularly those based on implementation of technology.

In 2010, our team developed the Champlain BASE™ (Building Access to Specialists through eConsultation) eConsult service, a model of asynchronous provider to provider communication whereby primary care providers (PCPs) and specialists communicate through the use of a secure web-based platform (Figure 1). The eConsult service began as a proof-of-concept in the Champlain Local Health Integration Network (LHIN), one of 14 health regions responsible for planning, integrating, and funding local healthcare in Ontario. Numerous studies have reported that the service reduced wait times for specialist advice (Keely et al. 2013), helped avoid unnecessary referrals (Keely et al. 2013), lowered costs (Liddy et al. 2016) and received high levels of satisfaction from patients and providers alike (Keely et al. 2013; Liddy et al. 2015a).

**FIGURE 1.** Diagram of the Champlain BASE™ eConsult service



BASE = Building Access to Specialists through eConsultation; PCP = primary care provider.

Given eConsult's success on a regional level, we realized that the service had the potential to improve patient, provider, and health system experiences for people across Canada. However, an examination of existing policies guided by our past implementation experience identified three policy areas that could deter eConsult's expansion to new provinces: privacy, financing, and delivery of services (Liddy et al. 2015a). The research team questioned how we could translate these challenges into a meaningful dialogue that could lead to a more favourable policy context for the scale and spread of eConsult in Canada.

The challenges of translating innovations into practice have been widely recognized and innovators have taken steps to overcome them. In their widely respected ‘knowledge to action’ framework, Graham and colleagues discuss the “know–do gap” separating research from actionable policy and highlight ways it can be successfully bridged (Graham and Tetroe 2009; Graham and Tetroe 2007; Graham et al. 2006). The framework describes the process of integration of knowledge creation with its application and emphasizes engagement of knowledge users – including policy makers – in this process. However, it does not move beyond this to describe the “how to” required to succeed.

Building on the work of Graham and colleagues, this paper describes the integrated knowledge translation (IKT) approach our research team took to identify policy issues affecting the spread and scale-up of the Champlain BASE™ eConsult service. IKT has been described and promoted by the Canadian Institutes for Health Research (CIHR 2012) and requires researchers and knowledge user stakeholder groups to develop partnerships and engage in a collaborative process, with the overarching goal being the co-production of knowledge, its exchange and its translation into action. While advocated as an approach for enhancing the relevance of research and facilitating its use, IKT has also been described as challenging and inconsistently applied. Despite the fact that the enablers, barriers, and conditions that have been reported to influence the IKT have been studied and described, their associations with relevant outcomes and contextual factors affecting these outcomes remain largely unknown (Gagliardi et al. 2015). In order to add clarity to the process, we have tailored the IKT approach to our needs by grounding it in a practical step-wise process we used when first establishing the eConsult service (Liddy et al. 2013). We discuss how a research team working together with interested partners and stakeholders, including patients, created a collaborative space to (1) identify critical enablers and opportunities/challenges, (2) articulate a policy agenda, and (3) define strategies intended to influence policy discussions and decisions in support of spread and scale-up of an eConsult service.

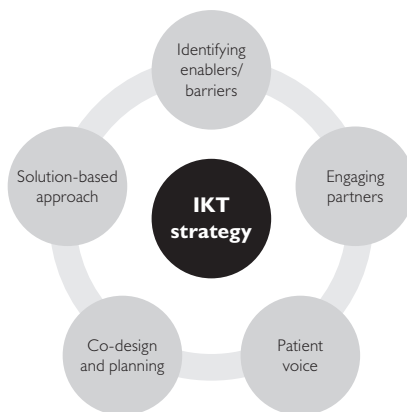
This paper will be of interest to those who are working in health system research and desire to identify strategies for scaled implementation, and will provide practical approaches to engaging stakeholders in deliberative policy dialogue to support the spread and scale-up of healthcare innovations in Canada.

## An IKT Approach to Shaping Policy

We assembled a collaborative, multidisciplinary team of researchers, healthcare providers, decision-makers, and patient advisors from across Canada. The team then met for a National eConsult Policy Think Tank (hereafter referred to as ‘the Think Tank’) held in Ottawa, Ontario, on December 5, 2016, to solicit a range of viewpoints on the policy issues affecting widespread dissemination and scale-up of eConsult.

To plan and implement this event, we engaged in five key activities that underpinned our IKT strategy: (1) identifying potential policy enablers and barriers; (2) engaging national and provincial/territorial partners; (3) including patient voices; (4) undertaking co-design and planning; and (5) adopting a solution-based approach. A model of our strategy is presented in Figure 2.

**FIGURE 2.** The IKT strategy undertaken by Champlain BASE™ team



BASE = Building Access to Specialists through eConsultation; IKT = integrated knowledge translation.

### *1. Identifying potential policy enablers and barriers*

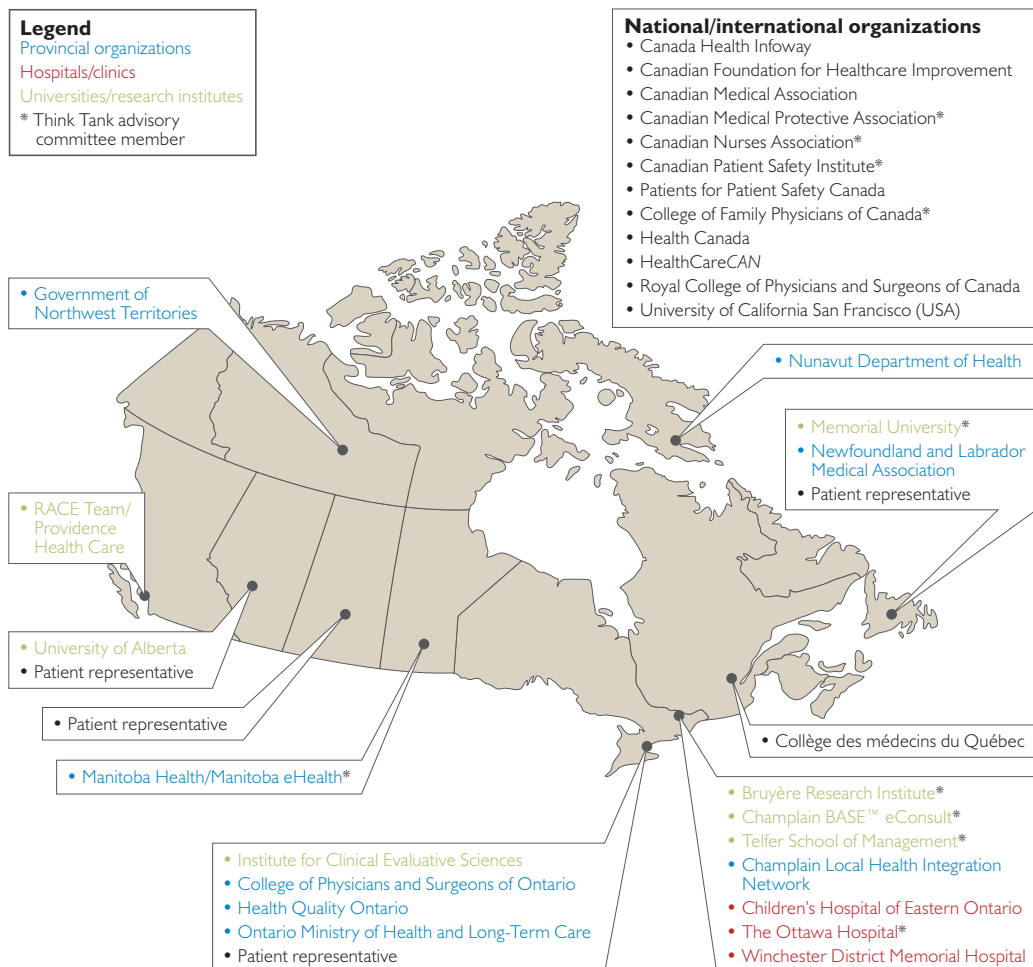
First and foremost, we identified the importance of proactively including policy aspects within our research work, which included identifying areas of policy that could act as potential enablers or barriers to scale-up. In a previous paper examining policy factors influencing eConsult, we identified three policy challenges which could deter the wide-scale implementation of an eConsult service: privacy concerns, lack of standard payment models, and ambiguity of roles for service delivery (Liddy et al. 2015a). For these particular areas of focus, our conclusions were that (1) concerns over privacy remain a barrier to the adoption of electronic platforms or innovations among healthcare providers, (2) standard payment models may not be applicable to eConsult, and (3) ambiguities in the specialist's role could create challenges in the service's expansion (Liddy et al. 2015a). Using these concepts as a foundation, we formulated key focus areas for discussion, modifying our initial conclusions to fit the current context. Notably, issues of privacy were not explicitly discussed in our Think Tank, whereas our exploration of policy challenges relating to delivery of services brought up issues of equity (i.e., how to ensure patients get equitable care regardless of jurisdiction or remoteness) and standards (i.e., how specialists are chosen and evaluated), which evolved into two distinct categories. The three chosen areas of focus were thus: (1) delivery of service and standards, (2) payment, and (3) equitable access.

### *2. Engaging national and provincial/territorial partners*

Successful IKT requires active and continuous collaboration between researchers and knowledge end-users such as policy makers, healthcare providers, and patients (CIHR 2012). End-users are defined as individuals who are likely to be able to use research results to make informed decisions about health policies, programs and/or practices. Given our intention to scale-up and spread eConsult from a regional to a national level, we engaged a range of stakeholders including representatives from provincial and territorial governments, national organizations, healthcare providers, researchers, and patients to ensure a sufficient breadth

of perspectives and experiences. Participants included representation from 11 national organizations, three provincial organizations, and a delegate from the US, as well as five patient advisors. The Canadian Medical Protective Association, a not-for-profit organization representing physicians across Canada, agreed to co-host the Think Tank. Of the 101 invited individuals, 47 participants attended the Think Tank. Thirteen per cent of attendees self-identified as government representatives, 13% as patients and 6% as healthcare providers. The majority represented national organizations (31%) and research institutes (31%). Participant distribution is outlined in Figure 3.

**FIGURE 3.** Map of institutions and organizations represented at the 2016 Think Tank



BASE = Building Access to Specialists through eConsultation; RACE = Rapid Access to Consultative Expertise.

### 3. Including patient voices

Patient input is a critical component of any healthcare innovation. Patient involvement in health policy, clinical care, and research has gained significant momentum recently along

with the idea that no policy should be reached without full participation of patients as stakeholders (CIHR 2018). To ensure patients' voices were included in the conversation, we partnered with the Canadian Patient Safety Institute, which engaged with its Patients for Patients Safety Canada volunteer network to recruit interested patient advisors from four provinces: Alberta (AB), Saskatchewan (SK), Ontario (ON), and Newfoundland and Labrador (NL). Patients actively participated in discussions, providing their invaluable perspective on how meaningful policies could ensure that eConsult continues to deliver high-quality patient-centred care.

#### *4. Undertaking co-design and planning*

In preparation for the Think Tank, we formed a pan-Canadian advisory committee consisting of 10 volunteer partners and collaborators. Members included representatives from four national organizations and academic/provincial institutions across three provinces (ON, Manitoba [MB] and NL), all of whom had previously supported funding applications and projects related to eConsult. The group met three times by teleconference to (1) develop the Think Tank agenda, (2) design the meeting format, and (3) establish strategies for ensuring representation of key stakeholder groups (i.e., healthcare providers, decision-makers and patient advisors). Discussion of the latter point included an emphasis on co-design between stakeholder groups, with a particular focus on promptly engaging decision-makers and ensuring they were empowered in their role and contributions as a central part of the development process – changing their role from “guest” to “member of the research family.”

#### *5. Adopting a solution-based approach*

To address issues in detail, participants broke into working groups based around one of the three areas of focus: delivery of service and standards, payment, and equitable access. Participants could choose to join a group on any of these topics, where they brainstormed answers to the following questions:

1. What are existing policies that could support and enable the spread/scale-up of eConsult?
2. What are your key recommendations?
3. Who else needs to be involved in the conversation to ensure success?

Following the small group discussion sessions, participants gathered for an afternoon plenary session where a representative from each working group presented each of the small groups' findings. Audience members asked questions and engaged the group in a dialogue on the chosen topic. Patient representatives were asked to offer their reflections on the day and recommendations for the next steps necessary to enable expansion of the eConsult service. To ensure a solution-based approach, the meeting concluded with a plan for next steps in reaching specific decision-makers on a national level and presenting them with actionable briefing notes from the Think Tank.

After the Think Tank, certain gaps were noted and additional jurisdiction-specific information was requested from the participants electronically as follows:

1. What are the existing interjurisdictional agreements in each Canadian province/territory?
2. What are the current cross-provincial/territorial referral patterns?
3. Who are other key organizations that should be involved?

## Results/Next Steps/Follow-Up Activities

Following the Think Tank, all stakeholders continued working together to synthesize and consolidate relevant, actionable solutions to identified policy gaps. Participants in the Think Tank have met via teleconference on a quarterly basis in order to follow up on outstanding items and discuss next steps for policy implementation. Additionally, several team members volunteered to join working groups, which meet regularly outside of the quarterly teleconferences in order to contribute to ongoing policy projects, including (1) an in-depth qualitative analysis of the breakout discussions that took place during the Think Tank, and (2) the development of policy briefing notes.

Several themes have emerged from the working groups' analysis, which speak to the key factors in supporting eConsult's expansion: maintaining patient-centredness, emphasizing its value for patients, ensuring effective regulation, and supporting implementation. The importance of keeping patients at the centre of the process cut across themes, a point neatly encapsulated by one participant, who described the question that should be at the centre of any implementation decision: "When [patients] look at the eConsult service, what is going to make them say 'yes, this is an equitable service'? What is it that patients are going to want to see?" Through the working groups, participants have offered great insight into the IKT process, highlighting barriers and enablers and developing recommendations for action. Furthermore, participants' willingness to engage in regular meetings and support additional studies speaks to their investment in eConsult, which is a critical factor to the overall success of the service's expansion.

Building on our analyses, we developed a series of briefing notes that provide guidance on the development of policies in five key areas: payment for providers, interjurisdictional licensing, patient privacy, quality assurance, and regulation (Appendix 1, available at: <https://www.longwoods.com/content/25551>). Their content was drawn from the analyses discussed in this paper, and further refined through input from our national partners. We held a follow-up meeting to the Think Tank, called the National Forum, in December of 2017, where 54 participants from across Canada engaged in tabletop sessions to workshop the policy briefs, identify gaps, and ensure they captured the best possible information and recommendations for action. Furthermore, our partners have assisted in this effort by generating their own statements. For instance, the Canadian Medical Protective Association has recently released a detailed statement about the use of eConsult services and outlining physicians' legal, ethical, and professional obligations when using them to provide care (Canadian

Medical Protective Association 2017). Further discussion of policy issues will take place at our third event, to be held in November 2018.

## Discussion

We have outlined an IKT approach that informed a process for exploring policy gaps affecting eConsult's scale-up from a regional to a national level, resulting in a series of thoughtful, relevant, and actionable recommendations for next steps. Our approach centres on the researcher's role, which includes identifying policy enablers and barriers, establishing partnerships capable of enacting supportive policy, coordinating discussion with key stakeholders from different groups (including patients), and linking the results of these activities to generate solutions. In this way, the researcher plays a much more extensive role in the translation and uptake of research findings that could transform and support healthcare improvement in Canada. This approach was effective at transferring knowledge into actionable policy recommendations and helped us to create a growing group of engaged individuals from across Canada, who continue to work together on the spread and scale of eConsult, and, through their enthusiasm, have made the Think Tank into an annual event due to host its third iteration in 2018.

We positioned our paper on the central tenet that policy barriers are among the most common factors impeding the translation of knowledge into action (Graham and Tetroe 2007). Informing and influencing policy requires a different approach than the traditional academic one (Clancy et al. 2012) as only legislators can remove the barriers to healthcare innovation stemming from current laws and regulations (Herzlinger 2006). In her work examining how policy makers use health service research, Marsha Gold revealed that healthcare policy makers' decisions to implement research programs are influenced by "underlying politics" (Gold 2009). To influence policy decisions, researchers must develop a deeper understanding of the context in which these decisions are made (Blendon and SteelFisher 2009). This includes being aware of existing healthcare policies, how evidence-informed public policy is developed, and which research topics have policy leverage, and presenting these factors in a way that engages policy makers' interests. By actively engaging in policy discussions and ensuring engagement of the knowledge users as per IKT approach, researchers could support better adoption and implementation of promising innovations (Graham and Tetroe 2007; Graham et al. 2006; Graham and Tetroe 2009).

