Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs
NOLA M. RIES ET AL.

Stepping Up to the Plate: An Agenda for Research and Policy Action on Electronic Medical Records in Canadian Primary Healthcare
AMANDA L. TERRY ET AL.

What’s Measured Is Not Necessarily What Matters: A Cautionary Story from Public Health
RAISA DEBER AND ROBERT SCHWARTZ

How Safe and Innovative Are First-in-Class Drugs Approved by Health Canada: A Cohort Study
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## CONTENTS

### From the Editor-in-Chief

8 Better Science, Better Science Reporting  
JENNIFER ZELMER

### Discussion and Debate

12 Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs  
NOLA M. RIES, MAUREEN DOUGLAS, JESSICA SIMON AND KONRAD FASSBENDER

### Research Papers

19 Stepping Up to the Plate: An Agenda for Research and Policy Action on Electronic Medical Records in Canadian Primary Healthcare  
AMANDA L. TERRY, MOIRA STEWART, MARTIN FORTIN, SABRINA T. WONG, INESE GRAVA-GUBINS, LISA ASHLEY, PATRICIA SULLIVAN-TAYLOR, FRANK SULLIVAN, LYNNE ZUCKER AND AMARDEEP THIND

33 Primary Care Performance Measurement and Reporting at a Regional Level: Could a Matrix Approach Provide Actionable Information for Policy Makers and Clinicians?  
JULIA M. LANGTON, SABRINA T. WONG, SHARON JOHNSTON, JULIA ABELSON, MEHDI AMMI, FRED BURGE, JOHN CAMPBELL, JEANNIE HAGGERTY, WILLIAM HOGG, WALTER P. WODCHIS AND KIMBERLYN MCGRAIL

52 What’s Measured Is Not Necessarily What Matters: A Cautionary Story from Public Health  
RAISA DEBER AND ROBERT SCHWARTZ

65 How Safe and Innovative Are First-in-Class Drugs Approved by Health Canada: A Cohort Study  
JOEL LEXCHIN

76 Variation in Emergency Department Transfer Rates from Nursing Homes in Ontario, Canada  
ANDREA GRUNEIR, SUSAN E. BRONSKILL, ALICE NEWMAN, CHAIM M. BELL, PETER GOZDYRA, GEOFFREY M. ANDERSON AND PAULA A. ROCHON
Ce qui est évalué n’est pas nécessairement ce qui est le plus important : un récit instructif provenant de la santé publique
RAISA DEBER ET ROBERT SCHWARTZ

L’innocuité et l’aspect innovant des nouvelles classes de médicaments approuvés par Santé Canada : une étude de cohorte
JOEL LEXCHIN

La variation dans les taux de transfert des foyers de soins infirmiers vers les services des urgences, en Ontario, Canada
ANDREA GRUNEIR, SUSAN E. BRONSKILL, ALICE NEWMAN, CHAIM M. BELL, PETER GOZDYRA, GEOFFREY M. ANDERSON ET PAULA A. ROCHON

Concevoir des approches intégrées pour aider les personnes souffrant de multimorbidité : messages clés de revues systématiques, de dirigeants de systèmes de santé et de citoyens
MICHAEL G. WILSON, JOHN N. LAVIS ET FRANCOIS-PIERRE GAUVIN

Une étude sur les processus de prédiction de congés de patients des hôpitaux de soins de courte durée
ANNA DE GROOD, KENNETH BLADES ET SACHIN R. PENDHARKAR

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There are two main reasons that articles submitted to Healthcare Policy/Politiques de Santé are rejected before going to peer review: they are outside the scope of the journal’s mandate or they do not follow established quality guidelines for research reporting. The latter are evolving and expanding over time, as illustrated by the fact that the EQUATOR Network now includes 345 guidelines in their library (Equator Network n.d.).

At Healthcare Policy/Politiques de Santé, we have recently added guidelines for Sex and Gender Equity in Research (SAGER) to our journal’s policies (Heidari et al. 2016). Sex (biological attributes) and gender (socially constructed roles, behaviours, expressions and identities) are deeply individual. They also matter collectively, including influencing patterns of health and disease. In some cases, sex and/or gender differences are well established. In others, their impact influence is subtle, complex and occasionally unexpected. But in many – perhaps most – cases, the effects are simply unknown. Researchers have not yet asked the necessary questions or reported the data needed to know the answers.

The new SAGER guidelines are designed to change that. They recognize that high quality research takes important factors that can influence outcomes into account. The guidelines are part of a broader portfolio of tools (CIHR 2016), including research funding requirements and educational resources, designed to make health research more rigorous and more useful by increasing integration of gender and sex considerations into the research process, when appropriate.

As a result, we encourage authors to follow the SAGER guidelines and to consider sex and gender in their studies, where relevant. Article titles and/or abstracts should indicate clearly what sex(es) the study applies to. Authors should also describe in the background, where relevant, whether sex and/or gender differences may be expected; report how sex and gender were accounted for in the design of the study; provide disaggregated data by sex and gender, where appropriate; and discuss respective results. If a sex and gender analysis was not conducted when it reasonably could have been, the rationale should be given in the Discussion. To operationalize this policy, we have added information to this effect to the instructions for authors and for reviewers.
This decision is part of our journal’s commitment to our readers and to our authors that we will continue to foster better research and better research reporting. Please join us in this journey by encouraging your colleagues and contacts to review and use established quality guidelines for research reporting.

JENNIFER ZELMER, PHD
Editor-in-chief

References
Il y a deux raisons principales pour lesquelles certains articles soumis à Politiques de Santé/Healthcare Policy sont rejetés avant l’étape de l’évaluation par les pairs : soit qu’ils ne correspondent pas au mandat de la revue, soit qu’ils ne respectent pas les directives mises en place pour assurer la qualité des rapports de recherche. Ces dernières évoluent et s’accroissent avec le temps, comme le démontrent les 345 directives que contient aujourd’hui la bibliothèque du réseau EQUATOR (Equator Network s.d.).

Politiques de Santé/Healthcare Policy a récemment intégré les directives SAGER (Sex and Gender Equity in Research) à ses politiques éditoriales (Heidari et al. 2016). Le sexe (caractéristiques biologiques) et le genre (rôles, comportements, expressions et identités socialement déterminés) sont éminemment personnels. Ils ont aussi une importance collective, notamment en raison de leur influence sur les schémas de santé et de maladies. Dans certains cas, les différences liées au sexe ou au genre sont bien établies. Dans d’autres, l’impact de leur influence est subtil, complexe et parfois inattendu. Mais dans plusieurs cas – peut-être la plupart – les effets sont simplement inconnus; les chercheurs n’ont peut-être pas encore posé les questions requises ou n’ont pas rapporté les données nécessaires pour connaître les réponses.

Les nouvelles directives SAGER ont été conçues pour y remédier. Elles reconnaissent qu’une recherche de grande qualité doit tenir compte de facteurs importants qui peuvent influencer les résultats et les conclusions. Ces directives font partie d’un plus vaste ensemble d’outils (IRSC 2016) – lequel contient aussi des exigences pour le financement de recherches et des ressources pour la formation – conçus pour rendre plus rigoureuse et utile la recherche en santé, et ce, en intégrant au processus de recherche, lorsqu’approprié, les considérations relatives au sexe et au genre.

Ainsi, Politiques de Santé/Healthcare Policy encourage dorénavant les auteurs à observer les directives SAGER et à tenir compte des considérations relatives au sexe et au genre dans leurs études, quand cela est pertinent. Le titre ou le résumé d’un article devrait clairement indiquer à quel(s) sexe(s) correspond l’étude en question. Les auteurs devraient aussi décrire, dans le contexte quand cela est pertinent, si on peut s’attendre à des différences liées au sexe ou au genre; expliquer comment on a tenu compte du sexe et du genre dans la conception de l’étude; fournir des données désagrégées en fonction du sexe et du genre, le cas échéant; et discuter des résultats respectifs. Dans les cas où il n’y a pas d’analyse en fonction du sexe et du genre, alors qu’une telle analyse aurait raisonnablement pu avoir lieu, la discussion...
doit donner les raisons de cette omission. Afin de faciliter la politique, nous avons ajouté les renseignements pertinents aux instructions pour les auteurs et pour les évaluateurs.

Cette décision s’inscrit dans l’engagement de la revue, envers les lecteurs et les auteurs, visant à favoriser une recherche encore meilleure et de meilleurs rapports de recherche. Joignez-vous à cet engagement en incitant vos collègues et vos contacts à consulter et à utiliser les directives mises en place pour assurer la qualité des rapports de recherche.

JENNIFER ZELMER, PhD
Rédactrice en chef

Références
Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs

Médecins, avocats et planification préalable de soins : innover et travailler ensemble pour satisfaire les besoins du client

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Abstract
Health organizations in Canada have invested considerable resources in strategies to improve knowledge and uptake of advance care planning (ACP). Yet barriers persist and many Canadians do not engage in the full range of ACP behaviours, including writing an advance directive and appointing a legally authorized decision-maker. Not engaging effectively in ACP disadvantages patients, their loved ones and their healthcare providers. This article advocates for greater collaboration between health and legal professionals to better support clients in ACP and presents a framework for action to build connections between these typically siloed professions.

Health organizations in Canada have invested considerable resources in strategies to improve knowledge of advance care planning (ACP) among health professionals and patients and to encourage people to think about and communicate their wishes for future healthcare (see, for example, the work of the National Advance Care Planning Task Group: www.advancecareplanning.ca/about-advance-care-planning/advance-care-planning-national-task-group). Despite these efforts, barriers persist: members of the public misunderstand ACP; professionals report they lack the time and confidence to broach ACP conversations with clients; and systems are inadequate to ensure plans are available when needed to guide healthcare decisions (Hagen et al. 2015; Lund et al. 2015). Many Canadians still do not engage in the full range of ACP behaviours, including writing an advance directive and appointing a substitute decision-maker to ensure their values, wishes and preferences are known (Teixeira et al. 2013).

Not engaging effectively in ACP disadvantages patients, their loved ones and their healthcare providers. Patients with an advance directive experience fewer medical interventions at the end of life, are less likely to be moved from their home or community care facility to a hospital and are less likely to die in a hospital (Lum et al. 2015). Substitute decision-makers often report a significant negative emotional burden (Wendler and Rid 2011), but this burden can be eased if the decision-maker is guided by the values and preferences expressed in an advance directive. A study of Canadian hospitals found alarmingly low rates of communication between healthcare providers and terminally ill patients about whether they had advance directives and about their wishes for care during their hospital admission (Heyland et al. 2013). It was reported that “close to 70% of the physician orders concerning intensity of treatment (such as cardiopulmonary resuscitation and intubation) were discordant with current patient wishes. In any other area of medicine, this would be viewed as an egregious ‘failure of communication’ error” (Allison and Sudore 2013: 787).

A recent systematic review concluded that improvement in the uptake and effectiveness of ACP depends on the ability to “transform systemic processes across a range of institutional settings” (Lovell and Yates 2014: 1027). We agree and propose that one important systemic transformation is greater collaboration between health and legal professionals to better support their clients in ACP. As Dr. Sinclair and others observe, we need the “silos of our healthcare ‘system’ to work together in a boundary-free way” (Sinclair 2015) but we also need to recognize that older adults and people with chronic or terminal illnesses typically have intersecting medical and legal issues, and failing to address those issues in a coordinated way undermines their quality of life and care.

Three Reasons Why Health–Legal Collaboration Is Important

First, working within their professional silos, neither doctors nor lawyers are optimally effective in helping their clients with ACP. Uncertainties about the legal validity of advance directives and the authority of substitute decision-makers are barriers to doctors having ACP conversations with patients. Fears about liability for limiting care at the end of life
are a further medico-legal obstacle. Lawyers also face challenges in helping their clients with ACP. A main criticism is that lawyers are too “transactional,” helping clients prepare ACP documents, but not promoting the ongoing communication that is vital to ensuring the client’s wishes are known and respected (Castillo et al. 2011). Physicians express frustration with directives that use vague phrases like “no heroic measures” and focus on the rarely encountered vegetative state, but do not provide guidance to inform the range of in-the-moment decisions needed in care at the end of life (Sudore and Fried 2010). Doctors encounter situations where decision-makers for an incompetent patient say they do not know what the patient would want (Shalowitz et al. 2006). Teams provide intensive medical interventions to sustain a patient’s life only to be informed days or weeks later that a directive has been found that says the person would refuse these life-prolonging interventions.

Second, some patients are more likely to talk to a lawyer than a physician about ACP. A Saskatchewan survey found that nearly half of people who had a written care plan had sought help from a lawyer to prepare the document, while only 5% had consulted with a doctor (Goodridge et al. 2013). Similarly, patients at an Ontario family practice clinic were more likely to have discussed ACP with a lawyer than their family doctor (O’Sullivan et al. 2015). A national study of sick, elderly patients and their family members found that participants discussed their end-of-life-care wishes as often or more often with a lawyer than with a family doctor or medical specialist (Heyland et al. 2013). These findings are not surprising when one considers that people seek help from lawyers to plan for their future in various ways such as writing a will and appointing someone to manage their finances. Planning for future healthcare is a logical topic for such discussions.