It is worth noting that some policy barriers are not based on prohibitive legislation but instead on users' perceptions. An example of this involves the various provincial privacy legislations, such as the *Personal Health Information Protection Act* (PHIPA) in Ontario, which are designed to protect patients' privacy when interacting with the healthcare system. While PHIPA does restrict some forms of online communication, such as e-mails between patients and providers (Canadian Medical Protective Association 2005), there are other PHIPA compliant online communication technologies, such as eConsult, which can offer greater access without sacrificing privacy (Liddy et al. 2015b). Nonetheless, confusion over PHIPA's scope can prevent some providers from engaging with electronic innovations, despite the fact

said innovations are fully permitted under current legislation. This illustrates how aggressive and inflexible policies can raise unintended barriers to innovation.

Our IKT approach had some limitations. Although we made a conscious effort to invite a diverse range of stakeholders, we were unable to engage some key parties. The distribution of organizations participating in the meeting may have influenced the established recommendations. Notably, we did not have any participants with the knowledge or decision-making authority to describe the existing agreements governing interjurisdictional referrals. Recognizing the limits to our own reach as researchers, we could, and should, leverage the networks of our stakeholders. To this end, we invited all working groups to share a list of stakeholders who should be involved in subsequent discussions, with the aim of obtaining a broader and more inclusive perspective. Furthermore, limiting the meeting to one day prevented an exhaustive discussion of all topics.

## Conclusion

Using an IKT approach, we leveraged a diverse set of stakeholders in strategic discussions following the identification of specific policy gaps. These stakeholders represented seven provinces/territories (plus one delegate from the US) and engaged in a valuable discussion on healthcare policy recommendations to support the expansion of the eConsult service across Canada. Participants provided thoughtful guidance and helped define actionable suggestions for next steps, which will serve to support decision-makers in developing a national implementation strategy. This paper will be of interest for those who are working in health system research and its implementation and will provide some practical approaches on engaging stakeholders in deliberative policy dialogue and, most importantly, on influencing policy change that will improve healthcare service delivery, and ultimately, patient experiences and health outcomes.

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# Community-Based Reform Efforts: The Case of the Aging at Home Strategy

## Efforts pour une réforme axée sur la communauté : le cas de la stratégie Vieillir chez soi



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### Abstract

This paper considers one of Ontario's largest reform efforts: the Aging at Home Strategy (AHS). The AHS was initiated in 2007 to enable people to live independent lives in their own homes. A document review was conducted on relevant government materials to assess the goals and objectives of the AHS as it was rolled out over the course of three years. The findings identify that by the third year of the AHS, there was a reduction in the discretionary powers of the regional health authorities to allocate funds based on local priorities. These findings also highlight that the "mainstream" subsectors of the healthcare system – medical

and hospital services – and those outside the mainstream (or the “marginal” subsectors) face different institutional boundaries, policy legacies, political actors and policy agendas. While interests within the mainstream subsector are organized and institutionalized, the marginal subsectors are fragmented, creating a power imbalance where the priorities of the mainstream subsector dominate.

## Résumé

Cet article traite d'un des plus grands efforts de réforme en Ontario : la stratégie Vieillir chez soi (VCS). Cette stratégie a été créée en 2007 afin de permettre aux personnes de vivre en autonomie dans leurs propres foyers. La documentation gouvernementale pertinente a fait l'objet d'une revue afin d'évaluer les buts et objectifs de la stratégie VCS sur une période de trois ans. Les résultats indiquent qu'après trois ans, il y a réduction du pouvoir discrétionnaire des autorités régionales de la santé leur permettant d'allouer les fonds selon les priorités régionales. Ces résultats mettent également en lumière le fait que les sous-secteurs « dominants » du système de santé – services médicaux et hospitaliers – et ceux hors du courant dominant (c'est-à-dire les sous-secteurs « marginaux ») font face à différentes limites institutionnelles ainsi qu'à divers acteurs, programmes ou traditions politiques. Alors que les intérêts du sous-secteur dominant sont organisés et institutionnalisés, les sous-secteurs marginaux demeurent fragmentés, ce qui crée un déséquilibre des pouvoirs où les priorités du sous-secteur dominant l'emportent.

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## Introduction

Policy makers across high-income countries face the challenge of sustaining already stretched health and social care systems while also meeting the needs of aging populations. In addition, increasing evidence suggests a need for broader community care options (Donner et al. 2015; Drummond et al. 2012; McNeil and Hunter 2014; Sinha 2012; Williams et al. 2016). Community care aims to maintain people and their caregivers as independently as possible, for as long as possible, in their own homes and communities through coordinated access to health and social supports – professional homemaking, attendant care, affordable housing. Such policies respond to the desire for people to age in familiar settings, and the growing perception that lower cost community-based care can substitute for more costly, and often inappropriate, care in hospitals and long-term care institutions. Yet, as we demonstrate, policy change aimed at building up community care options has been hard to achieve.

This paper considers the historical legacy of policy decisions for older persons in Ontario, Canada. We discuss policy priorities in the community subsector and the implications this has for the delivery of long-term care services. To do this, we rely on an analysis of one of Ontario's largest community-based reform efforts: the Aging at Home Strategy

(AHS). The AHS was initiated in 2007 by the Government of Ontario to enable “people to continue leading healthy and independent lives in their own homes” (Williams et al. 2009). The strategy was supported with a financial outlay of approximately \$1.1 billion over four years seeing an increase of \$143.4 million for community-based programming in the first year alone. The AHS was a provincial-level strategy, to be implemented regionally by the newly created Local Health Integration Networks (LHINs). This was the first large-scale initiative to be led by the newly implemented regional health authorities in Ontario – the LHINs (MOHLTC 2007). The LHINs were established in 2006 under the authority of the *Local Health System Integration Act* (LHSIA). The LHSIA set out that each LHIN be governed by a board of directors appointed by provincial Cabinet, and each LHIN establish an accountability agreement with the province that outlines performance goals, targets and standards (LHSIA 2006). The LHSIA also ensured that the provincial government may set provincial priorities in order to provide direction to the regions. The LHINs’ mandate included the planning, funding, and coordination of hospital, community support, long-term care, mental health and addiction, and limited primary care services within their respective regions. Independent physician services remained outside of the LHIN mandate. The LHSIA provided LHINs with the ability to reallocate funds among service providers, but unlike regional health authorities in other provinces, the LHINs had no responsibility for service delivery. This means that pre-existing healthcare delivery organizations remained intact.

Our analysis is presented in two sections: first, we highlight the history of community care in Ontario and present an overview of reforms to the community care subsector over nearly a decade. Here we also briefly discuss strategies that were intended to fundamentally redesign our health and social care structures.

Second, we highlight one of Ontario’s largest attempts at community care reform: the AHS. We rely on findings from a document review where we track the objectives of the AHS over a three-year period. We conclude with an analysis of the AHS within the context of the policy literature to identify theoretical lessons learned and explore the challenges of attempting to implement reform efforts in the community care subsector.

## Background

Canada’s healthcare system is an amalgamation of 13 provincial and territorial healthcare systems. National consistency in the funding and delivery of healthcare services is maintained by federal contributions to healthcare funding, which are conditional on the provinces and territories adhering to the provisions of the *Canada Health Act*. The *Canada Health Act* applies only to “medically necessary” services, which has been interpreted to refer only to hospital and physician care (Romanow 2002b). Other healthcare sectors, including the community care subsector, remain largely on the periphery and the funding and delivery of these services varies considerably across Canada.

In Ontario, starting in the early 1990s, community care has seen a series of significant and contrasting reform efforts and recommendations that altered the delivery of

community-based services. The first significant change was implemented in 1993 when the left-of-centre New Democratic Party government introduced the Multi-Service Agency (MSA) model (Williams et al. 2016). The implementation of the MSA legislation formally moved community care outside the auspices of the “mainstream” medically necessary hospital and physician services – thereby having distinct sub-entities that compile Ontario’s healthcare sector.

Appeals for the expansion of community care were featured in the recommendations of the Ontario Health Services Restructuring Commission (HSRC) – a body established in 1996 with a mandate to make decisions on restructuring Ontario’s public hospitals, and to make reinvestments in other subsectors to support the restructuring process (Baranek et al. 2004; HayGroup 1997; Ontario Health Services Restructuring Commission 2000; Williams et al. 2016). The HSRC recommended an expansion of the number of long-term care “places,” which included increased community care capacity, institutional care beds and maintenance of patients in the lowest level of care possible. In fact, the HSRC recommended an expansion of 388 long-term care places by 2003, 40% of which were to be beds in institutional settings. However, in 1998, the Ontario Progressive Conservative Party led by Harris responded with the announcement of a 20,000 institutional long-term care bed expansion over the following six years (Williams et al. 2016). These investments largely failed to address demands to improve capacity in the community care subsector. In 2002, the “Romanow Report” noted that community care needed to be considered the next “essential service” in order to see gains made to improve the health sector (Romanow 2002a; Williams et al. 2016).

In 2007, the Ontario Government announced the implementation of the \$1.1 billion AHS, which had the explicit aim of enabling people to live independently in their own homes, by shifting resources to the community (MOHLTC 2007). In 2008, the provincial government championed a parallel initiative in the hospital subsector aimed at reducing alternative levels of care (ALC; people who remain in the hospital but who do not require that level of care) and emergency department wait times (Guerriero and Nord 2009).

Recommendations to place greater attention on the community subsector are not new – the AHS was a continuation of previous efforts to shift care to the community to lower the burden on the hospital and physician subsectors. However, the AHS was also a test case for regionalization in Ontario, and the ability of the LHINs to deliver on their promise of local integration. In addition, the AHS brought greater attention to the issue of aging in place and to the expanding role of the community care subsector.

Although, as we will demonstrate, large-scale initiatives like the AHS are not implemented in a vacuum. Historical factors impact implementation and decisions are made in a context that has deep-rooted models, practices, and established actor/institutional networks (Rayner and Howlett 2009). Particularly relevant is the *Canada Health Act* of 1984, which guarantees comprehensive coverage only for physician and hospital services. This established

a biomedicalized approach to care where the medicare mainstream (hospital and doctor care) is guaranteed and the marginal community subsector is delivered, funded, and governed outside of the medicare mainstream (Canadian Healthcare Association 2009; Tuohy 1999). This complicates the funding, eligibility, and universality of these non-medicare mainstream services across and within jurisdictions in Canada.

As we will see, the objectives of the AHS have been difficult to achieve, in large part due to the imbalance between the mainstream and marginal subsectors. The Ontario AHS failed to realize significant shifts in the balance of resources from the mainstream to the marginal community care subsector. Even with ongoing stated objectives noting a desire to structurally reform the funding and delivery of community care services, competing policy agendas developed into contradictory policy outcomes.

## Materials and Methods

A document review was conducted to obtain an in-depth understanding of the context, goals, and objectives of the AHS as it was rolled out over the course of three years. Document reviews have been identified as a valuable tool to track change and development through comparison of documents (Bowen 2009). We accessed newsletters, press releases, policy briefings, reports and budgets that made mention of the AHS. Each of the 14 LHIN websites and the Ontario News Room were searched. To better understand the geographical context of each LHIN, see the map of Ontario's 14 LHIN regions (Figure 1).

**FIGURE 1.** Map of Ontario's 14 LHIN regions



LHIN = Local Health Integration Network. 1. Erie St. Clair; 2. South West; 3. Waterloo Wellington; 4. Hamilton Niagara Haldimand Brant; 5. Central West; 6. Mississauga Halton; 7. Toronto Central; 8. Central; 9. Central East; 10. South East; 11. Champlain; 12. North Simcoe Muskoka; 13. North East; 14. North West.

Search terms included: “Local Health Integration Network” AND “Aging at Home”, “Erie St Clair LHIN” AND “Aging at Home”, “South West LHIN” AND “Aging at Home”, “Waterloo Wellington LHIN” AND “Aging at Home”, “Hamilton Niagara Haldimand Brant LHIN” AND “Aging at Home”, “Central West LHIN” AND “Aging at Home”, “Mississauga Halton LHIN” AND “Aging at Home”, “Toronto Central LHIN” AND “Aging at Home”, “Central LHIN” AND “Aging at Home”, “Central East LHIN” AND “Aging at Home”, “South East LHIN” AND “Aging at Home”, “Champlain LHIN” AND “Aging at Home”, “North Simcoe Muskoka LHIN” AND “Aging at Home”, “North East LHIN” AND “Aging at Home”, “North West LHIN” AND “Aging at Home”. In total, 62 documents were pulled for further review and analyzed to identify any shifts in mission, vision, or goals over the course of the three-year AHS (see Appendix 1, available at: <https://www.longwoods.com/content/25550>, for a breakdown of number of reports found per year in each LHIN).

### *Analysis*

This document analysis involved two stages. First, it involved reading the documents to classify relevant information. For our case, this included any information on the changes and developments of the AHS as it was rolled out (Bowen 2009). Two members of the research team (JL and AP) used data extraction forms to make note of any relevant details from each of the documents. Using Excel, we captured the data for each LHIN. The Excel spreadsheet included an inventory of documents and key details that were compiled into the following categories:

- Document source: where the document was found.
- Year published: what year the document was uploaded.
- Year of focus: what year of the AHS it was focusing on.
- Overall vision: what is it that the LHINs hope to achieve over time.
- Primary objectives, outcomes and goals: what were the identified outcomes of importance.
- Funding allocation: what types of supports were funded.

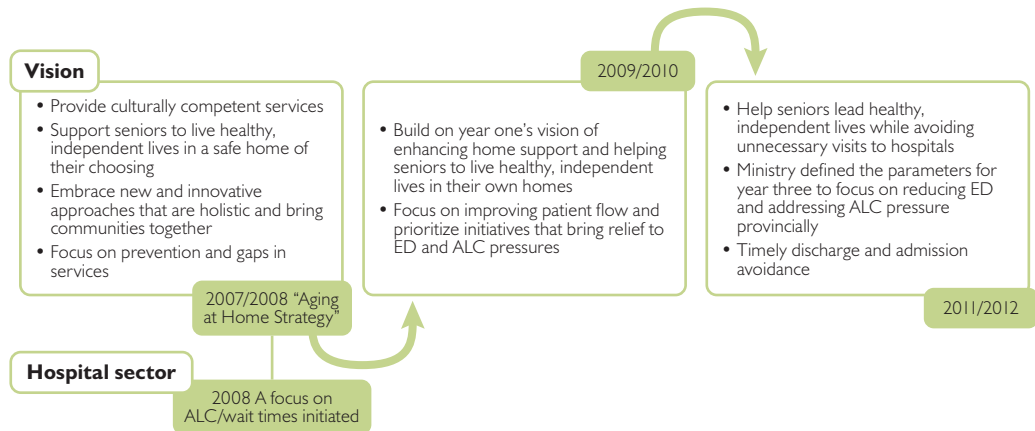
During the second stage of our review, JL, AP and SD conducted a thematic analysis where major themes and trends (i.e., shifts in decision-making concerning the AHS) were categorized based on LHINs and year of focus.

### **Results**

#### *Vision of the AHS from 2007 to 2012*

Our findings suggest that there were shifts in the vision of the AHS over time (as outlined in Figure 2). In year one, three LHINs made note of holistic approaches to care, specifically for older adults and their caregivers (South West, Central West and North West). The AHS aimed to offer culturally appropriate and preventative approaches to addressing current gaps in services.

FIGURE 2. Timeline of the Aging at Home vision



ALC = alternative level of care; ED = emergency department.

"Embracing new and innovative approaches to offer a full spectrum of services across the continuum that reach out to seniors and their caregivers, focusing on prevention and gaps in services, considering the whole person, the family, the carers and all factors that have an impact on health status" (quotation compiled from various LHIN documents [Central West LHIN 2009, 2010; North West LHIN 2009a,b; South West LHIN 2007]).

In year two, visions built upon year one. Specifically, the AHS sought "to enhance home support and help seniors live independent and healthy lives in their own homes" (Central West LHIN 2009; Champlain LHIN 2009; Erie St. Clair LHIN 2009; Laukner 2009). In addition, focus was on patient flow and to support initiatives that could bring "relief to emergency department and alternative level of care pressures" (Central West LHIN 2009; Erie St. Clair LHIN 2009; Laukner 2009; North West LHIN 2009a,b).

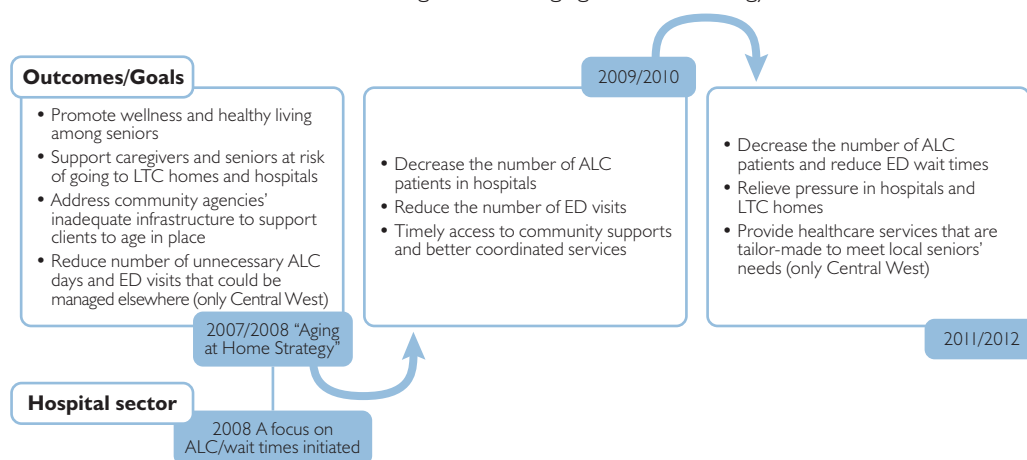
In year three, the vision was to ensure Ontario seniors had access to services to lead healthy independent lives, "while also avoiding unnecessary visits to hospitals" (Central East LHIN 2010; Central LHIN 2010; Central West LHIN 2010). LHINs noted that the ministry defined the parameters for year three to focus on services to enable ALC patients to leave hospital sooner, reducing emergency department and long-term care wait list pressures (Champlain LHIN 2010; Erie St. Clair LHIN 2010; North West LHIN 2010; Waterloo Wellington LHIN 2010b).

### *AHS outcomes and goals from 2007 to 2012*

Outcomes and goals that were identified for the AHS also shifted over time and varied across LHINs (documented in Figure 3). There was one LHIN, Central West, that was an

outlier in terms of its goals for year one of the AHS. In year one, many of the documents reported that the AHS attempted to address inadequate infrastructure that limited the community's ability to support clients to age in place (Central LHIN 2007a,b), to promote wellness and support caregivers and seniors who were at risk of going to long-term care facilities (Mississauga Halton LHIN 2007; North East LHIN 2008; South West LHIN 2007; Toronto Central LHIN 2007) and, lastly, Central West (Central West LHIN 2007) spoke to reducing the percentage of ALC days and emergency department visits by seniors who could be supported elsewhere.

**FIGURE 3.** Timeline of the outcomes and goals of the Aging at Home Strategy



ALC = alternative level of care; ED = emergency department; LTC = long-term care.

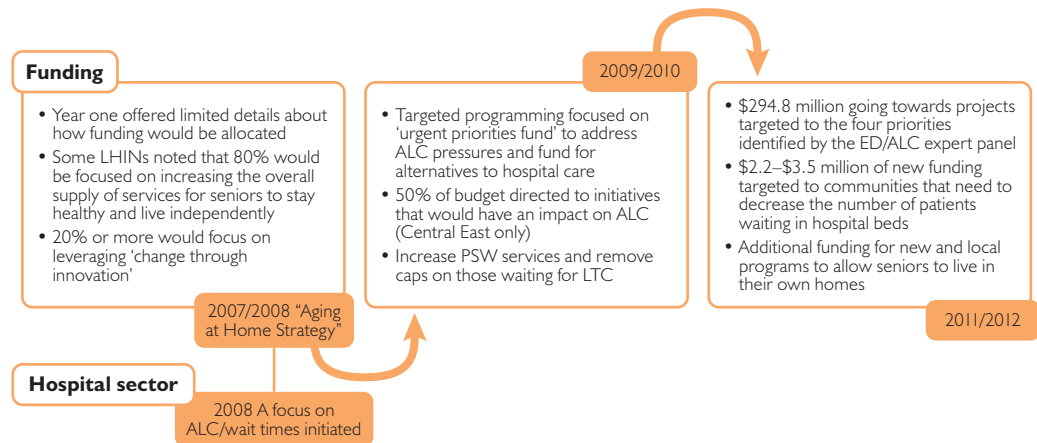
By year two, outcomes and goals envisioned for the AHS were aligned across LHINs. Most documents suggested the ultimate outcome was to "decrease [the] number of ALC patients in hospitals" (Champlain LHIN 2009; Hamilton Niagara Haldimand Brant LHIN 2009; Mississauga Halton LHIN 2009; North West LHIN 2009b), and to reduce the use of emergency departments (Hamilton Niagara Haldimand Brant LHIN 2009; Mississauga Halton LHIN 2009; North East LHIN 2008) and ensure there was better coordination of services (Laukner 2009).

Year three emulated the goals set out in year two. LHINs reported that goals and targets aimed to decrease the number of ALC patients (Central East LHIN 2010; Central LHIN 2010; Erie St. Clair LHIN 2010; North East LHIN 2010; MOHLTC 2007; Waterloo Wellington LHIN 2010a), relieve pressure in hospitals and long-term care homes (Champlain LHIN 2010), reduce emergency department wait times and ALC days to increase temporary bed capacity (Erie St. Clair LHIN 2010). Interestingly, Central West was an outlier; its documents highlighted goals related to providing healthcare services that are tailor-made to meet local seniors' needs.

### Program funding for the AHS from 2007 to 2012

With respect to programs and services that were funded over the course of the AHS (Figure 4), year one offered limited details around how money was to be spent and on what types of programs, outlining that funding was being directed to local programming (Erie St. Clair LHIN 2007; Erie St. Clair LHIN 2008). Other LHINs were more specific, noting that 80% of the AHS budget was being targeted to increase the supply of services for seniors to stay healthy and live independently with the additional 20% of the budget being spent to “leverage change through innovation” (Central West LHIN 2007).

**FIGURE 4.** Timeline of documented funding of the Aging at Home Strategy



ALC = alternative level of care; ED = emergency department; LHINs = Local Health Integration Networks; LTC = long-term care; PSW = personal support worker.

By year two, funding directives targeted programming focused on an “urgent priorities fund” to address ALC pressures by delivering alternatives to hospital care (Champlain LHIN 2009; Hamilton Niagara Haldimand Brant LHIN 2009; Mississauga Halton LHIN 2009). It was noted in Central East (Central East LHIN 2009) that 50% of its AHS budget would be directed to initiatives that would have a direct impact on ALC.

By year three, a general AHS document noted that \$294.8 million would be going towards programs to meet the four priorities identified by the emergency department/ALC expert panel (MOHLTC 2007). While other LHIN-specific documents spoke to funding local programming and “new programs” (Central West LHIN 2010; Waterloo Wellington LHIN 2010a,b).

### Discussion and Conclusion

Our analysis demonstrates that by the third year of the AHS there was a reduction in the discretionary powers to allocate funds according to local and regional priorities. New funding was shifted even further away from building capacity in services like supportive housing and caregiver support into services like specialized geriatric emergency teams and post-acute rehabilitation (Central East LHIN 2010).

There are several key lessons learned concerning the difficulty of sustaining policy change aimed at supporting community-based care. First, community care in Ontario is different by virtue of it being outside Canadian medicare policy, including legislation that only protects the public and universal funding of hospital and physician services. This leaves provincial governments with the responsibility of determining how to respond to increasing demands for services in subsectors outside the mainstream, with no obligation to do so (Baranek et al. 2004). These once medically necessary services provided in the mainstream are now provided in the marginal subsector, placing them beyond coverage (Baranek et al. 2004). Second, health policy change with respect to building capacity of the community subsector remains difficult as a result of competing political agendas. These competing agendas have been a result of persistent fragmentation within the community and social care subsectors, while the mainstream subsectors have remained relatively homogenous. This complexity is a by-product of the subsectors' historical emergence as a collection of community-based initiatives to meet local needs, with variability across and even within jurisdictions around service offerings, entry points, eligibility criteria and accountability guidelines. Community care organizations are also subject to competitive bidding processes, which challenge efforts to unify. Furthermore, community care is often provided by professionals (e.g., personal support workers) who do not share similar mobilizing powers as those in the mainstream subsector like doctors (Baranek et al. 2004; Williams et al. 2016).

This imbalance between subsectors has been the result of a policy legacy of accommodation toward the medical profession. Much of the literature on policy change builds off of the notion of "policy legacies," made famous through the work of Paul Pierson (Pierson 1993; Pierson 2000). The policy legacy literature stresses the importance of history and that there are path-dependent effects of policy decisions that can shape political dynamics and delimit the scope of future decisions (Tuohy 1999). In her book *Accidental Logics*, Carolyn Tuohy discusses the contingent way in which the features of health systems are shaped by political ideas and agendas that appear during windows of political opportunity. Furthermore, these actions create path-dependent effects that shape the subsequent actions of policy makers (Tuohy 1999). According to Tuohy, in Canada, more than any other comparable nation, characteristics of the healthcare system have been shaped by the "logic of accommodation" between governments and the medical profession. In the 1960s, the Canadian government established medicare by agreeing to ensure hospital and physician services, largely based on the existing structure of healthcare delivery in Canada. The establishment of medicare under, what Tuohy calls, "generous terms" has had contingent effects that institutionalized negotiation and funding relationships between the state and the hospital and medical subsectors in Canada (Tuohy 1999). This institutionalized logic of accommodation has limited the scope of policy change by providing these subsectors with the ability to influence policy change and maintain existing structures and resource allocations, resulting in remarkable stability in the Canadian healthcare system and a continued focus on hospital and physician services.

There is value in acknowledging power imbalances within subsectoral policy networks. Competing policy agendas in some subsectors can appropriate competing policy agendas in marginalized subsectors. In the case of AHS, reform efforts that attempted to provide the community with the necessary resources to offer preventative supports for aging populations were largely appropriated by the interests of more dominant actors in the mainstream (hospital) subsectors. With the rollout of the 2008 focus on ALC and wait times, community care was directed to target persons requiring acute level services, leaving fewer services available to offer preventative supports (Baranek et al. 2004; Williams et al. 2016).

Our study had some noteworthy limitations. Firstly, we were not able to retrieve documents equally across all three years for each of the 14 LHINs. This may reflect differences in archiving and public reporting practices. Thus, our findings may not be reflective of the entire province. However, in those LHINs with publicly available records, the story remained remarkably consistent. Second, we retrieved a variety of different document types, including: newsletters, press releases and policy briefings. Since each document type is produced for different purposes and audiences, some documents contained inconsistent data or the information provided was quite vague. Future study could combine document analysis with qualitative methods (e.g., key informant interviews with policy makers) to corroborate the data.

## Conclusion and Future Research

In summary, the Mainstream and Marginal subsectors in Ontario are different by virtue of facing different institutional boundaries and historical policy legacies, having distinct arrangements of political actors and having competing policy agendas. Competing interests within the healthcare sector, and the incongruence of the community subsector, mean mainstream approaches (those of the hospitals, doctors, medical professions) dominate as a result of the historically significant position. We suggest that this explains why it remains difficult to sustain community-based efforts of preventative health and social care and helps us understand why the original intent of the AHS was difficult to maintain. Future research may look to the role that policy feedback may play in implementing future community-based reform efforts; the early shifts to the AHS may explain policy outcomes that have further transformed the community care landscape (Pierson 1993). The direction that the AHS went could set a legacy for future decisions aimed at implementing community-based services.

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# The Changing Landscape of Continuing Care in Alberta: Staff and Resident Characteristics in Supportive Living and Long-Term Care

Paysage changeant des soins continuels en Alberta : caractéristiques du personnel et des résidents en logements supervisés et dans les services de soins prolongés



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## Abstract

With provincial policy changing institutional care provision for older adults who are unable to safely remain at home, supportive living represents a new middle-ground to provide care for older adults. We compared characteristics of supportive living staff and residents to those in long-term care (LTC), using facility and staff surveys, as well as administrative Resident Assessment Instrument (RAI) data, to describe differences and similarities between

facility types. Data analysis included *t*-tests, chi-square tests, ridit analyses and odds ratios. Participants from 15 supportive living facilities were compared to participants from eight LTC homes. Supportive living healthcare aides were younger, worked fewer years and were more likely to work full time than LTC healthcare aides. LTC residents were more likely than supportive living residents to have: cognitive impairment, medical instability, and activities of daily living dependence. This knowledge, which situates supportive living in the new care continuum, is useful for policy makers and administrators deciding on interventions and clinical guidelines for care groups.

## Résumé

Avec les politiques provinciales qui transforment la prestation de soins institutionnels pour les aînés incapables de demeurer à la maison, les logements supervisés (LS) représentent un nouveau moyen pour la prestation de soins aux aînés. Nous avons comparé les caractéristiques du personnel et des résidents dans les LS avec ceux des services de soins prolongés (SSP), et ce, au moyen de sondages auprès des établissements et du personnel, de même qu'en utilisant les données du Instrument d'évaluation des résidents, pour décrire les différences et les similarités entre les deux types d'établissements. L'analyse des données comprenait des tests *T*, des test du Chi carré, la méthode « ridit » et des rapports des cotes. Les participants de 15 établissements de LS ont été comparés aux participants de 8 établissements de SSP. Les préposés aux soins dans les LS étaient plus jeunes, travaillaient depuis moins d'années et étaient plus enclins à occuper un poste à temps plein que les préposés aux soins des SSP. Les résidents en SSP étaient plus susceptibles que ceux en LS de présenter les états suivants : trouble cognitif, instabilité médicale et dépendance pour les activités quotidiennes. Ces connaissances, qui placent les LS dans le nouveau continuum des soins, sont utiles pour les responsables des politiques et les administrateurs qui prennent des décisions au sujet des interventions et des directives cliniques pour les groupes de soins.

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## Background

Supportive living facilities in Canada began to expand in the late 1990s as a bridge in the continuum of care between home living and provincially regulated long-term care (LTC) facilities (Alberta Health and Wellness 2008; Canadian Centre for Elder Law 2008; Golant 2001; Stevenson and Grabowski 2010). Supportive living facilities, in contrast to LTC facilities, have been promoted as providing a more home-like environment offering room and board, in addition to 24-hour oversight and assistance with activities of daily living (ADLs) (Zimmerman et al. 2003). This type of facility targets the more functional independent client than LTC. These supportive living facilities have wide variation in the structure and services provided to a heterogeneous group of residents (Golant 2004; Park et al. 2006). Likewise, the nurse staffing mix in supportive living is diverse, with the availability of services

related to the presence or absence of licensed nurses (Beeber et al. 2014). In Canada, supportive living facilities are privately owned by either for-profit or not-for-profit groups and receive varying levels of funding from provincial governments, resulting in a wide range of care and services. A subset of supportive living spaces are considered designated spaces wholly funded by the provincial government. Other non-designated spaces, such as lodges or retirement communities, operate with little to no regulation or external funding.

In Alberta, the Broda Report was the health policy impetus for expanding accommodation types and more accessible home care services to meet the diverse needs of older adults (Alberta Health and Wellness 1999). Designated supportive living is seen as a cost-saving option for the provision of basic healthcare services for older adults without complex or unstable medical conditions (Alberta Health and Wellness 2000). Both designated supportive living and LTC residents pay an accommodation fee, regulated by the government, to cover room and board expenses, while health service costs are paid by the provincial government. Specialized healthcare services and allied health professionals are not available on-site in supportive living settings, minimizing healthcare costs; however, services are provided by home care. Facility-based case managers, who are regulated health professionals, develop resident care plans and monitor the care provided in these settings. Conversely, residents in provincially regulated LTC facilities require the 24-hour presence of a registered nurse and are understood to have multiple chronic or unstable medical conditions requiring specialized care (Alberta Health and Wellness 2010). These trends, focusing on increasing individual choice and a range of service delivery options, are mirrored in the US and worldwide (Hudson 2014).