Third, each Canadian province and territory has its own legislation governing ACP (see Resource Library here: http://advancecareplanning.ca/resource-library/#resource-library|category:your-province-or-territory). Doing ACP right requires an accurate understanding of the rules and policies in effect in the jurisdiction where the patient lives and receives care.

Health–Legal Collaboration to Support Advance Care Planning: A Framework for Action

How can we break down the silos between doctors and lawyers to better support clients with ACP? We suggest a framework for interprofessional collaboration along a continuum that represents a gradually increasing degree of connection between health and legal professionals. Professionals can develop specific activities within this framework based on local needs and can move back and forth along the continuum. This framework advances the recommendation of other Canadian ACP researchers that “new forms of interprofessional collaboration should be considered to increase the interface between physicians and lawyers” (Goodridge et al. 2013: 4). We advocate that new approaches should be evaluated and findings disseminated through health and legal sector organizations to build a strong evidence base for collaborative practices.
Legal and health practitioners use common best practices to assist clients
Interventions to build professionals’ skills and confidence in discussing ACP are typically implemented and evaluated in health settings; however, best practice approaches can be adapted for use by legal professionals, including resources such as conversation scripts, workbooks and training programs available on national and provincial websites (for example: www.advancecareplanning.ca/resource/acp-workbook/ and https://myhealth.alberta.ca/Alberta/Pages/advance-care-planning-resources.aspx). Organizations that produce ACP resources should disseminate them to the legal profession. Clients should receive common messages and information about ACP. For example, both health and legal professionals should promote ACP not as a one-time event but rather as a process of communication, and clients should be encouraged to share a care directive with key people who need to know their wishes.

Legal and health practitioners cooperate in interprofessional training
Continuing professional development events should bring legal and health professionals together for joint ACP training so they can learn from one another. Health professionals can increase their awareness of the law and lawyers can gain a better understanding of the practical realities of healthcare delivery. In Alberta, our research team recently delivered a continuing education event, Advance Care Planning: How Lawyers Can Help Their Clients. A palliative medicine specialist and a wills and estates lawyer shared their experiences of the challenges of doing effective ACP and suggested solutions and resources to an audience of Alberta legal professionals.

Legal and health practitioners collaborate in ACP clinics
Clinics would bring together lawyers and health professionals to lead ACP sessions for clients in community settings, aged care facilities and hospitals. This strategy can improve access to lawyers for people who are physically unable to attend law offices. Interprofessional clinics would facilitate the delivery of consistent messages and follow-up referral pathways can also be developed between legal and health organizations. Clinics can help identify clients who may need additional support, especially those with more complex situations, so they can access professional help before medical and legal crises develop.

Lawyers are integrated into healthcare settings and teams
The medical–legal partnership model (which is most developed in the US: http://medical-legalpartnership.org/) may be used to establish formal arrangements for lawyers to provide...
services to clients in healthcare settings. Examples exist of lawyers working with cancer and palliative care programs to help clients with legal matters, including estate and guardianship planning and benefit claims (Hallerman et al. 2014). Hallerman et al. observe that “[e]merging evidence demonstrates that patient-clients benefit substantially from the addition of legal expertise to the patient care team” (2014: 184) and, indeed, high-quality evaluation data are crucial to sustain innovative models of collaborative service delivery beyond pilot projects. The Advisory Panel on Healthcare Innovation heard “laments about the pervasiveness of pilot projects in Canada” and noted the “failing … in the capacity of our healthcare systems to spread or scale up the best ideas from those projects” (2015: 27). Others have reflected on factors that support the spread of successful innovations to achieve integrated systems (Suter et al. 2009), especially collective work to engage and train key groups and shift cultures of practice (Zelmer 2015).

Each increasing degree of connection in the health–legal collaboration framework presented here involves costs, benefits and a need to determine the cost-effectiveness of specific collaborative activities. Importantly, when using interprofessional approaches, members of each profession must meet their ethical duties to clients. These are not insurmountable barriers, however, as demonstrated by the success of medical–legal partnerships involving pro bono legal services (such as Pro Bono Law Ontario’s Medical–Legal Partnerships for Children: www.pblo.org/volunteer/medical-legal-partnerships-children/).

ACP requires more “interdisciplinary attention, conversations, health research and practice [and] joining up professions …” (Russell 2014). Just as researchers have asked health professionals about barriers and enablers to ACP, we need to find out similar information from lawyers. Our research team will soon report on a survey of lawyers in Alberta to find out more about their experiences with ACP, their perspectives on barriers and facilitators and the resources that would help them. To our knowledge, no such survey has been done elsewhere and the results will help stakeholders in health, legal and government sectors to understand better the role that lawyers play. The results will also provide an evidence base for strategies to advance the first two components of the collaboration framework, namely, how legal and health practitioners can use common best practices to assist clients and ways in which legal and health practitioners can cooperate in interprofessional training.

Healthcare providers and lawyers need not be estranged by different professional cultures and language. To realize the benefits of ACP, they ought to find a common ground in preparing people for serious illness and death, helping people communicate what is important to them and allowing them to guide their care even beyond a time when they can speak for themselves.

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Stepping Up to the Plate: An Agenda for Research and Policy Action on Electronic Medical Records in Canadian Primary Healthcare

Passer à l’action : programme de recherche et suggestions d’orientation sur les dossiers médicaux électroniques dans les soins de santé primaires au Canada

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Abstract
Building on a previous study, which identified gaps in primary healthcare electronic medical record (EMR) research and knowledge, a one-day conference was held to facilitate a strategic discussion of these issues. This paper offers a multi-faceted research agenda and suggestions for policy actions as a way forward in bridging the gaps. One facet focuses on the need for research. The second facet focuses on harnessing the knowledge of primary healthcare EMR stakeholders. Finally, the third facet focuses on policy actions. This paper offers consensus-based suggestions with a view to improving the overall primary healthcare EMR landscape in Canada.

Résumé
En réponse à une première étude qui identifiait des lacunes dans la recherche et les connaissances concernant les dossiers médicaux électroniques (DME) dans les soins de santé primaires, une conférence a eu lieu afin de permettre une discussion stratégique sur cette situation. Cet article présente un programme de recherche multifacette et des suggestions d’orientation afin de combler ces lacunes. La première facette souligne le besoin de faire de la recherche. La seconde facette porte sur la canalisation des connaissances des parties prenantes liées aux DME dans les soins de santé primaires. Finalement, le troisième aspect soulève
des suggestions d’orientation. Cet article présente un consensus sur la manière d’améliorer le portrait global des DME dans les soins de santé au Canada.

Introduction

Electronic medical records (EMRs) have the potential to be a transformational force in both primary healthcare research (PHC) and practice in Canada (Birtwhistle and Williamson 2015; Report of the Advisory Panel on Healthcare Innovation 2015). Despite mixed evidence regarding the impact of EMRs on clinical practice (Lau et al. 2012), levels of adoption continue to grow across Canada (Chang and Gupta 2015; College of Family Physicians of Canada et al. 2014; Schoen et al. 2012). Variability exists among provinces, however, with areas of lower physician EMR use (e.g., Newfoundland and Labrador) and areas with higher use (e.g., Alberta) (Chang and Gupta 2015). Positive signs include clinicians perceiving a benefit from EMRs (Bassi et al. 2012), particularly with increasing experience in their use and when the EMR supports advanced use (King et al. 2014). Benefits to be gained from EMR use are likely dependent upon the use of fully functional systems that are integrated into practice (Friedberg et al. 2009). Yet there is a small amount of research evidence, particularly in the Canadian context, to support this integration.

Given this reality, we conducted a pan-Canadian study, which identified 12 key gaps in research and knowledge facing PHC EMR stakeholders (Terry et al. 2014). Other work in the Canadian context has identified the need for research focused on EMR adoption and for initiatives that would aid advanced EMR use (Canada Health Infoway 2013; CMA 2015; Price et al. 2013; Rimmer et al. 2015). This prompts the question of how to bridge these gaps from both a policy and research perspective. Building on the findings of this initial study, this paper provides a strategic discussion of the identified gaps and identifies a way forward.

Methods

To facilitate this discussion, we held a one-day conference in Toronto, Canada (March 2012) in partnership with the Canadian Institute for Health Information (CIHI 2012). Prior to the conference, participants received an information package, which outlined the 12 gaps in EMR research and knowledge; participants were asked to self-select their preferred topic to discuss during small group discussions. We reviewed these selections, as well as those chosen by conference participants at the beginning of the day, and identified seven gaps of the original 12, which the majority of participants wanted to discuss. The small groups were guided by a facilitator; notes were recorded by a designated group member on a template that was provided to them.

Over 100 conference participants chose to discuss seven gaps in EMR research and knowledge (value of EMRs, EMR implementation and adoption, data entry and extraction procedures, data sharing, overarching framework for interoperability, define data elements
and develop an ideal EMR design). In the following, we discuss how the ideas generated by participants might be addressed through research or policy initiatives. Though the conference occurred in 2012, the issues identified remain salient today (Canada Health Infoway 2013; CMA 2015; Pare et al. 2014; Price et al. 2013; Report of the Advisory Panel on Healthcare Innovation 2015; Rich 2015). Given that overall PHC EMR adoption in Canada has greatly advanced since 2012, some of the gaps discussed at the conference, such as EMR implementation and adoption, would be more relevant in parts of Canada where adoption rates are lower. Other gaps, including data sharing, may be more of a concern in areas where EMR adoption has occurred over a longer period of time and where levels of use are higher.

Conference Findings
The findings from each topic group are presented, followed immediately by a discussion regarding how the gap might be addressed through research or policy initiatives (Table 1).

**Value of EMRs – findings**
This theme focused on the value proposition of EMRs for a broad group of stakeholders, including clinicians, decision-makers and health system planners. Within this theme, participants offered three ideas for how to address this issue. The first was to explore the

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<td>1. Value of EMRs</td>
<td>• Explore connection between maturity of use and accrued value</td>
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<td>2. EMR implementation and adoption</td>
<td>• Understand trade-off: effort of adoption versus value</td>
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<td>3. Data entry and extraction procedures</td>
<td>• Create a value map/matrix (stakeholders on one axis, value EMR brings on other axis)</td>
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<td>4. Data sharing</td>
<td>• Supply basic and advanced training, support and education for users</td>
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<td>5. Overarching framework for interoperability</td>
<td>• Understand value of implementation and adoption</td>
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<td>6. Define data elements</td>
<td>• Identify non-adopters – identify barriers to adoption and how to overcome them</td>
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<td>7. Develop ideal EMR design</td>
<td>• Identify best practices of advanced users – success and supports, conduct economic analysis</td>
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<td>4. Data sharing</td>
<td>• Identify non-adopters – identify barriers to adoption and how to overcome them</td>
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<td>• Identify best practices of advanced users – success and supports, conduct economic analysis</td>
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<tr>
<td>6. Define data elements</td>
<td>• Synthesize existing data and research reports</td>
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**Value of EMRs – findings**
This theme focused on the value proposition of EMRs for a broad group of stakeholders, including clinicians, decision-makers and health system planners. Within this theme, participants offered three ideas for how to address this issue. The first was to explore the

<table>
<thead>
<tr>
<th>Gap in knowledge and research</th>
<th>Summary of action points</th>
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<tr>
<td>1. Value of EMRs</td>
<td>• Explore connection between maturity of use and accrued value</td>
</tr>
<tr>
<td>2. EMR implementation and adoption</td>
<td>• Understand trade-off: effort of adoption versus value</td>
</tr>
<tr>
<td>3. Data entry and extraction procedures</td>
<td>• Create a value map/matrix (stakeholders on one axis, value EMR brings on other axis)</td>
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<tr>
<td>4. Data sharing</td>
<td>• Supply basic and advanced training, support and education for users</td>
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<td>5. Overarching framework for interoperability</td>
<td>• Understand value of implementation and adoption</td>
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EMR = electronic medical record; PHC = primary healthcare research.
connection between practitioners’ maturity of EMR use (for example, level of use of elements of the EMR, participation in peer-to-peer support networks) and the value that the practitioner accrued from the EMR. The second was to understand the possible trade-offs between the effort or cost of adoption and the value realized. Participants suggested there may be a point of diminishing returns in terms of EMR use, and they wanted to promote research that would search out when and where this might occur. The third idea was to create a value map or a matrix on which the stakeholders would be represented on one axis, while the type of value the EMR could bring to them (e.g., financial, satisfaction) would be noted on the other axis. This matrix would illustrate the type of value associated with EMR use that would apply to each stakeholder.