Although the provincial government has clearly defined criteria for the allocation of residents to publicly funded designated supportive living facilities and LTC facilities (Alberta Health and Wellness 2010), evidence supporting the differences between these groups is sparse (Grimshaw et al. 2012). Understanding the similarities and differences of facility, staff and resident characteristics of supportive living and LTC settings helps to situate them within the relatively new continuum of care. This description of the two settings clarifies how they align with provincial health policy. It also becomes possible to appropriately target implementation strategies and policy by accounting for varied staff and facility characteristics (Grimshaw et al. 2012). The purpose of this study was to describe and compare the characteristics of the healthcare staff and residents in designated supportive living facilities and LTC facilities in Alberta.

## Methods

For this observational study, data were obtained from two sources: (1) the Sustaining Transfers through Affordable Research Translation (START) study, and (2) concurrently gathered administrative data from Alberta Health Services. START was a cluster randomized controlled trial that examined the effect of knowledge translation interventions on health provider behaviour change in supportive living facilities and LTC facilities in Alberta, Canada (Slaughter et al. 2013).

### *Participants and recruitment*

A purposive sample of 15 supportive living facilities and eight LTC facilities in the Edmonton health region of Alberta participated in the study. Given the evidence suggesting that nurse staffing and care outcomes in LTC facilities are associated with profit status (Harrington et al. 2012; McGrail et al. 2007; McGregor et al. 2010), purposive sampling ensured that 50% of the LTC facilities and 50% of the supportive living facilities were for-profit while the other half were not-for-profit. Facilities were included if the site administrator agreed to participate in the trial and the facility had a minimum of 15 supportive living or LTC beds. Convenience sampling was used to recruit healthcare aides and residents. Healthcare aides were eligible to participate if they had worked three months or more in that setting and worked a minimum of six shifts per month. In supportive living, only data from residents assessed by an Alberta Health Services case manager, who met the provincial criteria for enhanced assisted living, were included (Alberta Health Services 2010). These residents were unable to be maintained safely at home and had physical care needs that could not be met at home (Alberta Health Services 2010).

### *Data sources and data collection*

Data were collected using surveys and secondary data. Research assistants collected data directly from sites and staff over a two-year period between March 2014 and March 2016 using facility surveys and healthcare aide demographic questionnaires. Routinely collected administrative data, Resident Assessment Instrument-Home Care (RAI-HC) for supportive living, and Resident Assessment Instrument-Minimum Data Set 2.0 (RAI-MDS 2.0) for LTC were obtained from the provincial custodian: Data Integration, Measurement and Reporting (DIMR), Alberta Health Services.

#### STAFF-LEVEL DATA

Facility leaders (nurse managers or site administrators) completed a facility profile form that included information regarding staffing ratios for healthcare aides, Licensed Practical Nurses and registered nurses. Healthcare aides self-selected to complete a demographic questionnaire that included: age group, sex, first language, level of education completed (high school, healthcare aide certificate, other diploma or degree) and employment history (usual shift worked, years worked as a healthcare aide, years worked on the unit, typical hours worked in a two-week period).

#### RESIDENT-LEVEL DATA

Anonymized RAI-MDS 2.0 (LTC) or RAI-HC (supportive living) data for each participating site was obtained for the calendar year that the site commenced the START trial (either 2013 or 2014). RAI data were available for the cohorts living in each of these facilities at the time the START study was conducted. That is, the data from one annual assessment were included for every resident who resided at the facility during that calendar year (either 2013 or 2014). Data derived from the RAI-MDS 2.0 and RAI-HC were

gathered for this study and included: the Depression Rating Scale, a three-level depression scale ranging from no mood symptoms to minor or major depressive disorder (Burrows et al. 2000); Cognitive Performance Scale, a seven-level scale ranging from intact to very severe impairment (Hartmaier et al. 1995; Morris et al. 1994); Changes in Health, End-Stage Disease, Signs, and Symptoms scale (CHESS), a six-level scale ranging from no health instability to very high health instability (Hirdes et al. 2003); and the ADLs long-form scale, a 28-level scale ranging from total independence to total dependence in ADLs (Morris et al. 1999).

### *Analysis*

Differences were assessed using *t*-tests for continuous data and chi-square tests for categorical data. Ridit analyses (Donaldson 1998) were used to compare the facilities in regards to the ordinal RAI scales. The summary measure outputted from a ridit analysis is a mean ridit. In comparing two groups, a mean ridit estimates the probability that a randomly selected individual from one group will have a higher score than a randomly selected individual from the other group. Dividing two corresponding mean ridits yields the odds of a higher score in one group relative to the other group. Results from the RAI scales were also summarized in terms of odds ratios (ORs) with corresponding 95% confidence intervals (CIs). To calculate the ORs, we dichotomized the depression rating scale using 0 (no depressive symptoms) versus 1–14 (any depressive symptoms), the cognitive performance scale using 0–3 (intact to moderate impairment) versus 4–6 (moderate/severe to very severe impairment), changes in health, end-stage disease, signs, and symptoms scale using 0–1 (minimal instability) versus 2–5 (low to very high instability), and ADLs long-form scale using 0–14 versus 15–28. All bivariate analyses were carried out using SPSS v22 and SAS 9.3.

Ethics approval was received from the Health Research Ethics Board at the University of Alberta (Pro00034781). Healthcare aides provided informed written consent to participate in the study. RAI data were anonymized prior to receipt and did not require ethics board review or written consent.

## **Results**

### *Staff level data*

The median (interquartile range) number of beds in the facilities was 145 (87) in supportive living and 155 (34) in LTC homes. A total of 249 healthcare aides were recruited from supportive living facilities and 276 from LTC facilities. The healthcare aides from supportive living were significantly younger than those in LTC facilities (42.1 years, standard deviation [SD] = 10.9, versus 46.3 years, SD = 10.0,  $p < 0.001$ ) and fewer held a healthcare aide certificate ( $n = 203$ , 81.5%, versus  $n = 244$ , 88.4%,  $p = 0.027$ ). Significantly more healthcare aides in supportive living worked full time hours ( $n = 174$ , 69.9%) compared with those in LTC facilities ( $n = 71$ , 25.7%) ( $p < 0.001$ ). Healthcare aides in supportive living had been working for approximately four fewer years both as a care aide and on their particular unit, in comparison to those in

LTC facilities. There was no difference in the number of healthcare aides who spoke English as a first language ( $n = 82$ , 32.9%, versus  $n = 81$ , 29.3%,  $p = 0.375$ ) or in number who completed high school ( $n = 243$ , 97.6%, versus  $n = 265$ , 96.0%,  $p = 0.308$ ). The staffing ratios were comparable between LTC facilities and supportive living facilities for the healthcare aides and Licensed Practical Nurses on both day and evening shifts (Table 1). The only difference in staffing between the two types of facility was the additional presence of a registered nurse in every LTC facility. There were no registered nurses in participating supportive living facilities.

### *Resident level data*

The RAI data included 1,337 residents across the 15 participating supportive living facilities and 5,029 residents across the eight participating LTC facilities (Table 2). The ridit analysis indicates there is a 59.1% chance that a randomly selected resident from a LTC facility is in a higher category of depression than a randomly selected resident from a supportive living facility. In other words, the odds are approximately 3 to 2 (0.591/0.409) that residents in LTC facilities had more depressive symptoms than those in supportive living facilities. Specifically, the odds of having at least some depressive symptoms was significantly twice as high among residents in LTC facilities compared to supportive living facilities (OR = 2.1; 95% CI:[1.9, 2.4]). The odds of cognitive impairment among residents was also significantly greater in LTC facilities compared to supportive living (667 to 333), and the odds of having moderate/severe cognitive impairment or worse was more than five times as high in LTC (OR = 5.2; 95% CI:[4.3, 6.4]). Similarly, the odds of health instability in LTC was also significantly greater than supportive living (663 to 374), with the odds of residents having at least a low level of instability almost three times as high in LTC facilities compared to supportive living facilities (OR = 2.8; 95% CI:[2.3, 3.4]). Most striking was the significantly higher prevalence of ADL-dependent residents in LTC facilities, with the odds of scoring 15 or higher on the ADLs scale being 52 times higher in comparison to supportive living facilities (OR = 52.3; 95% CI:[42.7, 63.9]).

Recent Alberta RAI data from the Canadian Institute of Health Information (CIHI 2016) suggest that our sample of LTC residents is representative of the Alberta population of LTC residents. According to CIHI, 14.0% of Albertan LTC residents are totally dependent in their ADLs; 16% of residents in our sample were in the most dependent category for ADLs. The CIHI data shows that 33.8% have severe cognitive impairment, while in our sample it was 32%. In the CIHI data, 64% have some health instability, compared with 60.6% in our sample. Finally, the percentage of residents with a possible depressive disorder was 37.3% in the CIHI data and 33.4% in our sample.

The representativeness of our sample of supportive living residents was verified with Alberta Health Services. Although Alberta supportive living RAI data are not available to the general public, an analyst with the Alberta Health Services data unit compared the supportive living RAI data extracted for our study with the provincial data and confirmed its representativeness (Deborah Katz, Personnel Communication, March 3, 2017).

TABLE 1. Staff characteristics

Facility staffing ratios (residents : staff)	Supportive living facilities (n = 15)	Long-term care facilities (n = 8)
Registered nurses		
Day shift	N/A	77 : 1
Evening shift		108 : 1
Licensed practical nurses		
Day shift	29 : 1	31 : 1
Evening shift	37 : 1	34 : 1
HCAs		
Day shift	8 : 1	7 : 1
Evening shift	9 : 1	8 : 1

HCA characteristics	Supportive living HCAs (n = 249)	Long-term care HCAs (n = 276)	p-value
Age in years, grouped mean (SD)	42.1 (10.9)	46.3 (10.0)	<0.001
Age category, n (%)			
20–29 years	37 (14.9)	12 (4.3)	<0.001
30–39 years	63 (25.3)	59 (21.4)	
40–49 years	86 (34.5)	101 (36.6)	
50–59 years	53 (21.3)	78 (28.3)	
>60 years	10 (4.0)	26 (9.5)	
Female, n (%)	222 (89.2)	263 (95.3)	0.008
Completed high school, n (%)	243 (97.6)	265 (96.0)	0.308
Completed HCA certificate, n (%)	203 (81.5)	244 (88.4)	0.027
English as first language, n (%)	82 (32.9)	81 (29.3)	0.375
Full-time employee, n (%)	174 (69.9)	71 (25.7)	<0.001
Years worked as HCA, mean (SD)	7.2 (6.2)	11.6 (8.1)	<0.001
Years worked on unit, mean (SD)	3.4 (3.5)	7.1 (10.5)	<0.001
Hours worked in two weeks, mean (SD)	70.3 (15.8)	62.8 (20.2)	<0.001

HCA = healthcare aide; N/A = not applicable; SD = standard deviation.

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**TABLE 2.** Resident characteristics

Scale	Supportive living (n = 1,337)	Long-term care (n = 5,029*)	p-value
Depression rating scale*, n (%)			
No depressive symptoms (0)	699 (52.3)	1,719 (34.2)	<0.001
Some depressive symptoms (1–2)	316 (23.6)	1,622 (32.3)	
Possible depressive disorder (3–14)	322 (24.1)	1,678 (33.4)	
Mean (SE) Ridit	0.409 (0.008)	0.591 (0.008)	
Cognitive performance scale, n (%)			
Intact (0)	179 (13.4)	389 (7.7)	<0.001
Borderline intact (1)	196 (14.7)	626 (12.4)	
Mild impairment (2)	476 (35.6)	711 (14.1)	
Moderate impairment (3)	376 (28.1)	1,696 (33.7)	
Moderate/severe impairment (4)	47 (3.5)	466 (9.3)	
Severe impairment (5)	53 (4.0)	660 (13.1)	
Very severe impairment (6)	10 (0.7)	481 (9.6)	
Mean (SE) Ridit	0.333 (0.007)	0.667 (0.007)	
Changes in health, end-stage, disease, signs, and symptoms scale, n (%)			
No instability (0)	952 (71.2)	1,982 (39.4)	<0.001
Minimal instability (1)	245 (18.3)	1,799 (35.8)	
Low instability (2)	98 (7.3)	860 (17.1)	
Moderate instability (3)	27 (2.0)	275 (5.5)	
High instability (4)	15 (1.1)	91 (1.8)	
Very high instability (5)	0 (0)	22 (0.4)	
Mean (SE) Ridit	0.337 (0.004)	0.663 (0.007)	
Activities of daily living long-form scale, n (%)			
0–4 (most independent)	786 (58.8)	127 (2.5)	<0.001
5–9	292 (21.8)	225 (4.5)	
10–14	138 (10.3)	459 (9.1)	
15–19	86 (6.4)	1,757 (34.9)	
20–24	23 (1.7)	1,654 (32.9)	
25–28 (most dependent)	12 (0.9)	807 (16.0)	
Mean (SE) Ridit	0.071 (0.004)	0.929 (0.004)	

SE = standard error. \*10 long-term care cases missing from depression rating scale (n = 5,019).

## Discussion

Differences in staff and resident characteristics were identified between purposively sampled supportive living and LTC settings in Alberta. Although the staffing mix was similar across facility type for healthcare aides and Licensed Practice Nurses, healthcare aides in supportive living facilities were younger, more likely to work full time and had worked fewer years compared to healthcare aides in LTC facilities. Meanwhile, compared with residents in supportive living facilities, residents in LTC facilities were more cognitively impaired, more dependent in ADLs and had more medical instability. These resident characteristics align with the provincial government admission criteria for the different levels of care (Alberta Health Services 2010). More residents in LTC had medical instability compared with supportive living residents; although every LTC facility had a registered nurse on-site 24/7 to support the additional complex care needs of LTC residents, this registered nurse is unlikely to be providing direct care to residents and is most likely working as a manager, mentor, or administrator. The higher levels of cognitive impairment and ADLs dependency of LTC residents, compared with supportive living residents, was not accommodated by increased numbers of healthcare aides and licensed practical nurses. Given the higher levels of direct care requirements associated with higher cognitive and physical disability, an LTC staffing mix that includes more healthcare aides and Licensed Practical Nurses may be warranted. A systematic review of longitudinal studies in LTC facilities found limited evidence to support the association between nurse staffing and quality of care outcomes (Backhaus et al. 2014); likewise, in the Canadian context, there is some limited evidence to suggest that more nursing hours in LTC facilities are associated with improved care outcomes for residents (McGrail et al. 2007; McGregor et al. 2010). Future research is needed to determine if staffing mix is aligned with resident characteristics and needs in both supportive living and LTC to ensure care requirements are met. The large discrepancy between full-time staff in supportive living (69.9%) and LTC (25.7%) in this study further calls into question the impact of continuity of care in these settings. Although this study cannot speak to the impact of these organizational features on quality of care in this sample, evidence suggests that staffing continuity is important for ensuring optimal care and health outcomes (Castle and Engberg 2005).

There were also similarities between the supportive living and LTC groups. A large number of the healthcare aide workforce in both groups was between the ages of 30 and 50, most were female, almost all had completed high school and English was a first language for less than one-third in both settings. Among residents, in general, the distribution of resident severity was shifted further to the severe extreme in LTC compared to supportive living; however, much of the lower severity categories had important overlap. For example, 28.1% of supportive living residents and 33.7% of LTC residents had moderate cognitive impairment. Although more residents in supportive living (71.2%) were medically stable than in LTC, nearly 40% were medically stable in LTC homes. Overlapping resident characteristics suggests that many of the care activities in both types of homes will be similar. Given these similarities, supportive living, a relatively new and under-researched area in Canada, may benefit from some of the research and experiences from LTC.

The relatively young and less experienced workforce in supportive living, compared to LTC, has implications for facility administrators and policy makers. Research has found that years of experience is associated with clinical expertise and with improved health outcomes among nurses (Heinz 2004). In supportive living, where there is a high proportion of residents with mild or moderate cognitive impairment, younger and less experienced healthcare aides may have fewer skills or abilities to manage the complex needs of these residents. In LTC facilities, where there is a high proportion of residents with dependence in ADLs, an older workforce is vulnerable to declining health and increased physical and mental strain from the demands of care work (Jeffs et al. 2014). Retirement resulting in a loss of institutional memory can have a negative impact on healthcare settings (Hart 2007). Retirements may also lead to staff shortages, creating further challenges in LTC facilities (Hussein and Manthorpe 2005). LTC administrators should be cognizant of the aging workforce and implement strategies to ease the burden of these transitions.

Although a profile of Canadian LTC residents has been published (Estabrooks et al. 2013), few Canadian studies have compared the residents of LTC facilities with those living in other accommodations (Poss et al. 2017; Strain et al. 2011). In Ontario, a cross-sectional study of administrative databases compared residents in LTC facilities with residents receiving home care services in private homes and retirement homes during 2014 (Poss et al. 2017). That study reported higher levels of cognitive impairment, higher levels of depression, and greater dependence in ADLs in LTC residents compared to those in private homes or retirement homes (Poss et al. 2017). Similar findings for cognitive impairment and ADLs were found when comparing LTC residents to home care clients across four Canadian provinces and one Canadian territory (Hirdes et al. 2011). Varying types of alternative accommodation across provinces make interprovincial comparisons challenging; however, comparing the findings of the current study to those of the Alberta Continuing Care Epidemiological Studies (ACCES) study may help to understand how services may have evolved in Alberta over time (Strain et al. 2011). Comparisons across care settings and provinces are only possible when comparable data are gathered systematically. We recommend the adoption of national reporting standards in supportive living homes, as is the practice in LTC homes, to enable future comparisons between supportive living and LTC. Future longitudinal research is indicated comparing supportive living and LTC structures and processes, which will deepen our understanding of the quality of care received across service settings.

In Alberta, the one-year ACCES cohort study examined the health and social needs of clients, the mix of services provided, and health outcomes in LTC and supportive living facilities between 2006 and 2009 (Strain et al. 2011). For the 59 participating supportive living facilities in the ACCES study, the staffing mix of healthcare aides and Licensed Practical Nurses was similar to that for the 59 participating LTC facilities; however, there were more on-site registered nurses in LTC facilities (98% of homes) compared with supportive living facilities (7% of homes). This staffing mix was comparable to that in our study. In contrast, characteristics of the supportive living resident participants

in the ACCES study differed from those in our study. Of the 1,089 supportive living residents in the ACCES study, 42% were independent in ADLs; while 59% of supportive living residents in our study were in the most independent group for ADLs. Of the 1,000 LTC residents in the ACCES study, 5% were independent in ADLs; which is comparable to those in our study (3%). More supportive living residents in the ACCES study had intact cognition than those in our study (32% in the ACCES study compared with 13% in our study). The cognitive abilities of LTC residents was relatively consistent across categories between the ACCES study and this study. More supportive living residents in the ACCES study had health instability based on the RAI CHES assessment (54% in the ACCES study compared with 29% in our study). These discrepancies in the CHES scores were not apparent for LTC residents, with an almost identical proportion of 60% of residents with health instability. Although the findings of these two Alberta studies suggest an evolution in the characteristics of supportive living residents from 2006 to 2014, characteristics of LTC residents appear relatively stable. Future research is indicated to assess changes in resident characteristics and staffing mix over time in both supportive living facilities and LTC to ensure optimal use of resources.

This study has limitations that warrant discussion. Although only one urban area was sampled, and convenience sampling was used to recruit residents and care staff to the study, we were able to confirm that our sample of participating residents was representative of the population of residents in supportive living and LTC facilities in Alberta. We do not know if our convenience sample of staff is representative of supportive living sites; however, the demographic characteristics of LTC healthcare aides align with similar data from a larger study (Estabrooks et al. 2015). Staffing ratio data provided by managers/administrators did not distinguish between paid hours and worked hours. The actual resident to staff ratios, based on worked hours, may be higher than our data indicate. This study provides updated information on the differences between supportive living facilities and LTC facilities in Alberta, which is particularly timely given the expansion of supportive living in the 21<sup>st</sup>-century care environment.

## Conclusion

As populations age and longevity increases, the importance of supporting older people in their communities is needed not only to accommodate individual preferences and service needs but also to contain healthcare costs. The emergence of the new supportive living care environments in Alberta is aligned with the Alberta government's vision, first articulated in the Broda Report of 1999, to develop "responsive services and settings" to achieve quality living for an aging population. This study has highlighted significant differences in the characteristics of supportive living and LTC settings in Alberta. These differences align with the intended policy direction of the provincial government; however, we do not know if residents' needs are being met in these environments. Further investigation is required to deepen our understanding of evolving supportive living environments.

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# State of the Evidence for Emergency Medical Services (EMS) Care: The Evolution and Current Methodology of the Prehospital Evidence-Based Practice (PEP) Program

## État des données pour les services médicaux d'urgence (SMU) : évolution et méthodologie actuelle du programme de Soins préhospitaliers fondés sur les preuves (PEP)



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## Abstract

*Background:* Emergency medical services (EMS) leaders and clinicians need to incorporate evidence into safe and effective clinical practice. Access to high-quality evidence, and the time to synthesize it, can be barriers to evidence-based practice. The Prehospital Evidence-Based Practice (PEP) program is an online, freely accessible, repository of critically appraised evidence specific to EMS. This paper describes the evolution and current methodology of the PEP program.

*Methods/design:* The purpose of PEP is to identify, catalog and critically appraise relevant studies. Following regular systematic searches, two trained appraisers critically appraise included studies and assign a score on three-point level of evidence (LOE) and direction of evidence (DOE) scales. Each clinical intervention is plotted on a  $3 \times 3$  (LOE  $\times$  DOE) evidence matrix, which provides a summary recommendation.

*Discussion:* The PEP program is a unique knowledge translation tool, specific to EMS. End-users can easily identify which clinical interventions are, or are not, supported by evidence.

## Résumé

*Contexte :* Les chefs et cliniciens des services médicaux d'urgence (SMU) doivent incorporer des données à une pratique clinique sécuritaire et efficace. L'accès aux données de haute qualité, et le temps nécessaire pour les synthétiser, peuvent être des obstacles à une pratique fondée sur les données probantes. Le programme de Soins préhospitaliers fondés sur les preuves (PEP) est un dépôt, en ligne et gratuit, de données propres aux SMU et évaluées de façon critique. Cet article décrit l'évolution et la méthodologie actuelle du programme PEP.

*Méthodes/concept :* L'objet du PEP est de repérer et d'évaluer de façon critique les études pertinentes. Suites aux recherches systématiques régulières, deux évaluateurs formés évaluent de façon critique les études incluses et leur attribuent des notes, selon une échelle à trois niveaux, pour le niveau des données (LOE) et pour la direction des données (DOE). Chaque intervention clinique est répartie sur une matrice de données  $3 \times 3$  (LOE  $\times$  DOE), qui fournit une recommandation sommaire.

*Discussion :* Le programme PEP est un outil unique pour la transposition des données, propres aux SMU. Les utilisateurs finaux peuvent facilement repérer quelles interventions cliniques sont, ou ne sont pas, appuyées par des données probantes.

## Background

As with other parts of the healthcare system, emergency medical services (EMS) leaders, medical directors, and clinicians strive to deliver high-quality, safe care consistent with best practice. This is dependent on easily accessible and accurate guidelines that are grounded on the best quality relevant evidence available. This is based on the principles of evidence-based medicine (EBM), which provides a framework for clinicians to determine whether interventions are effective and suitable for use in their practice (Sackett et al. 1998). The theory of EBM can guide the development and implementation of structures and processes to access, appraise, and integrate research evidence into practice (Sackett et al. 1998).

Barriers to effective EBM are present in EMS, as they are in other parts of healthcare. These include: accessing and using the most up-to-date evidence at the point of care is often challenging for clinicians; and there are limited resources dedicated to EBM and knowledge translation (KT), including organizational capacity to collect and appraise research (Ellen et al. 2014). There are several barriers that are highlighted in the EMS setting, including: many EMS patient interactions are of an urgent nature, limiting opportunity for EMS clinicians to search for or refer to resources; wading through the growing body of research and determining what is relevant to EMS can be challenging and time-consuming; EMS clinicians often have limited training on literature searching and evidence appraisal; the evidence base for EMS is still maturing, making the synthesis and application more challenging (Cone 2007). Clinical interventions used in the EMS setting are frequently the result of studies conducted in other settings such as emergency departments, operating rooms and intensive care units (Bigham and Welsford 2015, Cone 2007). Finally, operationalizing the relevant evidence into EMS can be a challenge. Factors such as system design, scope of practice, logistics of deployment, and of course cost, can delay *knowledge to action* (Graham et al. 2006; Jensen et al. 2013).

The Prehospital Evidence-Based Practice (PEP) program strives to overcome these barriers by ensuring access to an online, freely available, continuously updated EMS evidence synthesis repository (Jensen et al. 2009). The primary objective of PEP is to systematically identify, catalog and appraise relevant studies, then provide a general recommendation level for each EMS clinical intervention. The evidence-based recommendation levels can be used to guide changes in EMS practice and in the development of clinical practice guidelines (CPGs) or protocols (Jensen et al. 2009; Jensen and Dobson 2011; NASEMSO 2017). The secondary objective of PEP is to identify gaps in the body of research informing EMS practice, thus guiding researchers on where to direct their efforts.

As the implementation science literature has developed, the methods used in PEP have evolved since its inception to become more rigorous and systematic, to improve validity and reduce potential bias. This report is a detailed description of the PEP methodology and its evolution over 20 years. Although PEP is primarily designed for EMS decision-makers, it has applicability beyond this context. PEP provides evidence on the design of systems of care for trauma, as well as cardiac and stroke care among others. The PEP program can serve as an example of how evidence can be effectively collected, appraised, and shared within other healthcare sectors.

### *Program history*

The PEP program was initiated in 1998 by the Dalhousie University Department of Emergency Medicine, Division of Emergency Medical Services, in collaboration with Nova Scotia Emergency Health Services (EHS) (PEP 2018) (Table 1). The initiation of PEP occurred in a time when large gaps in the EMS body of knowledge were identified and accepted practices were coming into question (Delbridge 2002). These were highlighted in an often-cited manuscript on the “scanty science of prehospital emergency care” (Callaham 1997). Its inception aligned with the launch of the first North American EMS peer-reviewed journal. Alongside this movement toward more rigorous EMS science, members of our team (DP, EC) realized the importance of cataloguing and appraising the existing body of knowledge on EMS care and that this knowledge base was comprised of multiple forms of evidence (not only randomized controlled trials) (Petrie 1998).

Initially, the primary purpose of PEP was to create an efficient mechanism to synthesize evidence for the paramedic protocols that were required in the newly established Nova Scotia provincial EHS system. It was meant to be a common resource for medical directors in the process of protocol development and a baseline from which EMS researchers could target priority areas (Petrie et al. 2002). From there, PEP quickly expanded to include interventions administered within any Canadian EMS system, and subsequently, to address EMS clinical care in other locations around the world with similar systems to North American EMS. PEP was designed to be open access to seek constructive criticism (Petrie et al. 2002).

### *PEP design*

The PEP process has been adapted from other established appraisal methodologies including the Centre for Evidence Based Medicine (CEBM 2015) and Canadian Task Force Guidelines (CTFPHE 1988). Systematic review methodologies are integrated into the PEP process. PEP searches and reviews are conducted according to a pre-specified topic calendar (Table 2), repeated annually.

### *PEP categories*

The PEP database and website are structured by nature of complaint and clinical presentation (e.g., hypoglycemia) as the main categories, and EMS interventions (e.g., glucagon) listed under each condition as sub-categories (<https://emspep.cdha.nshealth.ca/TOC.aspx>). Clinical interventions include assessments (e.g., 12-lead ECG and clinical decision rules), treatments (e.g., oxygen) and dispositions (e.g., direct [transport] to percutaneous intervention (PCI) [centre], treat and release). Related research studies are listed under each clinical intervention. Previously, the clinical conditions and interventions listed in PEP were based on the treatment algorithms of the local EMS service, EHS Nova Scotia. Over time, there has been a transition from evidence informed linear protocols to evidence flexible CPGs. The current iteration of PEP focuses on clinical presentation categories and interventions developed by reviewing approximately 20 other EMS systems protocols. More clinical conditions and intervention categories were added as PEP expanded to address the full breadth of EMS

clinical care delivered across Canada. Currently, PEP includes 34 clinical conditions and 684 interventions (as of January 26, 2018). Studies are organized under the relevant intervention categories, appearing under more than one intervention category if the study examined more than one intervention. If a study includes an intervention not currently evaluated in PEP, senior appraisers will discuss if the intervention should be added. This is determined by consensus and considers current and future interventions used in a paramedic-based EMS model. Studies that suggest a unique recommendation for the critical care transport (CCT) environment are placed in separate intervention categories. An example is rapid sequence induction – CCT ([https://emspep.cdha.nshealth.ca/LOE.aspx?VProtStr=Medication for Airway Management&VProtID=229](https://emspep.cdha.nshealth.ca/LOE.aspx?VProtStr=Medication%20for%20Airway%20Management&VProtID=229)). Other recently added clinical condition categories include EMS-delivered palliative care (<https://emspep.cdha.nshealth.ca/LOE.aspx?VProtStr=Agitation&VProtID=251>).

### *Search strategy*

Systematic searches are conducted monthly in a single citation database, PubMed. PubMed was chosen because of its extensive collection of 28 million citations and because it captures several of the main EMS and emergency medicine journals (US National Library of Medicine 2018), accessed on January 26, 2018. The database is searched for studies published in English that meet the inclusion criteria in order to ensure an expeditious and feasible process for regular PEP updates while maximizing the capture of relevant research. While PubMed houses a large proportion of the relevant published research, we also acknowledge that this could introduce bias in terms of only identifying research that is available within this database. Search strings are developed using Medical Subject Headings (MeSH) and title/abstract key words. Search strategies are developed following a Population, Intervention, Comparison, Outcome (PICO) format. The population search includes a string of EMS search terms in most cases (see Appendix 1, available at <https://www.longwoods.com/content/25548>). Filters, Comparison and Outcome terms, and the EMS search string, may be omitted if the initial search strategy returns few articles. Specific searches are created for each clinical topic. Search strategies are developed by (1) identifying the most appropriate MeSH term for key words, (2) reviewing related terms and locating them within the term trees, (3) hand-searching the reference lists of current studies already in PEP for index terms, and (4) including Title (TI) and Abstract (AB) terms when the MeSH terms do not adequately represent the condition and intervention. A second senior appraiser reviews search strategies for the use of Boolean and proximity operator, subject headings, natural free text language, limits, and the use of filters, prior to execution. For searches that have been conducted previously with the same search strategy, the date range is limited to two years, unless the strategy was identified as requiring improvement. In some cases, study method filters may be used to refine searches. Searches are tested for their ability to identify seminal articles. Finally, results are imported into reference management software (Refworks, Ann Arbor, MI) and duplicates removed. Search strategies have been developed with the assistance of a medical librarian.

**TABLE 1.** History of major changes and evolution of the PEP program

Year	Change	Description/rationale
1998–2000	Genesis of PEP program	PEP was developed following an EMS Agenda for the Future – Making it a Reality conference on May 21, 1998, in Alexandria, Virginia. A major barrier identified at this meeting was the lack of an EMS evidence repository. PEP's goal was to collect and appraise the existing EMS literature (DP) and was built around the renewal of Nova Scotia EMS protocols (EC). The initial section editor panels were mostly emergency physicians who were members of the Royal College Physicians and Surgeons of Canada and from seven provinces across Canada.
2000	Database displayed online	Use technology to expand reach of the project and streamline appraisal communication.
2001	First PEP coordinator	First PEP coordinator assigned to program (CD) to ensure sustainability.
2003–2009	Expanding appraisers from only emergency physicians to include paramedics, nurses, researchers, students and others	To include and engage all members of the EMS community.
2011	Replacing COR table with 3 × 3 table	Assigning a COR to an intervention required much subjective judgment. Now, appraisers and senior editors can assess the distribution of level and direction of related studies to determine best spot on 3 × 3 table for an intervention.
2012	Expanding appraiser group from only Canadians to those from locations around the world	To expand the exchange of ideas and collaboration with other innovative systems so that we can communally benefit from the knowledge.
2012	Appraisers all assigned articles to appraise from the scheduled topic, rather than having an assigned 'section'	Initially, section editors were assigned to specific topic areas (e.g., cardiac arrest). To encourage ongoing engagement of all members of the appraisal team, the choice was made to distribute articles evenly amongst the team.
2013	PEP recommendations integrated into the provincial CPGs	To marry the clinical practice officially with the evidence.
2014	Designating specific clinical interventions if CCT	The evidence for an intervention may be different if administered by standard EMS paramedics compared to CCT teams. At this point, there was enough literature that we could separate these interventions by level of care.
2014	Addition of second party appraiser step and senior appraiser team.	To increase our internal validity by increasing our rigour.
2014	Addition of palliative care/end-of-life category	There was a noted gap in ability to care for palliative patients from a clinical standpoint. In order to address this practice gap, we needed to understand the existing evidence in palliative care.
2016	List primary outcome of each study	We had feedback from our end-user group that it would be helpful to know what the study primary outcome was when making decisions about practice.