Value of EMRs – author discussion
Participants’ suggestions of exploring the connection between maturity of use and accrued value, as well as the trade-off between effort of adoption and value, could be realized through health economics studies. Creating a value map should be completed by harnessing the input of primary healthcare EMR stakeholders in Canada. There is existing work in Canada regarding frameworks to assess the value of e-Health (Lau et al. 2014), EMR value (Canada Health Infoway 2013; Rubinowicz et al. 2016) and return on investment (Jang et al. 2014); other broader economic analyses and frameworks exist elsewhere in the literature (Bassi and Lau 2013; Payne et al. 2013). Despite mixed evidence of EMR effects on practice, we do know that the likelihood of positive impact is dependent upon optimal EMR use (Friedberg et al. 2009) and successful integration into workflow (Jang et al. 2014). Therefore, the next step in realizing the full value of EMRs is to better understand how to achieve optimal use by building on existing work focused on EMR optimization in Canada (CMA 2015; Price et al. 2013; Raymond et al. 2015), elsewhere (Ornstein et al. 2015; Pandhi et al. 2014) and the use of specific tools within the EMR such as electronic prescribing (e-prescribing) (Motulsky et al. 2013; Randhawa et al. 2013). The knowledge gained from this research should then be scaled up more broadly across the PHC setting to enable practitioners to advance their EMR use and to realize the potential full value of EMRs.

EMR implementation and adoption – findings
The main concept of this theme revolved around determining how and why primary healthcare practitioners are adopting or not adopting EMRs into practice. Participants offered a number of options for moving forward. On the policy side, a need to support basic EMR implementation was identified, as well as more advanced training, support and education for EMR users. Funding and incentives to facilitate implementation and adoption were also cited as examples of such support that would fall within the policy domain. From a research perspective, there were four areas that participants pinpointed: (1) understanding the value of EMRs from a patient outcome, financial, productivity and efficiency perspective; (2) seeking out EMR non-adopters to understand the barriers to adoption and how to overcome them; (3) analyzing best practices
of existing successful EMR users over time, identifying the policies and procedures that support this type of use and conducting an economic analysis based on successful users; and (4) using existing data and research reports on implementation and adoption to inform this topic.

**EMR implementation and adoption – author discussion**
Addressing issues of EMR implementation and adoption would benefit from a series of studies focused on successful EMR users and those who do not use EMRs at all, as well as research synthesizing current information on this topic in Canada (Archer and Cocosila 2011; Greiver et al. 2011b; Lai et al. 2009; McGinn et al. 2012; Pare et al. 2014; Paterson et al. 2011; Price et al. 2013; Terry et al. 2009; Vedel et al. 2012) and elsewhere (Boonstra and Broekhuis 2010; Castillo et al. 2010; McGinn et al. 2011). Further work could be done on identifying the policy levers that best support EMR implementation and adoption. While barriers and facilitators to EMR implementation and adoption have been identified (Archer and Cocosila 2011; Boonstra and Broekhuis 2010; Castillo et al. 2010; Greiver et al. 2011b; Lai et al. 2009; McGinn et al. 2012, 2011; Pare et al. 2014; Paterson et al. 2011; Price et al. 2013; Terry et al. 2009; Vedel et al. 2012), this issue remains prominent in the EMR landscape in Canada, including consideration of longer-term adoption issues (Green et al. 2015; Terry et al. 2012). Recent work has identified exemplars of successful health information technology adoption (Jones and Wittie 2015; McAlearney et al. 2010; Ornstein et al. 2015; Ryan et al. 2014), provided guidance for the adoption of information technology at a broader level (Cresswell et al. 2013) and explored the adoption of e-prescribing in primary care (Sicotte et al. 2013). Best practices in implementation and adoption need to be explored and summarized, particularly as they relate to PHC EMRs. In addition, the structures supporting the application of these best practices in the PHC setting should be determined. These findings, when translated into supports and structures at the level of the healthcare system and the practice, would enable comprehensive implementation and adoption across Canadian PHC.

**Data entry and extraction procedures – findings**
This theme was centred on how to get data into the EMR, and how to get it out of the EMR, in the best possible way. A combined research and policy strategy discussed was to examine EMR vendor-specific structural differences across jurisdictions. This could be done with a view to creating unified capacity and mandated content standards to support high-quality data entry and extraction. From the policy perspective, participants thought it was important to have practitioner incentives in place to support the goal of complete and accurate data on specific topics such as preventive care tests. Three areas were identified that required further research: (1) technologies to search EMR data regardless of how the data were entered; (2) intervention programs for practitioners focused on data entry, which would consist of feedback and a peer-to-peer training approach; (3) best practices that lead to high optimization and data quality levels. Within these strategies, participants emphasized the need to strike a balance between the resources that would be required to support data entry and its ultimate usability.
Data entry and extraction procedures – author discussion

Recommended steps to address this gap include: (1) conducting a literature review to identify best practices leading to optimal use and data quality from other settings that are potentially transferable to PHC; and holding a series of policy dialogues focused on unified EMR capacity, implementation of rigorous content standards and priorities for EMR data entry supports. This would build on existing best practices, for example, in system design (Horsky et al. 2012) and the work of CIHI in developing and disseminating the “Pan-Canadian PHC Electronic Medical Record Content Standards” (CIHI 2012). Research in this area could focus on identifying existing and emerging data searching technologies to be tested in different EMRs in the PHC setting. Trials could be conducted to build on existing work and to test interventions focused on optimal data entry (Brouwer et al. 2006; Greiver et al. 2011a, 2015).

A problem central to this issue is the reality that different stakeholders often have different reasons for their interest in data entry and extraction. PHC practitioners may be interested because they want to be able to treat and track individual patients over time and examine their practice populations as a whole. Policy makers may be interested in the potential to have access to standardized PHC data for planning health system change. Researchers need high-quality PHC data for their studies. Vendors are concerned due to potential future requirements for EMR designs. The next step, therefore, is to understand these perspectives more thoroughly, prior to embarking on research or policy action. Identifying shared areas of focus and priority for most stakeholders would be a logical starting place for these actions.

Data sharing – findings

This theme reflects existing uncertainty about how EMR data can be shared, with whom, under what circumstances and for what purpose. There were three main strategies identified by participants regarding data sharing. The first two of these are policy-related: (1) define standardized data sets, and determine who should share them and under what circumstances they could be shared. Conference attendees thought that patients, policy makers and practitioners should all be engaged in this work; (2) work towards achieving interprovincial consistency in data sharing. The final strategy was research-related – polling the public regarding their attitudes and opinions about healthcare data sharing.

Data sharing – author discussion

A necessary precursor to work on defining data sets and working towards interprovincial consistency is the need to more fully understand the views of patients regarding data sharing, particularly in terms of EMRs in PHC. Studies in the Canadian context have examined the perspectives of individuals about health information privacy and the circumstances under which data may be shared (Perera et al. 2011; Willison et al. 2003, 2007, 2009), and Canada Health Infoway has offered guidance on information governance in relation to interoperable electronic health records (EHRs) (Canada Health Infoway 2007). Canadian opinion polls
also exist, which have explored broader questions of privacy, protection of personal information and security and safety of personal health information (Angus Reid Public Opinion 2013; Ipsos Reid 2012; Phoenix Strategic Perspectives Inc. 2013). Given that the availability of data in electronic form will continue to grow and much uncertainty remains about data sharing, more clarity around this issue is required. This work is critically important as optimal EMR use depends, in part, upon information flows among providers (Friedberg et al. 2009). We know that in Canada, among adopters of EMRs in general (Schoen et al. 2012), and e-prescribing in particular, this is already a challenge (Motulsky et al. 2015). Therefore, a next step would be to conduct a review of the literature, which would summarize the state of current knowledge regarding patient views of data sharing and identify any remaining gaps for which further research is required. This improved understanding of the issues would inform a pan-Canadian effort towards achieving policy- and practice-level consistency, which is required to move forward.

Overarching framework for interoperability – findings

This theme focuses on interoperability or data flows among practitioners, parts of the healthcare system and among software types. Participants emphasized the need for an overarching framework in Canada, which could ensure interoperability. The framework should include elements relating to governance, infrastructure, privacy, the value of the data, implementation and technology. Furthermore, it was considered important to develop a communication strategy pertaining to the overarching framework and to leverage national bodies such as the College of Family Physicians of Canada to drive action forward on this topic.

Overarching framework for interoperability – author discussion

The complexity of creating an overarching framework for interoperability necessitates a multi-jurisdictional policy-related initiative; this could potentially build on models such as interoperability-defining use cases (Sittig and Wright 2015). This policy work will require strong links among those who set EMR standards, EMR vendors, patients, healthcare practitioners and other policy makers. Widespread adoption of CIHI’s “Pan-Canadian Primary Health Care Electronic Medical Record Content Standards” is a necessary first step to the interoperability question. Canada Health Infoway coordinates pan-Canadian work on digital health standards and recently released the Clinical Interoperability Action Plan to foster collaboration on this issue. Much more remains to be done. Building upon this solid, already existing work, a pan-Canadian policy initiative is necessary to continue the work required towards achieving provincial implementation solutions for this issue.

Define data elements – findings

This theme was focused on primary healthcare practitioners defining the actual data elements in the EMR that would be needed for patient care and on researchers and policy makers suggesting what would be needed to answer questions about primary healthcare.
Suggestions made by conference participants regarding defining data elements were policy-oriented: (1) include data in the EMR on the illness, not only the diagnoses, such as the patient’s personal experience, health history, social determinants of health, death and quality of life; (2) include data elements such as those held by specialists, patients and what might be found in other data repositories; (3) build in a standard data element into each EMR which could calculate a “data completeness score.”

**Define data elements – author discussion**

As the adoption of EMRs matures, questions about how to make these data even richer have arisen. A pre-requisite to ultimately deciding what might be included in an EMR would be a consensus list of prioritized data elements. The list could be developed by building upon existing work, such as the Institute of Medicine’s EHR measures for social and behavioural determinants of health (Adler and Stead 2015). A consensus could be achieved through a Delphi process with Canadian PHC EMR stakeholders. This would enable policy-related steps to be taken, linked with existing work on content standards, and would facilitate discussions with EMR vendors regarding the consistency of data element inclusion. The development and testing of a data completeness scoring system should be undertaken within multiple EMRs. If testing was successful, such a system could be implemented in all EMRs for practitioner use. Thus, a next step would be to initiate two studies – one to create a consensus on data elements and the second to develop and test a data completeness scoring system that could be used by practitioners for self-assessment.

**Develop an ideal EMR design – findings**

Conference participants thought that EMRs should be designed to be reflective of the evolving interdisciplinary and team-based nature of primary healthcare. Additionally, it was suggested that individuals who may not usually be present for discussions of EMR design in primary healthcare, such as software engineers and pharmacists, should be included. In the research domain, participants thought it was important to build on the research that already exists in terms of EMR design in primary healthcare but that more research was needed specific to the Canadian context. This research should involve observing what is happening in primary healthcare practices to help inform ideal EMR design.

**Develop an ideal EMR design – author discussion**

An interdisciplinary network, where ideas to support EMR design could be exchanged and fostered with focused dialogues, could help address gaps in EMR design. This network would harness the existing research-based knowledge, as well as facilitate the emergence of new ideas, building on existing work examining EHR functionality in primary care (Krist et al. 2014). The group would also coordinate collaborative research ventures focused on informing ideal EMR design. There are existing networks across Canada, such as the Canadian Primary Care Sentinel Surveillance Network, eHealth Benefits Evaluation Knowledge Translation...
Community and the National Institutes of Health Informatics, which could inform this work. An important aspect of EMR design is the concept of the computer as a third party in the encounter (Pearce et al. 2011). A further dimension of EMR design should be focused on the organizational dimension of PHC practice – how does the EMR integrate into the functions of the practice (Beasley et al. 2011; Unertl et al. 2009)? Development of a multidisciplinary network of individuals across Canada interested in EMR design is an important next step.

Limitations
The following limitations of these discussions are noted. For some topics, there were clearly identified areas where more research was needed, whereas in others, it was more self-evident that policy-related actions needed to occur. There were also some grey areas in which the two facets of research and policy intertwined for particular issues, such as data entry and extraction. In addition, although patient-specific gaps were not discussed, it should be acknowledged that the patient perspective is a foundational element that underpins all of these issues.

Summary and Conclusions
Synthesizing the results of the topic group discussions, this paper offers a multi-faceted research agenda and suggestions for policy actions as a way forward in bridging the gaps in PHC EMR knowledge and research in Canada. One facet focuses on the need for research in this area. The second facet focuses on harnessing the knowledge of PHC EMR stakeholders together into a network. Finally, the third facet focuses on EMR-related policy actions.

These facets obviously intertwine, with a network of PHC EMR stakeholders being involved with both the research agenda and policy actions. Finally, we suggest that Canada needs to further develop its capacity to conduct EMR research and to tackle policy-relevant PHC EMR issues. This paper offers consensus-based suggestions with a view to improving the overall PHC EMR landscape in Canada.

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References


Amanda L. Terry et al.


Primary Care Performance Measurement and Reporting at a Regional Level: Could a Matrix Approach Provide Actionable Information for Policy Makers and Clinicians?

Mesures du rendement et rapports sur le rendement des soins de santé primaires au niveau régional : une approche matricielle pourrait-elle fournir des données exploitables pour les responsables et les cliniciens?

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Abstract

Objective: Primary care services form the foundation of modern healthcare systems, yet the breadth and complexity of services and diversity of patient populations may present challenges for creating comprehensive primary care information systems. Our objective is to develop regional-level information on the performance of primary care in Canada.

Methods: A scoping review was conducted to identify existing initiatives in primary care performance measurement and reporting across 11 countries. The results of this review were used by our international team of primary care researchers and clinicians to propose an approach for regional-level primary care reporting.