CCT = critical care transport; COR = class of recommendation; CPGs = clinical practice guidelines; EMS = emergency medical services; PEP = Prehospital Evidence-Based Practice.

### *Inclusion and exclusion criteria*

Studies are selected for inclusion by the PEP coordinator (JG), by title and abstract review for relevance. Full text articles of included studies are obtained, and it is confirmed that they meet PEP inclusion criteria (Table 3). Studies are prioritized for send-out using pre-determined criteria (Table 3). Any included studies not assigned to appraisers are retained and sent out during a catch-up month or the following calendar year. A study will be excluded if the study setting is too dissimilar from the EMS environment to inform EMS practice. These decisions are made by senior appraiser team consensus.

**TABLE 2.** PEP appraisal topic calendar

Topic (adult and pediatric)	Appraisal month
Advanced airway management, airway emergency	1
Cardiac arrest	2
Cardiac arrhythmia, chest pain	3
Altered mental state – decreased level of consciousness, stroke/CVA/TIA	4
Respiratory distress	5
Shock	6
Catch-up month	7
Trauma, acute pain, burns	8
Headache, malaise/sick, psychiatric	9
Allergic reaction, environmental emergency, EENT, end-of-life care, GI/GU/Gyne, toxicological emergency, perinatal care	10
Catch-up months	11/12

CVA = cerebral vascular accident; EENT = eyes, ears, nose and throat; GI/GU/Gyne = gastrointestinal, genitourinary and gynecologica; PEP = Prehospital Evidence-Based Practice; TIA = transient ischemic attack.

**TABLE 3.** PEP inclusion and exclusion criteria, and criteria to prioritize included articles for primary appraisal assignment

Inclusion criteria	Exclusion criteria	Criteria to prioritize included articles for appraisal assignment
Studies of live patients	Animal studies*	Study conducted in EMS setting or by EMS clinicians
Registry/retrospective studies	Opinion articles/editorials	New publication
Simulation studies	Descriptive epidemiological reports	High-quality study
Systematic reviews	Surveys	Pediatric or critical care transport
	Narrative and scoping reviews	'Landmark' study or referred by appraiser or PEP user
		Canadian study

\*Animal studies may be considered for inclusion if there is little other evidence available; decision is made by consensus of the senior appraiser team. EMS = emergency medical services; PEP = Prehospital Evidence-Based Practice.

## Evidence appraisal

PEP appraisers include physicians, paramedics, nurses, and researchers trained in critical appraisal. Appraisers are from several countries and include CCT. Appraisers are oriented to the PEP process and updated regularly. Appraisals are completed using online forms, which are logged in the PEP database upon submission. The purpose of the primary appraisal is to review each study and assign a level and direction of evidence for the intervention(s) studied. Included studies are scored on a three-point level of evidence (LOE) scale, based on study design and quality (Table 4) and a three-point colour-coded direction of evidence (DOE) scale, which indicates if the study is supportive, neutral, or opposing for the use of the intervention in EMS clinical practice (Table 5). PEP senior appraisers perform secondary review on every submitted appraisal.

**TABLE 4.** Level of evidence

Level	Criteria
Level 1	Evidence obtained from adequately powered, properly randomized controlled trials on live human participants or systematic reviews or meta-analysis that contain only randomized controlled trials. No pilot studies to be included here.
Level 2	Evidence obtained from adequately powered, non-randomized studies with a comparison group of live human participants or systematic reviews of non-randomized studies with a comparison group. Prospective or retrospective registry-type studies in which comparisons are made; cohort and case control studies are included here.
Level 3	Evidence from studies with no randomization and no comparison group, simulation/manikin studies and animal studies. Pilot studies and underpowered studies are included here.

**TABLE 5.** Direction of evidence

Colour	Direction of evidence
Green	Direction of results of this study are supportive for the use of this intervention
Yellow	Direction of the results of this study are neutral for the use of this intervention
Red	Direction of the results of this study oppose the use of this intervention
White	Direction of results of this study are not yet evaluated

### *Primary outcomes of included studies*

Appraisers abstract the primary or main outcome reported in each study. If the primary outcome is not explicitly stated, the first reported result is used. This is presented on the PEP website (PEP 2018). The DOE is determined by reviewing the results for the identified primary outcome of included studies.

### *Level of evidence*

The PEP three-point LOE scale (Table 4) is a similar hierarchy of evidence used in other grading schemes, namely Centre for Evidence-Based Medicine (CEBM 2015). The LOE was developed to be useful and pragmatic for all clinicians (and experience levels) who accessed the database. The initial grading scheme took into account the type of evidence being evaluated and research experience of the appraisers. Both are important factors that inform decisions on the selection of a grading system (Baker et al. 2011). The LOE does not change if non-EMS practitioners perform the intervention, nor does it change if conducted in other environments beyond EMS. The LOE scale is specific to the study design and quality so is the same throughout the PEP database, regardless of the intervention category under which the study is categorized. The three-point LOE scale can be easily interpreted when there is high-quality evidence (e.g., adequately powered randomized controlled trials); however, it poses challenges when the evidence is of lower quality. For example, underpowered randomized controlled trials are scored Level III, the same category as simulation research or studies with no comparison group. The three-point LOE allows for consistency between appraisers and addresses research included in PEP in a way that makes sense from a clinical point of view.

### *Direction of evidence*

A major change to PEP involved moving away from providing a class of recommendation (COR) to a DOE. The COR was a five-level scale ranging from A (good evidence to support procedure or treatment) to D (evidence to support that the procedure or intervention should not be used) and I (indeterminate). The more recent DOE scale provides improved clarity for the reader by both its words and colour. At a similar time, the American Heart Association was also moving away from their COR scale.

The DOE indicates if the study findings for the primary outcome are supportive (green), neutral or unclear direction (yellow) or opposing (red). One study may be listed under several clinical interventions and may have different DOEs for each intervention. For example, a study examining intubation versus bag mask ventilation in out-of-hospital cardiac arrest may have opposing DOE for intubation (see Fouche et al. 2014 under 'Direct Laryngoscopy [No airway reflexes]': <https://emspep.cdha.nshealth.ca/LOE.aspx?VProtStr=Intubation&VProtID=226>) and supporting DOE for basic airway management ('BVM': <https://emspep.cdha.nshealth.ca/LOE.aspx?VProtStr=Alternative Rescue Airway Management&VProtID=225>). Studies in which the results for the primary outcome find no difference between the interventions studied may have a supportive DOE applied for each if both were effective, i.e., this is not necessarily "neutral" (conversely both could be opposed if both were harmful). The neutral DOE is not used to indicate that both interventions perform equally when both were beneficial or harmful. Studies are assigned an opposing DOE if the results of the study demonstrate the intervention could negatively impact outcomes. When assigning DOE, the primary appraiser considers generalizability to EMS settings and practitioners. If a setting is substantially different from EMS, but the article is still somewhat informative, the appraiser will assign DOE neutral if it is likely that the application of the study intervention could lead to significantly different clinical outcomes in the EMS setting.

### *Second party appraisal*

Senior appraisers perform a second party review of primary appraisals. Disagreement between primary and secondary appraisal (primary outcome, LOE, DOE) is resolved by consensus at the monthly senior appraisers meeting.

### *Evidence recommendation*

Once all studies are appraised and reviewed, the senior appraiser team plots interventions for each clinical condition on  $3 \times 3$  evidence matrix (LOE  $\times$  DOE) (Table 6). The senior appraiser consensus decision on  $3 \times 3$  evidence matrix placement takes into account the number of studies, LOEs, DOEs, effect sizes, relevance, current practice, and applicability.

### *PEP KT*

In 2017, PEP began obtaining website analytics to identify patterns of use. PEP receives over 1,700 hits per month, with most occurring from desktop computers (84%). PEP end-users

have come from each Canadian province and territory, as well as the US, South America (Brazil), Europe (UK), Africa (South Africa), Asia (Thailand and Taiwan) and Australia.

In 2017, the PEP editors also sought feedback from end-users via an electronic survey, focus groups, and teleconferences with end-users and primary appraisers. Feedback was received from 52 end-users from seven provinces. The comments were mostly supportive of the current program output, including the  $3 \times 3$  evidence matrix and list of appraised evidence. Respondents reflected an interest to have more information presented on individual studies (e.g., intervention-related adverse events, patient- versus process-related outcome, setting).

PEP has been involved in several KT initiatives. PEP is a KT product; intending to get the evidence straight and get the evidence used (Cone 2007). PEP's approach is simple; making it easy to apply, understand and present; however, it may be too simple to include a comprehensive review for the risk of bias and other methodological limitations of each study (Atkins et al. 2004). All clinicians should be able to use PEP regardless of their EBM experience. The PEP program has been presented at several national (CAEP) (Carter et al. 2016) and international conferences (Carter et al. 2015). More recently, PEP was presented as a plenary at the National Association of EMS Physicians annual meeting in January 2018 and PEP continues to have a standing update during the conference. Senior PEP editors and appraisers have constructed an online EBM course and have instructed an in-person EBM program in five provinces. In this program, paramedics are taught the fundamentals of EBM, including how to use PEP to inform their practice. PEP has a social media presence managed by the PEP KT coordinator. One of PEP's main KT successes has been engaging the PEP appraiser team (comprised of over 40 national and international appraisers). The PEP appraisers have a vested interest in the program and have integrated PEP into their own services simply by being involved. PEP has shared information with teams in Australia and the UK, and have been cited in the US National Clinical Guideline documents (NASEMSO 2017). The PEP editors continue to seek and encourage collaboration with other EBM groups in EMS around the world.

**TABLE 6.** An example of a  $3 \times 3$  evidence matrix – intubation\*

Level	Supportive (green)	Neutral (yellow)	Against (red)	Not yet graded (white)
<b>1 (strong evidence exists)</b>		<ul style="list-style-type: none"> <li>• Direct laryngoscopy (no airway reflexes)</li> <li>• Direct laryngoscopy (with airway reflexes)</li> <li>• Lighted stylet</li> <li>• Nasotracheal intubation</li> <li>• Optical (non-video) visualization (e.g., Airtraq)</li> <li>• Video visualization (e.g., Glidescope)</li> </ul>		<ul style="list-style-type: none"> <li>• Passive oxygenation during ETI</li> </ul>
<b>2 (fair evidence exists)</b>	<ul style="list-style-type: none"> <li>• Laryngeal manipulation</li> </ul>	<ul style="list-style-type: none"> <li>• Bougie</li> <li>• Intubating LMA</li> <li>• Securing tube</li> </ul>	<ul style="list-style-type: none"> <li>• Cricoid pressure</li> </ul>	
<b>3 (weak evidence exists)</b>		<ul style="list-style-type: none"> <li>• Digital intubation</li> </ul>		

ETI = endotracheal intubation; LMA = laryngeal manipulation.

\*From September 1, 2015. Source: PEP 2018: Intubation (<https://emspep.cdha.nshealth.ca/LOE.aspx?VProtStr=Intubation&VProtID=226#Direct>).

## Discussion

This manuscript describes the methodology and evolution of the PEP program. The PEP program is the only known openly available repository of appraised research evidence specific to EMS care. PEP is a continuously updated KT initiative, providing evidence synthesis for EMS clinical interventions, which can in turn be used by EMS guideline developers and system leaders to inform local EMS CPGs and protocols. Its open format enables PEP to be “peer reviewed” by site users (Petrie et al. 2002). The annual PEP topic review could decrease the lag time between the recognition of scientific advancement to application into clinical care via evidence inclusion into local CPGs or protocols (Province of Nova Scotia 2015; Vernooij et al. 2014).

The PEP methods seek to balance the requirements for a rigorous and transparent process with a practical need for rapid evidence synthesis. The monthly process includes execution of search strategies and subsequent selection, appraisal, blinded peer review and recommendation scoring. This is possible with PEP’s pragmatic methodological design. There are many other evidence appraisal methods, each with advantages and disadvantages (Atkins et al. 2004), some of which are continuously re-developed to overcome identified shortcomings. The Grades of Recommendation, Assessment, Development, and Evaluation (GRADE) approach has been widely implemented (Guyatt et al. 2008), including into the International Liaison Committee on Resuscitation (ILCOR) evidence review process (Olasveengen et al. 2017). GRADE evaluates evidence for specific questions by outcome, which differs from PEP, which evaluates all related evidence per specific intervention. The GRADE approach is comprehensive and the recommendations are made with clear terms, such as ‘strong recommendation’. Similar to other appraisal schemes, the use of GRADE recommendations to inform CPGs when the science is elusive can be challenging (Guyatt et al. 2012; McGregor 2014). Others are more complex. The Australian National Health and Medical Research Council (NHMRC) uses an evidence matrix that lists five components that should be considered when grading evidence: (1) the evidence (the number of studies, LOE, and quality of studies), (2) consistency of study results, (3) potential clinical impact, (4) generalizability, and (5) applicability (NHMRC 2015; Cone et al. 2012). The guiding philosophy of PEP was that the evidence grading system should be as simple as possible and still enable valid judgment of quality and direction of evidence. This enables PEP recommendations to be easily used by clinicians and policy makers. The recent introduction of abstracting primary outcomes is intended to provide more granular information for PEP-users on how the interventions were measured.

### *Applicability of PEP to the Health System*

As many parts of the healthcare system interact with EMS, the findings in PEP are applicable to those settings. Evidence-based approaches can be used for decisions and interventions such as prehospital cardiac catheterization lab activation, bypass direct to a percutaneous coronary intervention centre, direct transport to pediatric tertiary care, direct transport to a trauma centre, palliative care collaboration, stroke, and sepsis care. PEP identifies gaps in the literature such as we see with EMS palliative care.

The Canadian EMS setting is the reference point, so many of our recommendations may not be generalizable to all EMS (e.g., interventions used by EMS physicians providing on-scene care in other countries may not be included). Evidence that PEP shortens the knowledge to practice gap is mostly anecdotal. A “How to Cite” reminder was recently published on the PEP website and publishing the methods will serve as a foundation document to build upon identifying how widely PEP is used to inform EMS systems. Future work will focus on optimizing how PEP accounts for risk of bias, consistency, directness, and precision of the evidence. There are also opportunities to partner with others interested in EMS EBM. PEP aims to be the foremost evidence resource informing EMS by focusing on its strength of being a repository of critically appraised evidence. Collaborations with clinician groups, EMS guideline developers, researchers and other stakeholders will ensure that this body of appraised evidence can be used to inform patient care.

## **Conclusion**

PEP is an online, freely accessible, repository of appraised EMS evidence. Literature is appraised using a modified grading system for level and direction of evidence with appraisals conducted by active EMS stakeholders. This evidence is summarized into easily interpreted evidence tables, which serve as recommendations. PEP project rapidly translates and disseminates EMS evidence, which can be useful for clinicians and policy makers. PEP is an important tool for moving the culture of evidence-based practice forward in EMS.

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**Availability of Data and Material:** The Prehospital Evidence-Based Practice (PEP) website is available at <https://emspep.cdha.nshealth.ca/>. Please contact [ems@dal.ca](mailto:ems@dal.ca) for more information. The primary appraisals are not publicly available due to the structure of the database; however, they are available on reasonable request. Individual study LOE, DOE and primary outcome are available on the website.

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# Stakeholder Views on Solutions to Improve Health System Performance

## Point de vue des parties prenantes sur les solutions visant l'amélioration de la performance du système de santé



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### Abstract

*Context:* Significant reforms are needed to improve healthcare system performance in Quebec. Even though the characteristics of high-performing healthcare systems are

well-known, Quebec's reforms have not succeeded in implementing many critical elements. Converging evidence from political science models suggests stakeholders' preferences are central in determining policy content, adoption, and implementation.

*Objective:* To analyze whether doctors', nurses', pharmacists' and health administrators' preferences could explain the observed inability to implement known characteristics of high-performing healthcare systems.