Results: We found a gap between conceptual primary care performance measurement frameworks in the peer-reviewed literature and real-world primary care performance measurement...
and reporting activities. We did not find a conceptual framework or analytic approach that could readily form the foundation of a regional-level primary care information system. Therefore, we propose an approach to reporting comprehensive and actionable performance information according to widely accepted core domains of primary care as well as different patient population groups.

Conclusions: An approach that bridges the gap between conceptual frameworks and real-world performance measurement and reporting initiatives could address some of the potential pitfalls of existing ways of presenting performance information (i.e., by single diseases or by age). This approach could produce meaningful and actionable information on the quality of primary care services.

Résumé

Objectif : Les services de soins primaires sont la base des systèmes de soins de santé modernes, mais l’étendue et la complexité des services ainsi que la diversité des patients peuvent présenter des défis quant à l’implantation de systèmes d’information efficaces sur les soins primaires. L’objectif est d’offrir de l’information au niveau régional sur le rendement des soins primaires au Canada.

Méthodes : Une étude approfondie a été menée afin de recenser les initiatives existantes en ce qui concerne la mesure du rendement et la production de rapports sur le rendement des soins de santé de 11 pays. Les résultats de cette étude ont été utilisés par notre équipe internationale de chercheurs et de cliniciens en soins de santé primaires afin de proposer une approche pour la production de rapports sur le rendement des soins primaires au niveau régional.

Résultats : Nous avons observé un écart entre, d’une part, les cadres théoriques pour la mesure du rendement présentés dans la littérature scientifique et, d’autre part, la mesure du rendement et la production de rapports que l’on trouve dans la réalité concrète des soins primaires. Les auteurs n’ont pas trouvé un cadre conceptuel ou une approche analytique qui pourrait servir de base pour un système d’information régional sur les soins de santé primaires. Par conséquent, nous proposons une approche en ce qui concerne la production de rapports sur le rendement : l’information doit être complète et exploitable, et elle doit être le fruit de ce qui est généralement accepté comme domaines centraux de soins de santé primaires, et elle doit aussi tenir compte des différents groupes de populations de patients.

Conclusions : Une approche qui comble les différences entre le cadre théorique et la réalité en ce qui concerne la mesure du rendement et la production de rapports pourrait aborder quelques-unes des difficultés potentielles qui existent actuellement sur les manières de présenter l’information sur le rendement (par exemple, pour une seule maladie ou par âge). Cette approche pourrait produire de l’information utile et exploitable sur la qualité des services de soins de santé primaires.
Introduction
Providing information about the functioning of healthcare systems to relevant stakeholders, including providers, policy makers, patients and the general public is considered essential to a learning health system (Etheredge 2014; Smith et al. 2009). Performance information can be used to achieve a variety of ends including operating pay for performance programs, research, accreditation/benchmarking, practice management, quality improvement and public reporting (Adair et al. 2006a, 2006b; Kontopantelis et al. 2015; Panzer et al. 2013).

Health systems with strong primary care sectors are achieving better population health, equity, efficiency and quality of care (Kringos et al. 2013; Martin-Misener et al. 2012; Stange et al. 2014; Starfield et al. 2005). These are key dimensions of quality as outlined by the Institute of Medicine in their landmark report, Crossing the Quality Chasm (IOM 2001), as well as many other evidence-based conceptual frameworks for understanding important features of primary care (Hogg et al. 2008; Starfield 1998; Watson et al. 2004).

Performance measurement can be used to evaluate whether health systems are delivering quality care. Despite the importance of primary care as part of a high-functioning health system, comprehensive performance measurement in primary care is challenging because of the range and complexity of services provided, the dispersion of primary care practices (vs. acute care facilities), heterogeneity of the patient population and the early development stage of data collection systems (Kontopantelis et al. 2015; Russell 2015; Stange et al. 2014). Unlike specialist practitioners, primary care practitioners are involved in the full spectrum of care from health promotion and prevention, diagnosis and treatment of acute health issues, through to management of complex chronic conditions and end-of-life care planning (Starfield 1998). The patients seen by primary care practitioners are considerably more diverse than the patient groups seen by other healthcare professionals (Porter et al. 2013; Stange et al. 2014). One example demonstrating the broad scope of primary care practitioners is the finding that Canadian fee-for-service family physicians use up to 10 times the number of ICD diagnosis codes compared with other fee-for-service specialties (Cunningham et al. 2014).

Primary care in Canada, as elsewhere, is in the process of experimentation and change in organization, funding and care delivery (Hutchison and Glazier 2013; Hutchison et al. 2011). A large proportion of primary medical care is provided through family doctors who are mostly independent business operators (unlike a single health authority), which makes system management challenging. As such, there is need for a primary care performance measurement system that supports pan-Canadian learning as well as regional planning and policy development, because health system changes often occur at the regional level. This includes a need for information on how the primary care system meets the needs of patients seen in primary care, including the most medically complex groups of patients who have been identified as the target of reform efforts (Hutchison and Glazier 2013; Lane et al. 2015).
Indeed, a central feature of successful performance measurement is alignment with the strategic direction and scope of healthcare systems. Furthermore, it is important for performance measurement to be underpinned with a robust conceptual framework to guide the selection of meaningful measures and indicators (Adair et al. 2006a, 2006b; IOM 2006; Smith et al. 2009). In other words, there should be a match between a primary care performance measurement system and accepted conceptual frameworks that articulate important features of high-quality primary care systems.

The objective of this project was to review existing trends and literature related to primary care performance measurement with the goal of identifying an approach that can form the basis of a regional-level pan-Canadian reporting system. The assumption is that improvement is always possible but is difficult to achieve in the absence of actionable information. We use the results of a scoping review of current initiatives in high-income countries and input from an international team of primary care researchers and clinicians to present an approach for measurement and reporting that can be used for system improvement.

Methods

Multidisciplinary research team

Our research team consists of a range of researchers (with expertise in both qualitative and quantitative methods) and health professionals (family doctors, nurses, psychologists and other allied health professionals) from Canada, the UK and Australia. This team was specifically established to reflect expertise in primary care research and performance measurement and reporting.

Scoping review of primary care measurement initiatives: A comparison across 11 countries

We conducted a scoping review of current practices in performance measurement and reporting to map what is currently known (or in our case, done) in this area (Arksey and O’Malley 2005; Levac et al. 2010). As our focus is pan-Canadian reporting, we sought to analyze the features of national primary care performance measurement initiatives across high-income countries, noting that many national initiatives include reporting at different levels of aggregation (e.g., practice-level, regional, state, national). The value in national approaches is standardization to support nationally consistent and locally relevant reporting such that regions can learn from high-performing regions across the nation. We selected the 11 countries included in the Commonwealth Fund’s international primary care and health policy surveys: Australia, Canada, England, France, Germany, Netherlands, New Zealand, Norway, Sweden, Switzerland and the US (Davis et al. 2014; Schoen et al. 2009). This choice allowed us to cover several healthcare systems that are most similar to Canada and that have been previously compared to Canada in relation to primary care performance (Schoen et al. 2009).
We used information in the Commonwealth Fund international profiles of healthcare systems to start our search to identify national primary care performance initiatives across the 11 countries (The Commonwealth Fund 2014). We also asked those affiliated with our project (including representatives from Australia, France and the UK) to provide details of any organizations meeting our inclusion criteria.

Results are based on web pages retrieved during the date range 30 November 2014 to 20 May 2015. Our inclusion criteria were: national primary care performance measurement initiatives; the organization presented primary care indicator sets or performance results in the public domain in English. We extracted information on frameworks, terminology used to describe primary care and reporting activities.

**Input from multidisciplinary research team**

As we did not identify an approach we could directly adapt to the Canadian setting, a new approach was developed based on existing models to offer regional reporting and population segmentation (to monitor performance for different patient groups with expected different levels of need for services). The model was reviewed and adapted iteratively over several sessions by the research team.

**Results**

**Primary care performance measurement initiatives**

Seven of the 11 countries had national initiatives in the form of primary care indicator sets/specifications or reporting; three countries had limited information available in English (Norway, Switzerland and France) and we did not identify any initiatives in Germany (see Table 1). There were differences in the information available, ranging from static reports (Netherlands, Sweden and the US), to online atlases mapping geographic variations in care (New Zealand, Australia and Canada), as well as routinely updated reports and interactive web displays (Australia, Canada and England). In some jurisdictions, there were multiple initiatives: for example, there are several websites in England providing practice-, regional- and national-level information and a recognition that information needs to be streamlined to avoid duplication (The Health Foundation 2015). In contrast, there was limited information on pan-Canadian primary care performance. This is not surprising given that Canadian healthcare is provincially organized and we only considered national-level initiatives as part of our review. Primary care performance measurement and reporting activities (including provincial initiatives) were subject to several federal–provincial agreements (from 2004 to 2014) to report on certain elements of primary care performance, yet no province met their reporting obligations under that mandate and there was almost no pan-Canadian comparative data at the end of that decade (Johnston and Hogel 2016). More recently, there have been a growing number of provincial-level performance measurement initiatives such as the Primary Care Performance Measurement Framework developed by Health Quality Ontario and this organization’s quality indicators are being reported to physicians and the public (Health Quality Ontario 2014).
## TABLE 1. Characteristics of national reporting systems that produce primary care performance information, by country

<table>
<thead>
<tr>
<th>Organizations reporting on primary care</th>
<th>Description</th>
<th>Reporting format</th>
<th>Framework: performance domains</th>
<th>Website</th>
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<tbody>
<tr>
<td><strong>Australia</strong></td>
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<td><strong>Canada</strong></td>
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<tr>
<td>Your Health System, Canadian Institute for Health Information (CIHI) Performance Measurement Framework</td>
<td>Independent agency, reports local-level and national health information. A small number of primary care indicators reported with other healthcare indicators; detailed in a report and interactive website.</td>
<td>Public reports and interactive website.</td>
<td>Whole of health system: Health system and context as inputs (e.g., social determinants of health). Health system outputs include access, person-centred, safe, appropriate, effective and efficiency.</td>
<td>&lt;www.cihi.ca/cihi-ext-portal/internet/en/tabbedcontent/health+system+performance/our+health+system/chi013620&gt;</td>
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<td><strong>England</strong></td>
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<tr>
<td>Care Quality Commission (CQC)</td>
<td>Monitoring system for general practices to help monitor the quality of care (e.g., used to plan inspection activities and also publicly available).</td>
<td>Public reports and interactive website.</td>
<td>Primary care specific: effectiveness, responsiveness and care.</td>
<td>&lt;www.cqc.org.uk/&gt;</td>
</tr>
<tr>
<td>NHS Choices</td>
<td>Launched to support the public become active consumers of healthcare and to make healthcare decisions.</td>
<td>Interactive website.</td>
<td>Whole of health system: user ratings, online facilities, patient experiences of care and quality of services, patients with long-term conditions, age of patients and use of hospitals.</td>
<td>&lt;www.nhs.uk/pages/home.aspx&gt;</td>
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### Organizations reporting on primary care

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<th>Name</th>
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<tr>
<td><strong>New Zealand</strong></td>
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<tr>
<td><strong>Norway – Limited information available in English</strong></td>
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<td><strong>Sweden</strong></td>
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<tr>
<td>Quality and Efficiency in Swedish Health Care, Swedish Association of Local Authorities and Regions</td>
<td>National and local-level reporting. Several measures related to primary care in the report.</td>
<td>Public report.</td>
<td>Whole of health system: overall indicators (e.g., mortality) and indicators by 12 clinical areas.</td>
<td>&lt;www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19072/2013-5-7.pdf&gt;</td>
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<td><strong>Switzerland – Limited information available in English</strong></td>
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<td><strong>US</strong></td>
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<tr>
<td>Physician Consortium Performance Improvement (PCPI)</td>
<td>Physician-led (American Medical Association) effort to drive improvement and support healthcare professionals.</td>
<td>Indicators available online. Results not publicly reported; direct to physicians.</td>
<td>Primary care: Indicators in 47 clinical areas.</td>
<td><a href="https://www.ama-assn.org/about/improving-health-outcomes">https://www.ama-assn.org/about/improving-health-outcomes</a></td>
</tr>
<tr>
<td>Quality Indicators, Agency for Healthcare Research and Quality (AHRQ)</td>
<td>Indicator specifications for providers and clinicians: the prevention quality indicators relate to primary care.</td>
<td>Indicators available online; results not publicly reported.</td>
<td>Whole of health system: prevention quality and safety indicators related to primary care.</td>
<td>&lt;www.qualityindicators.ahrq.gov/Modules/pqi_resources.aspx&gt;</td>
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</tbody>
</table>
We found that most indicator sets reported by national organizations focused on clinical areas of performance (e.g., technical quality of care measures) with no specific over-arching conceptual framework. An exception to this was the Quality and Outcome Framework (UK), which was developed around a conceptual primary care framework that included organizational, clinical and patient experience dimensions, though most measures are focused on technical aspects of the quality of care. In fact, clinical, or technical, quality of care measures for single diseases such as diabetes and cardiovascular disease and prevention measures such as immunization rates currently dominate measurement, terminology and reporting efforts in many jurisdictions (Higgins et al. 2013). Where broader dimensions of primary care are considered, access to care is most commonly reported. This may evolve in the near future with agencies such as the National Quality Forum in the US (responsible for endorsing thousands of measures/indicators, including HEDIS measures) developing new approaches to measuring quality in specific patient populations particularly relevant to primary care such as patients with multi-morbidity.

There was a range in the level of focus on primary care, for example, the US HEDIS indicator set was developed specifically for primary care. And while there is currently no national primary care reporting system in Canada outside of the work produced by the Commonwealth Fund, the Canadian Institute for Health Information (CIHI) has developed some indicator specifications designed for pan-Canadian reporting (CIHI 2012). Some initiatives produced information on primary care as part of a broader conception of the healthcare system that included hospital care plus primary care and in some cases, population health (e.g., Dutch Health Performance Report, National Health Performance Authority, Quality and Efficiency in Swedish Health Care, Swedish Association of Local Authorities and Regions, CIHI Your Health initiative and reporting framework). The frameworks driving these initiatives were broad (i.e., not specifically focused on primary care), but measures remain in healthcare silos rather than, for example, tracking patient pathways from primary care to acute care.

Bringing it all together: input from a multidisciplinary research team to propose a matrix for performance measurement in primary care

In primary care, there is a history of research that has produced frameworks to capture the nature of primary care patients and organizational structure for the purposes of quality evaluation and system improvement (Hogg et al. 2008; Kringos et al. 2010; Starfield 1998; Watson et al. 2004). In terms of performance measurement and reporting, there appears to be a proliferation of measures and public reporting but little evidence of conceptual frameworks (e.g., Hogg et al. 2008; Kringos et al. 2010; Senn et al. 2014; Starfield 1998; Watson et al. 2004) being used to organize performance measurement activities. There is thus a mismatch between researcher-developed frameworks, which will not necessarily focus on implementation, and system-developed indicators not rooted in robust conceptual frameworks. To address this, our international team of primary care researchers and clinicians proposes an approach to bridge research and real-world primary care measurement and reporting building on the strengths of each initiative.
Rigorous conceptual frameworks help anchor measurement in some kind of logical system and convey why and what we are measuring. Indicator systems, in contrast, are practically focused, with indicators specific to patients who are the target of specific concern (e.g., diagnoses of interest). We propose that a fruitful path forward is a matrix approach to performance measurement, incorporating the focused approach of measurement in identified patient or population segments that represent different primary care needs (the rows), with measures chosen to reflect performance domains representing accepted features of high-quality primary care (the columns) (see Figure 1).

**FIGURE 1. Proposed performance measurement framework**

![Proposed performance measurement framework](image)

*This framework is a matrix structure of domains of primary care performance by patient population segments. The selection of performance domains and population segments can be modified depending on the intended use of the framework or the specific jurisdiction.*

We suggest that population segmentation can address the heterogeneity of primary care patients and produce actionable information on primary care functioning. The most common ways of stratifying or segmenting the population include presentation of information by age or specific diagnoses; however, these approaches may not accurately determine health system burden (Evans et al. 2010; Morgan and Cunningham 2011) or may produce many small categories, each of which account for only a small percentage of primary care patients. For example, not all elderly patients have high healthcare needs and patients with very different chronic conditions may share the same needs for resources or benefit from common care organization (Caminiti et al. 2013; Mukhi et al. 2014; Ricci-Cabello et al. 2015). As a result, existing approaches can require the use of hundreds of individual disease-specific measures but struggle to capture and measure patients with multi-morbidities (Caminiti et al. 2013; Mukhi et al. 2014) or to represent a practice or system overall. In the context of increasing complexity of patient diagnoses (e.g., multi-morbidity), patient populations could be grouped, not by specific diseases but by health status, functional ability and/or healthcare needs (Lynn et al. 2007). This has been proposed as an approach to support planning and organizing health

As the need for primary care services may be vastly different for patients in different groups, reporting by population segment may directly inform resource allocation efforts or the organization of services (i.e., to match services to patient need). For example, in Figure 2, continuity for all patients is average, whereas performance by patient group ranges from low (healthy patients) to high (multiple chronic conditions, advanced chronic conditions). In this example, the lower continuity scores for healthy patients might not be of concern to a regional healthcare planner as these patients are relatively stable with relatively few primary care needs; yet the high scores for more complex patients suggest success in the delivery of primary care for this particular dimension. If in this example continuity of care was low for the most complex patients, this may be a cause of concern for clinicians and decision-makers in a given region. Specifically, it is important that continuity of care is adequate for patients with multiple complex chronic disease, both from a quality and cost perspective; these patients use significantly more healthcare services, including multiple providers, prescriptions and routine tests, compared to a healthy patient with no chronic conditions who uses very few health services, and high continuity of care has been associated with reduced use of hospital services, which are the most expensive part of the healthcare system (Burge et al. 2003; Haggerty 2012; Haggerty et al. 2003). This example demonstrates that population segmentation would allow fine-tuning of performance on important dimensions according to patterns of care associated with improved patient outcomes and reduced healthcare costs.

**FIGURE 2.** Demonstration of the performance measurement framework in practice*

*This figure shows that results for healthcare regions may be average across “all patients” but vary within different population segments. For the purposes of simplicity, results are mapped for each domain; in reality, there will be multiple measures for each performance domain. The vulnerability distribution for each patient group will be factored into some measures to assess equity.
DETERMINING POPULATION SEGMENTS

We propose categorizing patients according to the nature and extent of expected primary care involvement, ranging from minimal (e.g., routine screening, treatment for minor time-limited conditions) through to high intensity involvement (e.g., care coordination, symptom management, ongoing tests, prescription management, and coordinating care across multiple settings and providers) (Ashman and Beresovsky 2013; Venkatesh et al. 2014).

While the specifics will vary by jurisdiction, using a set of principles (Box 1), we provide an example of five population segments that we plan to test for acceptability as part of our pan-Canadian stakeholder engagement plan for the Transformation project (Table 2). The five groups are: healthy, at risk of developing a chronic condition, one chronic condition, multiple chronic conditions and advanced complex chronic conditions (including patients approaching the end of life). We note that groups will not be of equal size; healthy patients will comprise the largest proportion of the total population in any primary care system and they will have the lowest per capita service use and relatively light requirements for primary care. In contrast, patients with multiple chronic conditions will be one of the smallest groups (by total population) but will in all likelihood account for the greatest per capita use of primary care services.

BOX 1. Principles for developing population segments to form the basis of a regional-level primary care information system

1. Captures the vast majority of people who interact with primary care services.
2. Based on anticipated (vs. actual) primary care involvement with an aim to identify groups based on “need for primary care” as opposed to utilization of primary care services. This is a more nuanced approach to developing groups using health service use, but it is likely to correlate with health service use given that sicker patients usually use more healthcare services (Bayliss et al. 2015; Ionescu-Ittu et al. 2007; Lynn et al. 2007).
3. Relatively homogenous in terms of the primary healthcare needs and health priorities of patients in each group (e.g., staying healthy, getting better, living with illness or dealing with a life-limiting illness).
4. Mutually exclusive such that the tallying of groups is equal to the whole population.
5. The number of groups would be large enough to enable regional comparisons yet small enough to enable reporting at smaller levels (e.g., practice-level reporting, if this became an area of interest at some stage in the future).
6. Enable tracking the quality of care longitudinally (i.e., patients may be classified into different segments over time as their health status improves or deteriorates).

Given that factors such as social determinants of health and other relevant risk factors may be dependent on local-level context (e.g., population characteristics, resource allocation priorities), we suggest incorporating these into the measurement system for specific measures/indicators rather than further segmenting population groups into more and less vulnerable patients.

IDENTIFYING PERFORMANCE DOMAINS

There are a variety of domains that have been used to describe primary care performance internationally (Hogg et al. 2008; Kringos et al. 2010). A recent synthesis of over 80 studies identified 10 core dimensions of primary care across three measurement domains of structure (governance, economic conditions and workforce development), process (access, comprehensiveness, continuity and coordination) and outcome (quality, efficiency and equity) (Kringos et al. 2010). For the purposes of regional primary healthcare performance measurement, we suggest
using commonly accepted domains that cover the broadest scope of primary care practice. Perhaps the most cited domains of primary care are those defined by Starfield (1998), who described primary care as having the following attributes: first point of contact (accessibility); person-focused and longitudinal care (continuity); provision of care for all but uncommon conditions (comprehensive); and coordination/integration of care provided by other healthcare providers (Starfield 1998). We also suggest inclusion of the Institute of Medicine’s six domains of quality proposed in the seminal report, *Crossing the Quality Chasm*, which continues to be the enduring definition of healthcare quality: access (or timeliness), safety, patient experience (patient-centredness), efficiency, effectiveness and equity (IOM 2001, 2006).

**TABLE 2.** Population segments for inclusion in primary care performance measurement framework

<table>
<thead>
<tr>
<th>Population group</th>
<th>Description</th>
<th>Rationale for inclusion in a primary performance measurement framework</th>
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<tbody>
<tr>
<td>Healthy</td>
<td>No ongoing medical conditions or behavioural risk factors. Possible acute conditions that require time-limited treatment (e.g., pregnancy, accidental injury).</td>
<td>Comprises the majority of the population; expected use of primary care is low (Porter et al. 2013). The role of primary care is maintenance of health and possible management of time-limited acute conditions.</td>
</tr>
<tr>
<td>At risk of developing a chronic condition</td>
<td>Presence of medical risk factors for developing a chronic disease (e.g., overweight or obese, smoking, excessive alcohol consumption, recreational drug use, sedentary lifestyle).</td>
<td>A growing proportion of the population; expected use of primary care is low but this is a priority group as primary care has a role in treatment plans for modifiable risk factors (Thorpe 2005). Primary care has an important role in preventive medicine such as behavioural programs for weight management and smoking cessation. Successful strategies could result in patients moving into the healthy population group as opposed to developing chronic disease(s) (Porter et al. 2013).</td>
</tr>
<tr>
<td>One chronic condition</td>
<td>One ongoing chronic condition with impact on functional status (e.g., diabetes mellitus, hypertension).</td>
<td>A growing proportion of the population; expected use of primary care is moderate with the majority of primary care patients having at least one chronic disease (Bayliss et al. 2014; Milani and Lavie 2014). Evidence-based guidelines are available to guide the care of these patients; technical quality of care metrics may be useful for this patient group. Successful management may prevent the development of additional chronic diseases. Primary care has a role in ongoing disease management and prevention of secondary complications (Porter et al. 2013).</td>
</tr>
<tr>
<td>Multiple chronic conditions</td>
<td>Two or more ongoing chronic conditions with impact on functional status.</td>
<td>A growing proportion of the population; expected use of primary care is high (Banerjee 2014; Bayliss et al. 2014; Fortin et al. 2012; Koller et al. 2014). There are few evidence-based guidelines or quality metrics currently available to guide care for this patient group. As such, data on the performance of primary care for this group has particular utility. Primary care has a role in ongoing disease management and prevention of secondary complications (Porter et al. 2013).</td>
</tr>
<tr>
<td>Advanced complex chronic conditions</td>
<td>Multiple advanced chronic conditions with complications or patient approaching the end of life.</td>
<td>The smallest population segment, but these patients use more healthcare services than any other group (Lunney et al. 2002; Lynn et al. 2007); expected use of primary care will vary and there are concerns about the quality of care (e.g., over-reliance on hospital services, underutilization of primary care or palliative services). Primary care has a role in ongoing disease management, prevention of secondary complications with the aim of avoiding the need for unplanned hospital care (Porter et al. 2013).</td>
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To complement the primary care performance domains, we suggest tracking information on health services use and cost (including physician visits, hospital services, emergency room visits, diagnostic and therapeutic procedures and medicines), overall and by healthcare sector. For example, we will examine the nature and costs of primary care service use and hospital use by population subgroups. Such information is important as effective use of primary care (e.g., health promotion, prevention) could impact total cost and health outcomes, and this lens...
allows for examination of the extent of integration across health sectors (Berwick et al. 2008). Presenting information on primary care in isolation perpetuates the fragmented nature of health service delivery and does not promote an environment of shared accountability across hospital and community settings (IOM 2006; Venkatesh et al. 2014). As Venkatesh et al. stated; “Unlike quality measures … the health of patients cannot be sliced into specific care settings or cut into pieces among provider types” (Venkatesh et al. 2014: 76).

Discussion
We compared national primary care performance measurement initiatives across 11 countries with the goal of identifying an approach we could use to drive the development of a regional-level pan-Canadian primary information system. Despite a growing range of reporting activity, few systems used conceptual frameworks of primary care. To address this, we propose a matrix approach to primary care performance measurement and reporting that is grounded in the organization of primary care services (Hogg et al. 2008; Kringos et al. 2010; Watson et al. 2004) and primary care needs of different population groups. Our approach looks beyond single-disease or age-based segmentation approaches because not all patients with a given condition or of a given age have the same healthcare needs and reporting by condition has decreasing value when a growing number of patients are diagnosed with multiple conditions (Banerjee 2014; Barnett et al. 2012; Bayliss et al. 2014).