*Design:* A questionnaire on various propositions identified in the scientific literature was sent to 2,491 potential respondents.

*Results:* Overall response rate was 37%. There was considerable consensus on identified solutions to improve the healthcare system. Resistance was observed in two major areas: information systems and changes directly affecting doctors' practice. The groups' positions cannot explain the inability to implement important characteristics of high-performing systems. The findings raise new questions on the actual sources of resistance.

## Résumé

*Contexte :* D'importantes réformes sont nécessaires pour améliorer la performance du système de santé au Québec. Même si on connaît bien les caractéristiques des systèmes de santé performants, les réformes entreprises au Québec n'ont pas permis la mise en place de plusieurs éléments essentiels. Les données provenant des modèles en science politique suggèrent que les préférences des parties prenantes jouent un rôle central dans l'élaboration du contenu, dans l'adoption et dans la mise en œuvre des politiques.

*Objectif :* Analyser dans quelle mesure les préférences des médecins, infirmières, pharmaciens et administrateurs des institutions de santé peuvent expliquer l'incapacité à mettre en place les caractéristiques propres aux systèmes de santé performants.

*Méthodes :* Un questionnaire portant sur plusieurs propositions identifiées dans la littérature scientifique a été envoyé à 2 491 répondants potentiels.

*Résultats :* Le taux de réponse général était de 37 %. Il y a un fort consensus sur les solutions identifiées pour améliorer le système de santé. On observe une résistance dans deux secteurs principaux : les systèmes d'information et les changements qui affectent directement la pratique des médecins. La position des groupes ne peut toutefois expliquer l'incapacité à mettre en place les caractéristiques essentielles aux systèmes performants. Ces résultats soulèvent de nouvelles questions quant aux sources réelles de la résistance.

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## Introduction

Despite consensus that significant reforms are needed to improve Canadian healthcare systems' performance, important characteristics of high-performing healthcare systems have been implemented slowly or even not at all. One plausible explanation is the potential

disagreement between or within stakeholder groups having an influence on health policies. In this article, we analyzed doctors', nurses', pharmacists' and health administrators' preferences regarding a set of propositions aiming at improving the healthcare system.

Many characteristics of high-performing healthcare delivery systems are well known and consensual (Baker et al. 2008; Casalino et al. 2003; Contandriopoulos and Brousselle 2010; Feachem et al. 2002; Ham et al. 2003; Katz et al. 2009; McMurchy 2009; Mechanic 2008; Robinson et al. 2004; Russell et al. 2009; Shortell et al. 2005). These include a system-wide focus on primary care implemented through integrated delivery systems (IDSs) responsible for a given population, in which doctors are remunerated in other ways besides pure fee-for-service. Clinical and managerial practices should be based on strong integrated information systems at the individual, clinical, organizational and population levels. IDSs should also be accountable at both individual and population levels.

In Quebec, all publicly appointed commissions since the beginning of Medicare (Castonguay-Nepveu Commission 1967–1970; Clair Commission 2000; Rochon Commission 1988) have identified similar characteristics and recommended policy options consistent with scientific evidence. In Canada, the Romanow Commission (Romanow 2002) also drew on scientific evidence to ensure the healthcare system's sustainability and improve timely access to good-quality care by recommending the development of an accountable, primary care-centred system relying on interprofessional teams and robust information systems. The same recommendations have appeared in other national and provincial commissions' reports (Drummond 2012; Fyke 2001; Health Council of Canada 2008; Ontario HSRC 2000; Romanow 2002).

However, analysis of reforms implemented in Quebec during the past 20 years suggests that, although they led to important structural changes, many critical elements were systematically ignored – such as revising doctors' compensation models, increasing access to primary care, and implementing an integrated information system – and consequently the desired results were not achieved (Contandriopoulos and Brousselle 2010). The convergence of scientific evidence and public commission recommendations shows that the obstacle to implementing reforms is neither lack of evidence nor ignorance about solutions (Lewis 2007). The logical conclusion is that the main challenge lies in translating recommendations into policy and implementing policy in actual delivery system structures and practices. Previous research (Contandriopoulos and Bilodeau 2008; Contandriopoulos and Brousselle 2010; Contandriopoulos et al. 2007) suggests most such obstacles arise from different interest group positions on the desirability of given policy options (Drummond 2012).

In this paper, we report on the positions of four stakeholder groups – doctors, nurses, pharmacists and health administrators – regarding a set of policy propositions supported by scientific writings. The objective was to examine the degree of convergence in those groups' support for various policy solutions and to identify points of resistance that might explain the observed inability to implement evidence-based healthcare system policy changes.

## Methods

This article reports on an anonymous survey that was part of a sequential qualitative–quantitative mixed-method study (Creswell and Plano Clark 2011). The survey content was based on analysis of the first-phase, individual interviews with 31 people having influence on Quebec health policy (Brousselle et al. 2014), and on solutions suggested by scientific articles and the above-cited Quebec health commissions. The interviews focused on healthcare system strengths, problems, and solutions and on identifying persons with the most influence on healthcare policies.

We invited a random sample of 750 doctors, 748 nurses and 750 pharmacists to participate in the survey. Inclusion criteria were membership in a professional order and active practice status. Contact information was obtained from Quebec's College of Physicians, Order of Nurses and College of Pharmacists. All senior administrators ( $n = 243$ ) of healthcare institutions were identified through public service e-mail directories and solicited. Administrators were the CEOs (Directeur général), vice-CEO (Directeur général adjoint) and clinical directors (e.g., directeur des services professionnels, directeur des soins infirmiers, etc.) from all hospital structures in Quebec. The questionnaire was sent by e-mail or mail to these 2,491 persons between August 17 and November 24, 2015.

The questionnaire elicited the degree of agreement with a series of propositions supported by the scientific literature and endorsed by leaders in the previous interviews. It included 29 questions on seven themes: (1) healthcare system performance; (2) information systems; (3) patients' roles; (4) primary care team functioning; (5) primary care accessibility; (6) coordination between hospital and primary care; and (7) clinical appropriateness and efficiency. Each theme was introduced by a fictional case study to illustrate the proposed solutions in day-to-day practice. In a last single open question, respondents were invited to make three suggestions to the Health Minister to improve the healthcare system. We also elicited demographic and practice information. The questionnaire was developed in French and English and made available both online and in paper form.

Statements about policy proposals were strongly worded to elicit degree of agreement on a 5-point Likert scale (1 = strongly disagree, 3 = neutral, 5 = strongly agree). A neutral point was included to identify the proportion of stakeholders not polarized on the issues. Within a given theme, the proposed changes were ordered on a gradient from what we believed would be perceived as more benign or consensual measures to more invasive or drastic changes. Results are presented in this order.

The questionnaire and the survey strategy were cognitively tested with 12 respondents from the four stakeholder groups. We adapted Dillman's Total Design Method (Dillman et al. 2009) to optimize response rate; since the survey was anonymous, all potential respondents were sent reminders and a second questionnaire. Administrators and nurses were invited to answer the survey online, as we only had their e-mail addresses. French paper versions were mailed to doctors and pharmacists, with instructions for responding online if preferred, or for obtaining an English paper version. Closed questions were analyzed using SPSS 22.0.

Open question responses were independently coded by two persons. The study was approved by the Human Research Ethics Committee of the Université de Sherbrooke Hospital.

Likert scores were analyzed in two ways. In the first, the numbers of respondents in each group supporting or opposing each survey statement were analyzed to assess the distribution of opinions. For each group, each statement was then categorized according to four possibilities. If more than 60% of the respondents in the group agreed or strongly agreed with a statement, we considered it supported. Likewise, if more than 60% of the respondents in the group disagreed or strongly disagreed with a statement, we considered it opposed. If neither the “agree” and “strongly agree” nor the “disagree” and “strongly disagree” proportions showed a clear majority, and the indifferent constituted less than 15% of the total respondents in the group, then the distribution of opinion was likely bimodal. Finally, if none of the above applied, it meant respondents were more or less evenly spread and no clear consensus was apparent. Table 1 (available at: <https://www.longwoods.com/content/25547>) presents this data using a colour code to facilitate reading.

In the second analysis, we computed the Likert score means and standard deviations for each group’s answers to each question. Mean scores are usually presented as bar graphs with error bars. However, even though the data are discrete, we added a connecting line between each group’s mean score, our rationale being that the order of the questions for each theme in the survey instrument was determined by our expectation of a dwindling level of support. The connecting lines put the emphasis on the similitude or divergence between groups in the variation of the support regarding each question.

## Results

In all, 934 persons answered the survey but only 919 completed surveys were included in the analysis due to missing responses. Response rates for the final sample were: pharmacists 45%, doctors 40%, administrators 33%, nurses 26%; overall 37%. The respondent sample was generally representative of the sex, training, and location of each group’s population, except that university-trained nurses were significantly over-represented. We weighted nurses’ responses to control for this bias. A total of 774 (82%) participants answered the open question, with a mean of 3.2 solutions (range 1–12) provided per respondent.

The overall response rate of 37% is somewhat lower than observed in surveys of professionals and managers (Blais et al. 1999; Gilbert et al. 2006; Haley et al. 2000; Maheux et al. 2006; Makni et al. 2002; National Physician Survey 2007; O’Loughlin et al. 2007; Richard et al. 2005; Sicotte et al. 2002; Tremblay et al. 2009). However, if we exclude nurses, the combined response rate for the other groups falls within the range generally observed. For nurses, our rate was lower than generally observed (Faulkner and Laschinger 2008; Laschinger et al. 2008; Laschinger et al. 2009; Lehoux et al. 2006; Lucas et al. 2008; Tremblay et al. 2009). While we have no definitive explanation for the lower than expected response rate, nurses were the only group for which we had to rely mostly on e-mails as the primary contact modality.

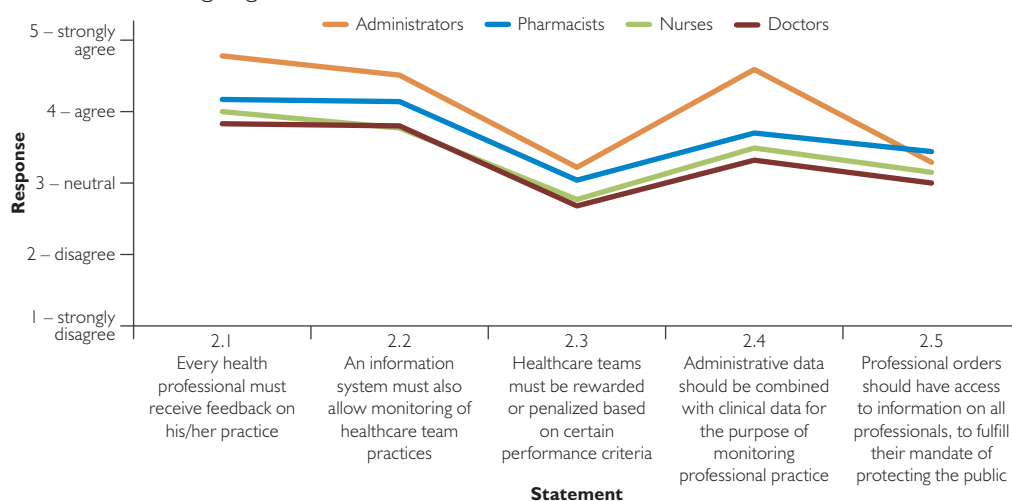
### Theme 1: Need for system improvement

The first question measured support regarding the need for general improvement in the system's performance. Results showed strong support, with all respondents (100%) agreeing Quebec's healthcare system needs improvement. The only variation was in the relative proportions of "agree" versus "strongly agree". This result tallies with the Commonwealth Fund survey for Quebec (Commissaire à la santé et au bien-être 2016).

### Theme 2: Information systems

There was strong support in all groups for the idea that all professionals should receive feedback on their practice and that information systems should make it possible to monitor healthcare team practices. A majority of respondents also agreed administrative data should be coupled with clinical data to monitor professional practice. It is noteworthy that although 56% of doctors agreed or strongly agreed, 27% disagreed or strongly disagreed. However, while respondents generally agreed feedback on clinical practice would be good at individual or team levels, there was less support for sharing this information with professional orders. The strongest support for this idea was observed among the pharmacists. Support for using clinical information systems to control incentives was even weaker, with only a minority of professionals supporting the idea and a majority of doctors disagreeing or strongly disagreeing. As illustrated in Figure 1, as statements linking clinical information to external control became stronger, support became weaker.

**FIGURE 1.** Overall agreement regarding the role and place of information systems with questions ordered in increasing degree of external control

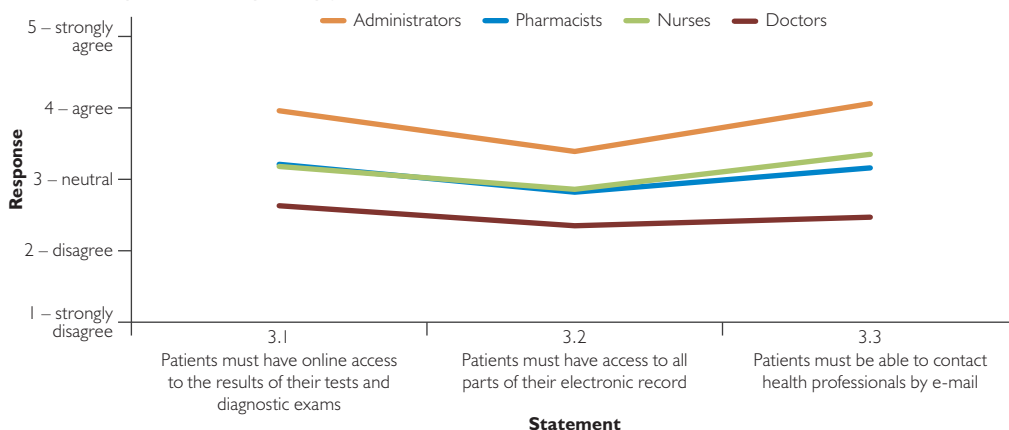


### Theme 3: Patients' roles

The first-phase qualitative interviews showed broad support for increasing patients' centrality in decision-making at individual and system levels. This tallied with pressure in this direction from professional groups, such as Choosing Wisely (<http://www.choosingwisely.org>),

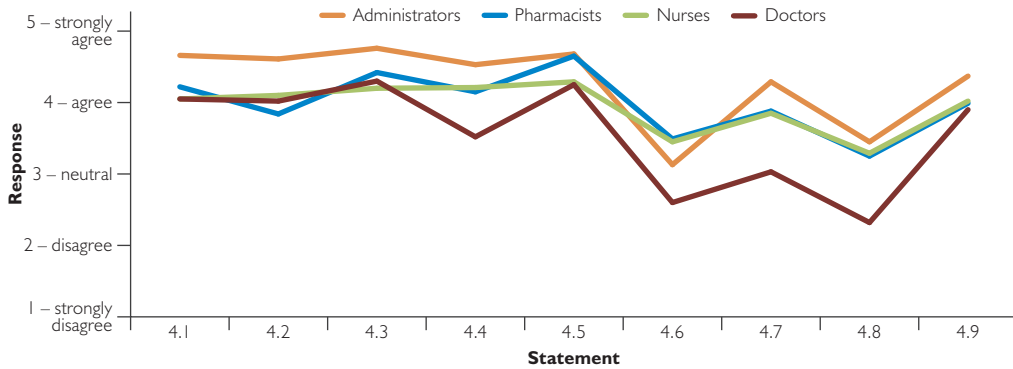
and with funding agency initiatives, such as the Canadian Institutes for Health Research (CIHR) Strategy for Patient-Oriented Research (<http://www.cihr-irsc.gc.ca/e/41204.html>). Our goal was to assess the acceptability of a greater role and more rights for patients. More specifically, we focused the questions on increasing patients' access to their clinical data and their clinicians (Figure 2). The acceptability of such a shift was rather low. More than 60% of doctors disagreed or strongly disagreed with all three proposals. Only administrators, among the four groups, clearly supported the idea that patients should have online access to tests and exams. Nurses, pharmacists and administrators were divided on this idea. When the question suggested giving patients full access to their electronic health record, only administrators supported this idea (with 58% agreeing or strongly agreeing), while other groups showed significant opposition (with 70% of doctors, 51% of nurses and 59% of pharmacists disagreeing or strongly disagreeing with the statement).