We suggest that population segmentation may mitigate or reduce the need for complex case-mix adjustment methods (Smith et al. 2009) – something that is usually recommended when producing comparative performance information. Risk adjustment attempts to account for differences in patient populations to allow for fair comparisons of health system performance, but even with cutting-edge risk adjustment and state-of-the-art data sets, we are currently unable to adequately measure all of the patient and health system factors that may influence health system performance (Doggen et al. 2014; Smith et al. 2009). In contrast, the population segmentation approach effectively serves as a stratification approach instead of trying to risk-adjust within a broader population grouping. Perhaps more importantly in this context, stratification is potentially more useful in providing actionable information because it identifies differences rather than trying to reduce differences or understand performance on average. At a local level, this allows for transparency about regional differences in patient characteristics and healthcare needs as well as being able to compare the performance of primary care with other regions.

Our matrix aligns with primary care service delivery and patient populations, thus optimizing the potential impact of performance measurement and reporting activities. This approach recognizes the variation in the type of care required by patients who use primary care, ranging from patients who are stable and require only acute and time-limited treatment to long-term chronic disease management, with the latter accounting for the majority of modern day primary care visits (Milani and Lavie 2014). We have deliberately chosen to identify patient groups based on expected primary care need/use (prospectively) rather than “high utilizer” approaches that select the most costly patients and track them over time (Emeche 2015; Newton and Lefebvre 2015). Our approach could provide more nuanced information
that will allow clinicians and decision-makers to identify gaps in the delivery of primary care (e.g., sick patients without access to care) and information for policy makers to channel resource allocation and efforts for improved efficiency and value for money in healthcare over time (e.g., duplication of tests for patients with low continuity of care) (Panzer et al. 2013; Porter 2010).

While beyond the scope of this paper, there will be many challenges to consider in implementing our approach into an actionable pan-Canadian primary care reporting system (Adair et al. 2006a, 2006b; Panzer et al. 2013). Our approach is designed to be flexible and adaptable to different settings and jurisdictions but implementation should include stakeholder engagement (Ivers et al. 2014; Oliver et al. 2014) to ensure that the framework and resulting performance information aligns with existing initiatives and meets the needs of the target users that may include patients, clinicians, decision-makers and health system managers. Our project team has embarked upon an extensive stakeholder consultation process using case studies, deliberative dialogues and workshops to gain input on implementing our performance matrix (developing patient subgroups and indicator selection).

Another important challenge is avoiding selecting and reporting measures based on what is easiest to measure given data availability and historically popular metrics. The approach we have taken is to develop a data infrastructure that combines patient, provider, primary care organization and health system perspectives. We are using our data infrastructure (surveys and health administrative data) to develop our population segments and choose measures to report on; however, there are other data sources (e.g., electronic health records, clinical data) that could be harnessed to develop population segments and report on primary care performance (Vuik et al. 2016). Regardless of what data are available, there is the challenge of choosing how to segment the population. We present one possible five-category segmentation approach, but again, the framework is meant to be flexible and calibrated to local needs. Determining the segments could be done very simply, for example, based on patient age, or in a more complex way, including morbidity and/or socio-economic status. These decisions will best be made with stakeholder engagement, as any segmentation must be meaningful to the potential users of the resulting performance information (The Health Foundation 2015).

The proposed matrix approach to primary care performance measurement reflects a need for regional planning based on healthcare needs of populations in an era of increasing patient complexity and multi-morbidity. To our knowledge, this is the first primary care performance measurement approach to make use of broad conceptual frameworks containing multiple dimensions of primary care and population segmentation – an approach that may move this field forward. Our work is timely in the context of the new Canadian health accord and suggestions that a per capita approach to funding be replaced with an approach that takes into account regional variations in population characteristics (Vogel 2015). While there have been suggestions that the age of populations might be a way to organize funding, we suggest that a more nuanced approach that groups patients according to complexity and healthcare needs may be a more useful way to understand the performance of primary care and other parts of the healthcare system (Lynn et al. 2007).
Acknowledgements
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References
Primary Care Performance Measurement and Reporting at a Regional Level


Primary Care Performance Measurement and Reporting at a Regional Level


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What’s Measured Is Not Necessarily What Matters: A Cautionary Story from Public Health

Ce qui est évalué n’est pas nécessairement ce qui est le plus important : un récit instructif provenant de la santé publique

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Abstract
A systematic review of the introduction and use of outcome-based performance management systems for public health organizations found differences between their use as a management system (which requires rigorous definition and measurement to allow comparison across organizational units) versus for improvement (which may require more flexibility). What is included in performance measurement/management systems is influenced by ease of measurement, data quality, ability of organization to control outcomes, ability to measure success in terms of doing things (rather than preventing things) and what is already happening. To the extent that most providers wish to do a good job, the availability of good data to enable benchmarking and improvement is an important step forward. However, to the extent that the health of a population is dependent on multiple factors, many beyond the mandate of the health system, too extensive a reliance on performance measurement may risk unintended consequences of marginalizing critical activities.
Résumé
Une revue systématique sur l’introduction et l’utilisation de systèmes de gestion du rendement par les organismes de santé publique a relevé des différences entre leur utilisation en tant que systèmes de gestion (qui demande des définitions et des évaluations précises afin de permettre une comparaison des unités organisationnelles) et leur utilisation pour l’optimisation (qui exige plus de flexibilité). La sélection des paramètres qui seront utilisés dans les systèmes de gestion du rendement est influencée par : ce qui est facile à évaluer, la qualité des données, la capacité de l’organisation à contrôler les résultats et à évaluer le succès en fonction de ce qui se fait (plutôt qu’en fonction d’actions préventives). Dans la mesure où la plupart des intervenants souhaitent faire un bon travail, la disponibilité de données pertinentes pour permettre des évaluations comparatives et des améliorations est un pas important dans la bonne direction. Par contre, dans la mesure où la santé de la population dépend de plusieurs facteurs, qui sont souvent en dehors du mandat du système de santé, une trop grande dépendance sur la mesure du rendement risque d’avoir des conséquences inattendues, telles que la marginalisation d’activités critiques.

Introduction
The New Public Management has been associated with an increased emphasis on measuring performance, often summarized using the phrase “What’s measured is what matters.” A growing literature has found potential limitations to this view (Bevan and Hood 2006; Exworthy 2010; Kuhlmann 2010). This manuscript, which grew from a synthesis of the literature on performance measurement and management in public health, presents a conceptual framework for viewing performance measurement and suggests an additional set of risks inherent in over reliance on these approaches.

Materials and Methods
Literature search
We adapted Pawson et al.’s (Pawson et al. 2005) approach to literature review, which recognizes that much of the analysis will, of necessity, be thematic and interpretive (Dixon-Woods et al. 2005; Pawson 2002), including use of cross-case analysis (Mays et al. 2005; Pope et al. 2006). As the ESRC UK Centre for Evidence Based Policy has noted, social science reviews differ from the medical template in that they rely on a “more diverse pattern of knowledge production,” including books and grey literature (Grayson and Gomersall 2003).

Our search strategy included multiple sources. We began with 213 references provided by our KT partner, the Public Health Practice Branch of the Ontario Ministry of Health and Long-Term Care. To capture published and grey literature, we searched such databases as PubMed, Web of Science and Google Scholar; these sites tend to capture different literatures, and thus helped ensure that key references were not missed, using such keywords as: indicators, accreditation, balanced scorecard, evidence-based public health, local public
health, performance measurement, performance standards and public health management, alone and in combination. We also searched relevant websites, both for the selected jurisdictions and for the papers and reports produced by the World Health Organization (WHO), Organisation for Economic Co-operation and Development (OECD) and the European Observatory on Health Systems and Policies. We then analyzed both backwards and forward citation chains from key articles – that is, checking the relevant articles cited by that paper (backwards) and the materials citing that article (forward). Other helpful sources were a US review of performance management in public health (Public Health Foundation 2009) funded by the Robert Wood Johnson Foundation, the materials on their website (available at http://www.phf.org/resources/tools/pages/turning_point_project_publications.aspx) and the proceedings of a WHO European Ministerial Conference on Health Systems, which focused on performance measurement for health system improvement (Smith et al. 2009).

The abstracts were then scanned for relevance by our team. The approach taken examined the general literature and then selected literature relevant to key case examples from Australia, New Zealand, the UK, the EU, the US and Canada. Case examples were chosen by looking at the jurisdictions selected, with a focus on those that matched, corresponded or contrasted with the Ontario Public Health Standards. This initial review yielded 970 references, which was subsequently augmented by new publications; we also deleted articles not relevant to this subject. The retained material on which this analysis is based was published between 1966 and 2015, with 13 references before 1990, 125 between 1990 and 1999 and 807 between 2000 and 2011, although we have subsequently examined additional more recent publications. Our analysis of the 55 public health measurement cases we selected has been published elsewhere (Schwartz and Deber 2016). This paper focuses on some key lessons for applying performance management and measurement approaches to public health.

Results

Defining our terms

Increasing attention is being paid to the use of information to improve performance. Much of this dialogue is couched in terms of accountability (Smith et al. 2009). There is an extensive literature from management science and from new public management on the use of performance measurement and management in both the public and private sectors (Bouckaert 1993; Freeman 2002; Julnes 2009; Kuhlmann 2010; Poister and Streib 1999). These authors place heavy emphasis on the role of organizational culture and political support in being able to implement change.

Accountability is defined as having to be answerable to someone for meeting defined objectives (Emanuel and Emanuel 1996; Fooks and Maslove 2004; Marmor and Morone 1980). It has financial, performance and political/democratic dimensions (Brinkerhoff 2004) and can be ex ante or ex post. This may translate into fiscal accountability to payers, clinical accountability for quality of care (Dobrow et al. 2008) and/or accountability to the public.
The actors involved may include various combinations of providers (public and private), patients, payers (including insurers and the legislative and executive branches of government) and regulators (governmental, professional); these actors are connected in various ways (Shortt and Macdonald 2002; Zimmerman 2005). As noted in a series of sub-studies on approaches to accountability published as a special issue of Healthcare Policy (Deber 2014), the tools for establishing and enforcing accountability are similarly varied, and they require clarifying what is meant by accountability, including specifying for what, by whom, to whom and how. Performance management and measurement is frequently suggested as an important tool for improving systems of accountability. As our review clarified, there is some variation within the literature and the cases examined in how various terms are defined and in the purposes of the performance measurement exercise (Solberg et al. 1997). Underlying most of these examples is the sense that managing is difficult without measurement (Gibberd 2005).

Performance measurement has been defined by the US Government Accountability Office (GAO) as “the ongoing monitoring and reporting of program accomplishments, particularly progress toward pre-established goals” (US Government Accountability Office 2005). Their definition notes that such activities are typically conducted by the management of the program or agency responsible for them. The GAO contrasts this with program evaluation, which is often conducted by experts external to the program, and may be periodic or ad hoc, rather than ongoing. The GAO definitions, like many performance measurement systems in healthcare often use the framework of Donabedian, which focuses on various combinations of structures, processes, outputs and outcomes (Donabedian 1966, 1980, 1988).

A number of approaches to performance measurement can be found in the literature (Abernethy et al. 2005; Adair et al. 2003, 2006a, 2006b; Arah et al. 2003; Stoto 2014; Veillard 2012). The focus of performance measurement systems can also vary, but increasing attention has been paid to using performance management as a way of improving system performance. Goals may also vary but are often aligned with quality. Published reviews of performance measurement efforts include both examination of individual countries and comparisons among OECD countries, including Canada, the US, the UK and Australia (Baker et al. 1998, 2008; Hurst 2002; Hurst and Jee-Hughes 2001; Kelley and Hurst 2006; Mattke et al. 2006; Smith 2002). Much of the literature focuses on using performance measurement to improve clinical quality of care across a variety of settings, including primary care and emergency care (Barnsley et al. 1996; Linder et al. 2009; Lindsay et al. 2002; Phillips et al. 2008). Other projects focus on using performance measurement to improve governance, often using the language of accountability. For this to occur, ongoing data collection is important, so that management and stakeholders can use up-to-date information to monitor the quality of care being provided (Loeb 2004). One approach is to use performance indicators.

Performance management, by contrast, both paves the way for and requires a performance measurement system. Many measurement systems are developed with the goal of defining where improvements can be made, with the assumption that managers can use them once the
measurement results are examined (Lebas 1995). Performance management can be defined as the action of using performance measurement data to effect change within an organization to achieve predetermined goals (Folan and Browne 2005). There is now broad recognition that while public sector organizations are doing a great deal of performance measurement, they often do not use the data well in full-fledged performance management systems (Schwartz 2011). Nevertheless, there are a number of success stories in public management of using well-designed measurement systems to improve performance (Ammons 1995). Although measurement may be necessary for management, not all performance measurement systems assume that they will be used for management.

Implementing performance measurement: Goals and indicators

The first step to developing a successful performance measurement system is to clearly define what will be measured. McGlynn and Asch suggest that three considerations should be taken into account when choosing an area to measure: (1) how important the area of healthcare being measured is, (2) the amount of potential this area holds for quality improvement and (3) the degree to which healthcare professionals are able to control quality improvement in this area of healthcare. They define importance in terms of mortality/morbidity, but also utilization of health services and cost to treat (McGlynn and Asch 1998). Again, there is likely to be variation, depending on whether one is focused on particular patient groups or on the health of the population. However, from the viewpoint of public health, these considerations point to the importance of surveillance systems to provide decision-makers with information about the prevalence of conditions, how they are being addressed and the outcomes of interventions.

Often implicit are what policy goals are being pursued. Different goals may imply different policies. Key goals are usually some combination of access, quality (including safety) (Baker et al. 2004), cost control/cost effectiveness and customer satisfaction (Monahan 2006; Myers and Lacey 1996). Behn suggests the objectives for accountability should be improved performance, fairness and financial stewardship (Behn 2001). This affects what organizations are accountable for. Often, policy goals may clash (Deber et al. 2004). An ongoing issue is the potential for unintended consequences if the measures selected do not reflect the full set of policy goals (Townley 2005). Indeed, one of the purposes of balanced scorecards is to make such potential conflicts between goals and measures more evident (Baker and Pink 1995; Kaplan and Norton 1996; Pink et al. 2001; Ten Asbroek et al. 2004; Weir et al. 2009).

Once an appropriate area has been identified for measurement, the next step in developing a performance measurement system is to identify potential indicators that will be used in the measurement system. Indicators have been defined as “a measurement tool used to monitor and evaluate the quality of important governance, management, clinical and support functions” (Klazinga et al. 2001). Indicators can be classified. For example, some authors assume that because performance must be measured against some specification, performance
indicators do infer quality. Others (who do not necessarily represent a common view) dis
tinguish between “Activity Indicators,” which measure how frequently an event takes place;
“Quality Indicators,” which measure the quality of care being provided; and “Performance
Indicators,” which do not infer quality but measure other aspects of the performance of the
system (for example, the use of resources) (Campbell et al. 2003).

The issue of measurement
Loeb (2004) argues that not everything in healthcare can or should be measured. Challenges
may arise when outcomes are influenced by factors other than the interventions being
assessed or beyond the control of those being held accountable. There are also issues asso-
ciated with balancing the number of indicators needed to provide enough information,
with usability and costs associated with having too many indicators. Developing and run-
ing a performance measurement system is often expensive, and the data produced needs
to be useful and interpretable for its users.

Many indicators are developed through a rigorous process by which they are developed,
defined and reviewed (Lindsay et al. 2002; McGlynn and Asch 1998). Data sources also need
to be identified when developing and choosing a set of indicators, with the most common
sources coming from healthcare enrollment, administrative data, clinical data and survey data.
Clear definitions will ease implementation of the measurement system and its data collection
processes across different organizations/users in a consistent fashion and help to ensure that
the data collected within the measurement system will be comparable and reliable across dif-
ferent users of the system. As Black has noted, this is not always the case (Black 2015).

Considerable efforts have been made to develop comparable indicators to enable cross-
jurisdictional comparisons. These include the OECD quality indicators project (Arah et al.
2006) and the reporting standards for public health indicators (Armstrong et al. 2008). An
offsetting concern is the recognition that strategic scorecards also must include locally rel-
vant indicators. Achieving the right mix between local relevance and the ability to compare
across organizations is crucial.

Discussion
One ongoing issue is what sorts of indicators should be used. A promising development
is the Canadian Institute of Health Information (CIHI) 2012 Performance Measurement
Framework for the Canadian Health System (CIHI 2012), which attempts to link performance
dimensions through expected causal relationships in four interrelated quadrants: Health
System Outcomes, Social Determinants of Health, Health System Outputs and Health
System Inputs and Characteristics. Proper application of this and similar frameworks may
help to ensure a more balanced approach to what is measured and what matters.

However, our review suggests that the factors important to those individuals providing clini-
cal services to clients often differ from those important to program managers, payers or health
systems (Tregunno et al. 2004). One class of indicators focuses on adverse outcomes, either at
the individual level (e.g., adverse events) or at the system level (e.g., avoidable deaths). Klazinga et al. argued that “epidemiological research has shown the difficulties in validating [negative health outcomes] as indicators for the quality of care that was delivered” (Klazinga et al. 2001).

In selecting indicators, a key factor is the extent to which the elements affecting the measurement are under control of decision-makers. Chassin et al. emphasized that for an outcome indicator to be relevant, it must be closely related to the healthcare processes that have an effect on the outcome (Chassin et al. 1998). In addition, there may be differences in what would be done with information; although the information may be valuable, it is difficult to hold managers accountable for things they cannot control. One obvious example is geography, which will often affect travel costs or access. Another, which affects population health, is the extent to which the various determinants of health (e.g., income, housing, tobacco use, etc.) are under the control of public health organizations. Information may thus be helpful in affecting policy levers (e.g., pricing of alcohol, tobacco) that other actors control, but less useful if program managers will be rewarded (or punished) for variables they cannot affect.

Other factors include whether different indicators are correlated (which can lead to double counting), how easy they are to measure (transaction costs), extent to which they are subject to “gaming” and whether they cover the outcomes of interest (Bevan 2010; Exworthy 2010; Ham 2010; Hamblin 2008; Irwin 2010; Klazinga 2010; Provincial Auditor of Ontario 2003).

Likely impacts
Another set of issues involves what will be done with the performance measures, including how they will be applied. Frequently, performance measurement involves setting performance targets and assessing the extent to which these are being met. In turn, these may be used for funding (e.g., results-based budgeting) and/or to identify areas for in-depth evaluation. External bodies may use the information to ensure accountability. Managers may use them to monitor activities and make policies. Townley argued that “the use of performance measures reflects a belief in the efficacy of rational management systems in achieving improvements in performance” (Townley 2005). In the UK, use of fiscal levers is sometimes referred to as “targets and terror” (Propper et al. 2008).

The way in which measures are likely to affect behaviour varies. Clearly, measurement is simplest if organizations produce a small number of services, have a limited number of goals, understand the relationship between inputs and results and can control their own outcomes. As Townley notes, “A failure to ground performance measures in the everyday activity of the workforce is likely to see them dismissed for being irrelevant, unwieldy, arbitrary, or divisive.” Other potential downsides are that “the time and resources taken to collect measures may outweigh the benefits of their use” (Townley 2005).

A related set of factors relates to the organizational infrastructure (Alexander et al. 2006). The workplace culture, including differences between the explicit goals and what some have called the “implicit theories” or “theories in use,” which affect day-to-day functioning, may affect the extent to which change initiatives are embraced and performance changes
(Aitken 1994). This is in turn related to concepts of “street level bureaucracy,” which deals with the extent to which it is simple to manage and observe the activities of those responsible for providing the given services (Lipsky 1980). Other less desirable organizational responses to performance measurement may include decoupling, a term used to refer to situations where specialist units are responsible for performance measurement, but where the measures have little impact on day-to-day activities and may lead to a sense that the measurement approach is “ritualistic” and “bureaucratic” rather than integral to improvement (Townley 2005). Even more alarmingly, measurement can lead to dysfunctional consequences, including focusing on measures rather than actual performance, impairment of innovation, gaming and creative accounting, potentially making performance worse (Hamblin 2008; Leggat et al. 1998). Other effects can be subtle; one example is placing less emphasis on prevention than on treating existing problems. The extent to which these positive or negative effects are realized may be heavily dependent upon context.

Conclusions
Selecting indicators
We found considerable differences in what sorts of performance measurement and management are actually being done, not just by jurisdiction (which we expected) but also by type of service. We found heavy emphasis on surveillance and far less on explicitly using the indicator data for management. Additionally, there is more focus on processes of how services are provided than on outcomes.

A number of rationales are provided for this state of affairs. An excellent synthesis can be found in the proceedings of a WHO symposium, which stresses the importance of clarifying causality and the difficulty in holding providers accountable for outcomes that they cannot control. As one example, “physicians working in socio-economically disadvantaged localities may be wrongly blamed for securing poor outcomes beyond the control of the health system” (Smith et al. 2009: 12). Risk adjustment methodologies can control for some, but not all, of this variation. Composite indicators can be useful, but only if transparent and valid. Similarly, it may be necessary to deal with random fluctuations before determining when intervention is needed to improve performance.

One striking finding that emerged from our review of how performance measurement and management are used in public health was the extent to which they focused on clinical services addressed to individuals (Smith et al. 2009). Activities directed towards improving the health of populations, particularly those with a preventive orientation, tend not to be included. As one example, the chapter in the report of the WHO symposium purportedly devoted to population health focuses almost exclusively on clinical treatment, including heavy focus on tracer conditions. One rationale given by these authors is that the performance measurement/management experiments they reported on wished to focus on the healthcare system. Their reaction to the fact that “it is often difficult to assess the extent to which variations in health outcome can be attributed to the health system” (Nolte et al. 2009) was accordingly to omit such measures.
One concern arising from our review is that performance measurement approaches, by focusing so heavily upon the healthcare system, may skew attention away from important initiatives directed at improving the health of the population. Indeed, another chapter in the WHO symposium volume on “measuring clinical quality and appropriateness” explicitly states (pp 88–89): “A number of potential actions to improve population health do not operate through the health-care system (e.g., ensuring adequate sanitation, safe food, clean environments) and some areas do not have health services that are effective in changing an outcome. Neither of these areas is fruitful for developing clinical process measures” (McGlynn 2009). Omitting such areas from measurement systems, however, may falsely imply that they do not matter.

Our review stresses the importance of being aware of unintended consequences. For example, in the UK pay-for-performance (P4P), success tended to be measured as doing more of particular things (e.g., screening tests, medication, some immunization) for particular populations (e.g., people with chronic diseases); prevention and population health risk being lost in the shuffle.

Some key variables that appear to influence what is being included in performance measurement/management systems include:

• Ease of measurement.
• Data quality. Jurisdictions vary considerably in how good the data are. For example, Canada does not yet have good data about immunization at the national level.
• Ability of organization to control outcomes.
• Ability to measure success in terms of doing things (rather than preventing things).
• What is already happening. One example is the UK P4P for physicians, which is generally considered to have been highly successful. However, there was some suggestion that what was being rewarded was better recording rather than changes in practice. The indicator systems appear to, in part, reward providers for things they were already doing, which in turn raises questions about who gets to set the indicators.

One important caveat for any performance measurement/performance management system is that it does not, and cannot, capture all activities. In that connection, as Black (2015) has noted, it is important to recognize that most providers are professionals who want to do a good job. Performance measurement/management is only one component, but can give tools to allow all stakeholders to know how they are doing and enable the use of benchmarking to improve performance. A second caveat is that we focused on published information; this may or may not reflect current activities in those jurisdictions. Successful interventions are also more likely to have been published.

To the extent that the health of a population is dependent on multiple factors, many beyond the mandate of the healthcare system (both personal health and public health), however, our review suggests that too extensive a reliance on performance measurement may risk unintended consequences of marginalizing critical activities. As ever, balance is key.
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References


How Safe and Innovative Are First-in-Class Drugs Approved by Health Canada: A Cohort Study

L’innocuité et l’aspect innovant des nouvelles classes de médicaments approuvés par Santé Canada : une étude de cohorte

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Abstract

Introduction: First-in-class drugs use a unique mechanism of action. This study assessed the therapeutic innovativeness and safety of these drugs approved by Health Canada from 1997–2012.

Methods: A list of new drugs was compiled and a database from the Food and Drug Administration was used to determine first-in-class status. Post-market safety warnings and drugs withdrawn for safety reasons were identified from the MedEffect Canada website. Therapeutic innovation evaluations came from the Patented Medicine Prices Review Board (PMPRB) and Prescrire International. The proportion of first-in-class drugs that were innovative was compared to the proportion of non-first-in-class drugs that were innovative. Kaplan–Meier survival curves assessed safety.

Results: In all, 462 drugs were approved by Health Canada during the period under study. Among these, 345 were evaluated by PMPRB and/or Prescrire, and first-in-class data were available for 292. Ninety-eight of the 292 were first-in-class and 16 were innovative compared to 9 of 194 drugs that were not-first-in-class. There was no difference in safety between the two groups.

Discussion: Overall, the benefit-to-harm ratio of first-in-class drugs, as measured by post-market safety warnings/withdrawals, is better than those that were not-first-in-class.
Résumé
Méthodes : Une liste de nouveaux médicaments a été compilée et une base de données de la Food and Drug Administration a été utilisée afin de déterminer le statut de ces nouvelles classes de médicaments. Les mises en garde diffusées après la commercialisation et le retrait de médicaments pour des raisons de santé ont été établis à partir du site Web MedEffet Canada. L’évaluation des aspects thérapeutiques et innovants provient du Conseil d’examen du prix des médicaments brevets (CEPMB) et de Prescrire International. La proportion des nouvelles classes de médicaments innovants a été comparée à la proportion des médicaments innovants qui n’appartenaient pas à de nouvelles classes. L’innocuité a été évaluée grâce aux courbes d’estimation de Kaplan–Meier pour la fonction de survie.
Discussion : En général, le ratio bienfait/méfait des nouvelles classes de médicaments, tel que mesuré selon les mises en garde et les retraits, est mieux que celui des médicaments n’appartenant pas à de nouvelles classes.