FIGURE 2. Agreement regarding patients' roles



#### *Theme 4: Primary care teams functioning*

The fourth theme focused on implementing strongly interdisciplinary primary care teams that would include doctors, nurse practitioners, clinical nurses, social workers, and other professionals, and in which doctors would be a minority of the workforce. A clear majority of respondents in each group agreed such teams would increase accessibility to services and improve care for patients with multi-morbidities, and that they should not be allowed to refuse patients with mental and drug addiction problems. Likewise, there was consensus that primary care teams should collaborate with pharmacies, implement a broader scope of practice for non-doctor professionals – on which even doctors agreed in majority (59%) – and coordinate diagnostic and specialized care for their patients. When asked whether teams should meet daily to discuss clinical cases, doctors mainly disagreed (56%); several commented that daily meetings would be too frequent. Nurses and pharmacists agreed with the proposition, while administrators were more polarized on this question (Figure 3).

**FIGURE 3.** Acceptability of strongly interdisciplinary primary care teams

- 4.1 – These interdisciplinary teams help improve access to healthcare services.  
 4.2 – These interdisciplinary teams can't choose to refuse to follow patients with mental health or substance abuse problems.  
 4.3 – These interdisciplinary teams ensure better treatment for patients with several co-morbidities.  
 4.4 – The scope of practice of non-doctor professionals must be increased.  
 4.5 – These interdisciplinary teams must work hand-in-hand with community pharmacies.  
 4.6 – These interdisciplinary teams must all meet every day to discuss their clinical cases as a team.  
 4.7 – Fee-for-service arrangements for paying doctors must be minimized to encourage interdisciplinary work.  
 4.8 – Doctors must earn less but have more resources to support their professional practice.  
 4.9 – In each interdisciplinary team, one or more professionals are responsible for coordinating diagnostic and specialized services.

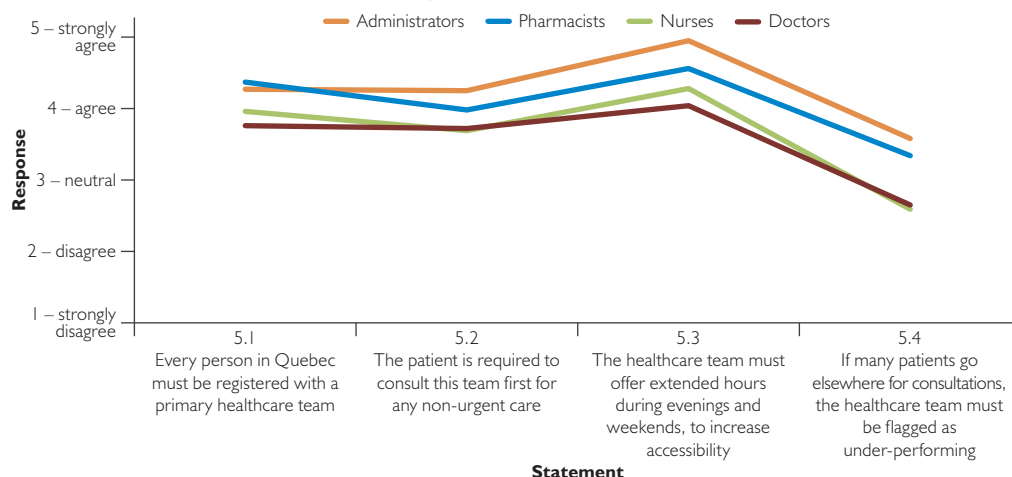
It is interesting to note that, when it came to modifying fee-for-service – the dominant doctor compensation model in Quebec – we observed similar agreement (40%) and disagreement (38%) proportions among doctors, with 21% being indifferent. Yet maintaining that model is likely to stifle interdisciplinary practice and is commonly seen as a barrier to implementing the primary care model described in the survey instrument (Mason 2016). It is interesting to note, from a policy perspective, that if those doctors declaring indifference to that issue were to change their minds and support the option, it could create the necessary conditions for a change in the way doctors are paid. There was strong support (72% of nurses and pharmacists and 91% of administrators) and almost no opposition from non-doctors to revising the doctor compensation model (only 6% to 9% of non-doctors opposing the idea). The idea of reallocating funds from doctors' compensation into more primary care resources was, on average, modestly supported by all non-doctor groups and clearly opposed by doctors.

### *Theme 5: Primary care accessibility*

The fifth theme was a continuation of the previous one but focused more specifically on primary care accessibility and patient rostering (Figure 4). Rostering patients to a primary care team was widely supported by all groups, as was the idea that patients should be required to consult this team first for non-urgent care. On the supply side, respondents strongly agreed on the desirability of extending opening hours, including evenings and weekends. However, support dropped, especially among doctors and nurses, when rostering was interpreted as a way to measure whether patients actually consulted their assigned team and to penalize teams when they did not. In other words, clinicians accepted rostering patients but were reluctant to be held accountable when patients sought care outside their rostered clinic.

## Stakeholder Views on Solutions to Improve Health System Performance

**FIGURE 4.** Acceptability of patient rostering and primary care accessibility



### *Theme 6: Coordination between hospital and primary care*

There is much evidence that optimizing patient care pathways could significantly enhance quality and efficiency. In Quebec, this idea dominated policy debates in two large-scale forced-merger laws enacted in 2004 and 2015 (Contandriopoulos et al. 2007; Québec 2003, 2015). In 2004, most hospitals, long-term care institutions (centres d'hébergement et de soins de longue durée [CHSLDs]), and community clinics were merged to create health and social services centres (CSSSs) mandated to develop geographically defined healthcare networks. However, the intended improvements in collaboration with autonomous primary care teams within those territories did not materialize. In 2015, almost all remaining autonomous hospitals and all CSSSs in each region were further merged to create 22 multisite, multi-mission care delivery institutions. Primary care structures were again not included, and no credible care-coordination mechanisms were implemented (Contandriopoulos et al. 2014). We therefore assessed support for propositions regarding sharing of responsibility and coordination of care between hospitals and primary care networks. As long as the question's formulation implied no transfer of resources or activities, all groups unambiguously supported the principle of improving coordination of hospital and primary care (Figure 5). When the question implied a transfer of activities, however, intergroup polarization increased.

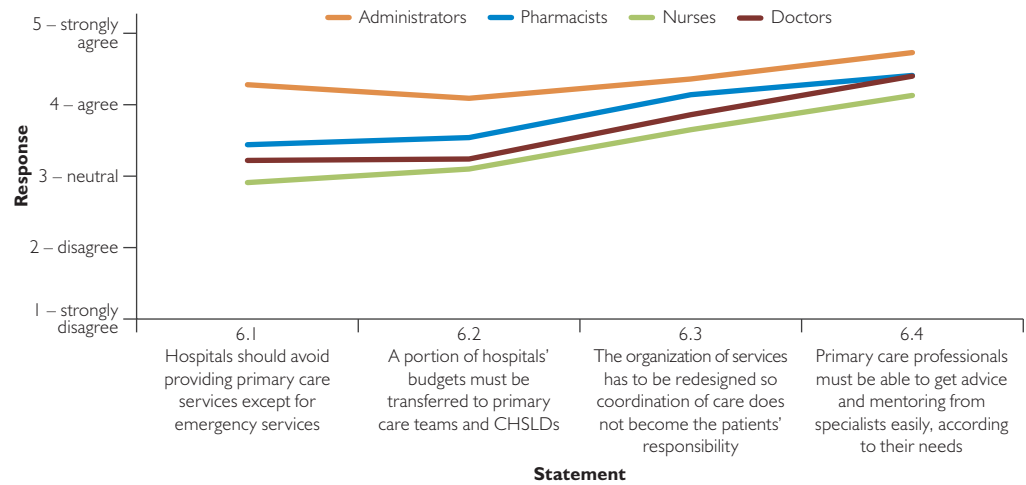
The statements that specialist doctors should support primary care teams as needed and that patients should not be left to assume the burden of coordinating their own care were both widely supported by all groups. The idea that hospitals should stop offering non-urgent primary care was still supported by a majority but with much more polarization: administrators 88%, pharmacists 61%, doctors 54% and nurses 51%.

### *Theme 7: Clinical appropriateness and efficiency*

There was strong support from all groups for greater use of scientific evidence in clinical practice (administrators 99%, doctors 92%, nurses 90%, pharmacists 96%) and institutional

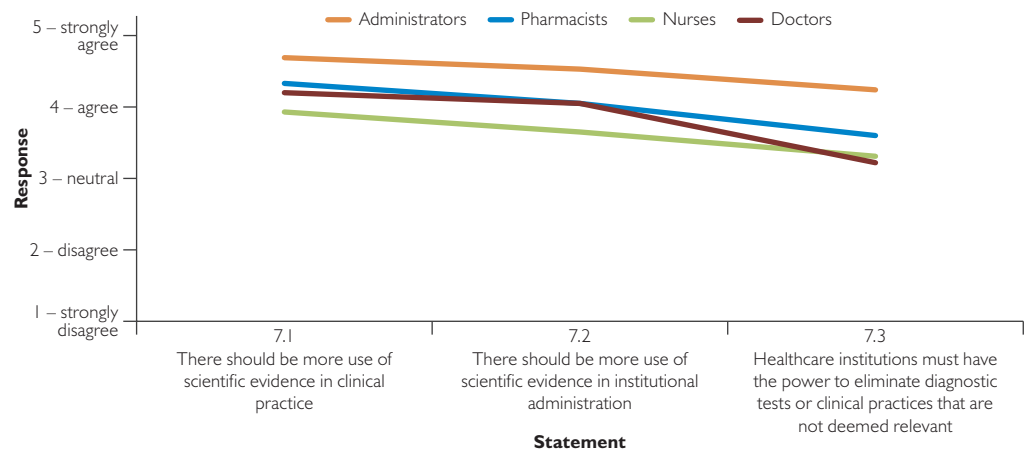
management. All groups agreed institutions should be allowed to eliminate diagnostic tests or clinical practices not deemed relevant, with stronger support among administrators (89%) than pharmacists (67%), nurses (62%) or doctors (53%) (see Figure 6). Again, support fell when the statement implied any coercion or limitation of professional autonomy.

FIGURE 5. Agreement regarding coordination between hospital and primary care



CHSLDs = centres d'hébergement et de soins de longue durée (residential and long-term care centres).

FIGURE 6. Agreement regarding clinical appropriateness and efficiency



*Open question: Respondents' suggestions to the Health Minister*

There was significant convergence in solutions proposed. All groups supported increasing interdisciplinary teams and redefining roles of non-doctor professionals. Likewise, all professionals saw improving access to primary care as a priority. Administrators proposed different action priorities, which included revising professionals' compensation models and improving care appropriateness (Table 2).

**TABLE 2.** Most salient solutions put forward by each professional group

Ranking	Solutions			
	Administrators	Doctors	Nurses	Pharmacists
1	Revise professional modes of payment	Increase interdisciplinarity and redefine roles on non-doctor professionals	Increase interdisciplinarity and redefine roles on non-doctor professionals	Increase interdisciplinarity and redefine roles on non-doctor professionals
2	Increase interdisciplinarity and redefine roles on non-doctor professionals	Improve access to technical platform and specialists	Enhance access to primary care services	Enhance access to primary care services
3	Increase care pertinence	Enhance access to primary care services	Improve working conditions and appreciate professionals' work	Implement a systemic patient file

## Discussion

This study offers new insights into how stakeholders compare in their support for specific implementable solutions. It revealed broad consensus among the four groups on solutions for improving healthcare performance. Furthermore, the impressive convergence in responses to the closed question suggest this consensus is not an artefact of closed question surveying.

In general, we did not observe major differences in the groups' support for the various propositions. General levels of agreement went in a similar direction for all groups, with only levels of support somewhat differing. Hence, our results do not suggest polarization or clear disagreement between administrators, pharmacists, nurses and doctors on most questions, but rather that some groups are more (or less) enthusiastic in their support.

Overall, administrators were more supportive of system reform than were other groups, often closely followed by pharmacists. While doctors' pattern of support for various statements was almost always the same as for the other groups, they were consistently below the others in their mean score for almost all statements tested.

Based on levels of support expressed, we would anticipate resistance to change in two major areas. The first relates to information systems and includes both patients having access to their clinical data and information being used for monitoring and team accountability. Although the majority in each group supported the statements related to information systems, clearly there was resistance, which may relate to the scope of intrusion into clinical practice and to fear of undesirable effects. This suggests the pace of information systems implementation should be kept in line with professional capacity for adoption and that experimental sites might be good starting points to learn from experiences and adjust systems according to what may be acceptable.

The second area where resistance was observed among doctors was on topics directly affecting medical practice: patients' right to access professionals by e-mail, doctor compensation models, and the proposition that doctors be paid less and, in exchange, receive more resources for their practice. These points all relate to compensation; at this time, e-mail contacts are not compensated, and the other two points directly affect income. Medical practice organization and doctor compensation are clearly elements that were side-stepped in reforms

of the past 20 years in Quebec. One important observation from this survey is that the balance of power lies in the hands of those doctors declaring indifference on the topic.

However, in our view, the real contribution of this paper lies elsewhere. As indicated, our results showed there is a margin of action for substantial improvement in healthcare system performance, such as removing barriers to interdisciplinary team work, using information systems to inform professionals on their practice and monitor performance, and applying scientific evidence more substantially to clinical and administrative practice. Yet even though our results show strong consensual support for many policy options, those solutions are not currently at the forefront of the transformations in Quebec's healthcare system.

Furthermore, our finding that there was strong consensus and broad support among professionals and administrators around many policy options contradicts the political allegation that failure in implementing those solutions is due to stakeholder resistance. This raises further research questions about why some evidence-supported policy avenues are consistently not implemented in Quebec and why reforms have repeatedly failed to implement important and scientifically sound solutions to improve performance. An intriguing avenue of investigation might be the influence of medical unions. In interviews, key spokespersons cited these unions as the actors with the most influence on health policies (Brousselle et al. 2014), far more influential than pharmaceutical companies, public opinion or even the government itself. Could they be so powerful that they prevent implementation of recommended changes even if their members support those changes? To what extent do medical unions represent doctors' opinions? These questions warrant closer examination.

### *Limitations*

This study has a few limitations worth mentioning. While we committed significant time and energy to survey data collection, the response rates were still far from perfect. Data collection also took place during a massive structural reform in Quebec that probably impacted respondent perceptions. Finally, the analysis presented here is mostly descriptive and exploratory. For those reasons, the precise level of support for each policy option should be interpreted with caution. However, we believe that the overall portrait of a large consensus for evidence-based solution isn't affected by those limitations.

### **Conclusion**

Quebec's healthcare system reforms over the past 20 years have mostly focused on transforming the structure of care (decentralization and recentralization, shift to healthcare networks, increased role for family medicine groups). However, little has changed with regard to medical practice, which remains largely centred around medical responsibility and is resistant to shifting to interdisciplinary teams and compensation models that support group work rather than individual productivity. However, this study suggests there is broad consensus among professionals for implementing important changes in the healthcare system and medical practice. Polarization among professionals is not the core issue. Could better evidence, communication, and open political debates be part of the solution?

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## Stakeholder Views on Solutions to Improve Health System Performance

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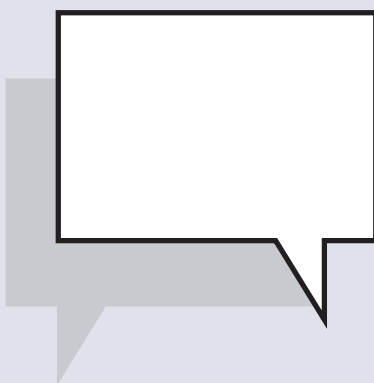
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# CONGRATULATIONS!

The **2018 Ted Freedman Award** was awarded to the **Baycrest Centre for Learning, Research and Innovation in Long-Term Care** in recognition of: *SOS Educational App for Healthcare*. The award was presented at CAHSPR 2018 in Montreal, QC, and accepted by Raquel Meyer on behalf of the Baycrest team. At a later ceremony on-site at Baycrest in Toronto, ON, individual certificates were presented to each team member.



The Ted Freedman Award for Innovation in Education: a self-portrait in bronze of the artist as a patient recovering from brain surgery, by award-winning sculptor Amy Switzer.

From left to right: Winners David Conn, Sandra Gardner, Faith Boucher, Raquel Meyer, Jennifer Reguindin and David Chandross, with Rebecca Hart and Matthew Hart from Longwoods.