Introduction
First-in-class drugs are ones that use a new and unique mechanism of action for treating a medical condition. These products are often referred to as innovative and cited as offering new treatment options for patients (Lanthier et al. 2013; Pharmaceutical Research and Manufacturers of America 2015b). However, the new mechanism of action can also mean that unexpected safety problems can develop with these products. The first glitazone for treatment of Type II diabetes, troglitazone, had to be removed from the market because of hepatotoxicity (Rawson and Kaitin 2003) and sibutramine, an oral anorexiant, was withdrawn because of cardiovascular toxicity (Lexchin 2014a).

The purpose of this study was to assess the therapeutic innovativeness of first-in-class drugs approved by Health Canada and to compare their safety with drugs that were not-first-in-class. Second, this study examines the review status that Health Canada assigned to both groups of products and whether there is any difference in the number of first-in-class drugs introduced into the Canadian market over time.
Methods

Data sources
A list of all new drugs approved from January 1, 1997 to December 31, 2012, their dates of approval and their review status (priority or standard) was compiled from the annual reports of the Therapeutic Products Directorate and the Biologics and Genetic Therapies Directorate of Health Canada. The 1997 reports from these directorates were the first ones to indicate which products received a priority review. The reports are available by directly contacting the directorates at publications@hc-sc.gc.ca. The priority review pathway is used for drugs under two conditions: (1) for drugs that treat “a serious, life-threatening or severely debilitating disease or condition for which there is substantial evidence of clinical effectiveness that the drug provides … effective treatment … [and] for which no drug is presently marketed in Canada” and (2) for drugs that represent “a significant increase in efficacy and/or significant decrease in risk, such that the overall benefit/risk profile is improved over existing therapies … for a disease or condition that is not adequately managed by a drug marketed in Canada” (Health Canada: Health Products and Food Branch 2009). The timeline for priority reviews is 180 days and for standard reviews, it is 300 days.

Health Canada does not indicate which products are first-in-class, so this determination was based on an analysis of 645 new drugs approved by the US Food and Drug Administration from 1987 to 2011 (Lanthier et al. 2013). In defining a drug as first-in-class, Lanthier et al. based their definition on a combination of factors including FDA-established pharmacologic class designations, approved indications and supplementary sources (for example, commercial databases such as Drug Facts and Comparisons and Pharmaprojects).

Post-market safety warnings and drug withdrawals, hereafter collectively referred to as post-market safety warnings, for the period January 1, 1997 to December 31, 2012, were identified through advisories for health professionals in the Recalls and Safety Alerts Database on the MedEffect Canada website at www.hc-sc.gc.ca/dhp-mps/medeff/advisories-avis/prof/index-eng.php. According to Health Canada, this database is a comprehensive list of recalls, advisories and safety alerts. For each safety advisory or notice of withdrawal of a product, the date was recorded. All serious safety advisories (those using bold black print and/or boxed warnings) were included except for those dealing with the withdrawal of a specific batch, or lot number due to manufacturing problems, or those issued because a drug was being used for an unapproved indication or because of medication errors (e.g., a warning about remembering to remove a transdermal patch before applying a second one). If a drug received more than one serious post-market safety warning, only the time of the first warning was used. When necessary, notices on the MedEffect website were supplemented by searching for the product’s name in the Drug Product Database (DPD) at http://webprod3hc-sc.gc.ca/dpd-bdpp/index-eng.jsp. The DPD website states that it contains product-specific information on drugs approved for use in Canada as well as all products discontinued since 1996, but it does not show changes to the Product Monograph.
The Patented Medicine Prices Review Board (PMPRB) is a federal agency that is responsible for calculating the maximum introductory price for all new patented medications introduced into the Canadian market. It is important to note that the PMPRB is not a payer and, therefore, its decisions about therapeutic value are not influenced by how much it might have to pay for the product. As part of the process of determining the price, the PMPRB's independent Human Drug Advisory Panel (HDAP) determines the therapeutic value of each product it reviews and these evaluations are published in its annual reports available online from 2003 to 2012 at www.pmprb-cepmb.gc.ca/english/View.asp?x=91 and for previous years by directly contacting the PMPRB at pmprb@pmprb-cepmb.gc.ca. HDAP determines the ratings for the drugs before the maximum price is established. For the purpose of this study, products that were deemed as breakthroughs and substantial improvement were termed “innovative” and products in other categories were termed “not innovative.” In deciding on the level of therapeutic innovation, HDAP considers two primary factors – increased efficacy and reduction in incidence or grade of important adverse reactions – and nine secondary factors – route of administration, patient convenience, compliance improvements leading to improved therapeutic efficacy, caregiver convenience, time required to achieve the optimal therapeutic effect, duration of usual treatment course, success rate, percentage of affected population treated effectively and disability avoidance/savings. The primary factors are given the greatest weight, followed by an assessment of any additional improvement as a result of the secondary factors (PMPRB 2014). In some cases, the PMPRB annual reports indicated that the therapeutic value of the product was still being determined and in those cases, the PMPRB was contacted directly to determine the final classification.

Prescrire (http://english.prescrire.org/en/Summary.aspx, subscription required) assesses the therapeutic value of medicines through a multistep process. First, it “examines the condition or clinical setting for which the drug is proposed; then, the natural course of the disease, the efficacy and safety of existing treatments, and the most relevant outcome measures. This is followed by a systematic search for clinical data on the efficacy and adverse effects of the new drug, and an assessment of the level of evidence. Based on [its] independent analysis of clinical data, [it] form[s] a judgement as to whether or not the new drug is beneficial for patients or whether or not its harmful effects outweigh the benefit” (Prescrire Editorial Staff 2011). Based on its analysis, it rates products using the following categories: bravo (major therapeutic innovation in an area where previously no treatment was available); a real advance (important therapeutic innovation but has limitations); offers an advantage (some value but does not fundamentally change the present therapeutic practice); possibly helpful (minimal additional value and should not change prescribing habits except in rare circumstances); nothing new (may be new molecule but is superfluous because it does not add to clinical possibilities offered by previously available products); not acceptable (without evident benefit but with potential or real disadvantages); judgment reserved (decision postponed until better data and more thorough evaluation) (Prescrire Editorial Staff 2002). The first 2 Prescrire
categories were defined as innovative and the other Prescrire categories were defined as not innovative. If Prescrire put the drug into the judgment reserved category, then no Prescrire evaluation was recorded.

Drugs were categorized using the first level of the World Health Organization (WHO) Anatomical Therapeutic Chemical (ATC) classification system into one of 14 main anatomical groups (WHO Collaborating Centre for Drug Statistics Methodology & Norwegian Institute of Public Health 2011).

Data analyses
If a drug was judged innovative by either the PMPRB and/or Prescrire, it was rated as innovative. If both organizations evaluated the drug and the ratings were discordant, i.e., one said it was not innovative and one said it was, the drug was still considered innovative. The proportion of first-in-class and non-first-in-class drugs rated as innovative was calculated and the proportions were compared with a z-ratio.

Kaplan–Meier survival curves, i.e., time to event curves, were calculated for the period from approval until a first post-market safety warning for first-in-class and non-first-in-class drugs and curves were compared using a Log rank (Mantel–Cox) test. A Kaplan–Meier analysis accounts for the fact that drugs were on the market for variable periods and, therefore, some drugs were more likely to have received a post-market safety warning by the end of the study period (December 31, 2012). The analyses combined drugs with post-market safety warnings and those withdrawn from the market to increase statistical power to detect differences. Previous work has shown that there are relatively few safety withdrawals (Lexchin 2014a).

Finally, the proportion of first-in-class and non-first-in-class drugs that received a priority review was calculated and the proportions were compared with a z-ratio. The z-ratio calculates the significance of the difference between two independent proportions (http://vassarstats.net).

The latter two analyses were repeated for just the first-in-class group of drugs. Comparisons were made for the proportion of innovative and non-innovative drugs in this group that received a priority review and for the time to a first post-market safety warning for innovative and non-innovative drugs.

The total number of first-in-class drugs and innovative first-in-class drugs introduced annually from 1997 to 2012 was plotted and the curves were analyzed using linear regression to determine any trends over time.

All analyses were done with Prism 6.0 (GraphPad Software, www.graphpad.com) and \( p < 0.05 \) was considered statistically significant.

Results
A total of 426 drugs were approved by Health Canada between 1997 and 2012 and 345 of these drugs were evaluated by PMPRB/Prescrire. Data on first-in-class status was available for 292 of these 345 drugs and the analyses were based on this group of
Appendix 1 (available at: http://www.longwoods.com/content/24851) lists all of the drugs by their first-in-class and innovation status and by ATC group. Ninety-eight drugs were first-in-class and 194 were not-first-in-class. Sixteen of 98 (16.3%, 95% CI: [10.3, 24.9]) were innovative compared to 9 of 194 (4.6%, 95% CI: [2.5, 8.6]), z-ratio = 3.371 (p = 0.0004). Table 1 shows the breakdown of first-in-class and non-first-in-class drugs by ATC group and innovation status, as determined by PMPRB/Prescrire, for 290 of the drugs. (Two drugs, neither first-in-class nor with a post-market safety warning, were not listed in the WHO ATC database.) Seventy of the 98 first-in-class drugs came from 4 of the 14 drug groups—antineoplastic and immunomodulating agents (35), alimentary tract and metabolism (14), anti-infectives for systemic use (12) and nervous system (9). Although the plurality of non-first-in-class drugs were in the antineoplastic and immunomodulating group, drugs were more evenly distributed throughout the various anatomical groups.

Almost half of the drugs in the antineoplastic group (45.7%) had a post-market safety warning, and similarly, almost half of all of the post-market safety warnings (48.5%) in first-in-class drugs were in this group. For non-first-in-class drugs, the antineoplastic and anti-infective groups each had 24.5% of the total number of post-market safety warnings. Of all of the non-first-in-class antineoplastic drugs, 34.3% had a post-market safety warning (Table 1). Out of the 98 first-in-class drugs, 33 had a serious post-market safety warning compared to 49 of the 194 non-first-in-class group. Figure 1 compares the time between approval and post-market safety warning for the two groups. There was no statistically significant difference between the curves, p = 0.0799, Log rank (Mantel–Cox) test. An analysis of just the antineoplastic drugs in the first-in-class and non-first-in-class groups shows no statistically significant difference in post-market safety warnings, p = 0.1816, Log rank (Mantel–Cox) test (curves not shown). Eleven drugs were withdrawn for safety reasons. Five were first-in-class and one of these was innovative. Of the six non-first-in-class, none were innovative (Table 2).

Forty-one of the 98 first-in-class drugs received a priority review (41.8%, 95% CI: [32.6, 51.7]) compared to 33 of the 194 non-first-in-class drugs (17%, 95% CI: [12.4, 22.9]), z-ratio = 4.605 (p < 0.0002).

Figure 2 compares the time between approval and post-market safety warning for the innovative and non-innovative first-in-class drugs. There was no statistically significant difference between the curves, p = 0.1734, Log rank (Mantel–Cox) test. Of the 16 first-in-class drugs that were innovative, 14 had a priority review (87.5%, 95% CI: [64.0, 96.5]) compared to 27 of the 82 that were non-innovative (32.9%, 95% CI: [23.7, 43.7]), z-ratio = 4.048 (p < 0.0002).

Figure 3 plots the total number of first-in-class drugs and the number of those that were innovative introduced from 1997 to 2012. Linear regression analysis shows no time trend for either group.
**TABLE 1.** First-in-class and non-first-in-class drugs grouped by innovation status and Anatomic Therapeutic Chemical classification*

<table>
<thead>
<tr>
<th>Anatomic Therapeutic Chemical classification (first level)</th>
<th>First-in-class</th>
<th>Non-first-in-class</th>
<th>Post-market safety warning/withdrawal</th>
<th>Non-first-in-class</th>
<th>Post-market safety warning/withdrawal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Innovative</td>
<td>Not innovative</td>
<td>Total number in group and per cent of total first-in-class</td>
<td>Number</td>
<td>Per cent of drugs in group (%)</td>
</tr>
<tr>
<td>Alimentary tract and metabolism</td>
<td>4</td>
<td>10</td>
<td>14 (14.3)</td>
<td>4</td>
<td>28.6</td>
</tr>
<tr>
<td>Anti-infectives for systemic use</td>
<td>1</td>
<td>11</td>
<td>12 (12.2)</td>
<td>2</td>
<td>16.7</td>
</tr>
<tr>
<td>Antineoplastic and immunomodulating agents</td>
<td>4</td>
<td>31</td>
<td>35 (35.7)</td>
<td>16</td>
<td>45.7</td>
</tr>
<tr>
<td>Blood and blood-forming agents</td>
<td>1</td>
<td>3</td>
<td>4 (4.1)</td>
<td>1</td>
<td>25</td>
</tr>
<tr>
<td>Cardiovascular system</td>
<td>0</td>
<td>3</td>
<td>3 (3.1)</td>
<td>1</td>
<td>33.3</td>
</tr>
<tr>
<td>Dermatologicals</td>
<td>0</td>
<td>3</td>
<td>3 (3.1)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Genitourinary system and sex hormones</td>
<td>1</td>
<td>1</td>
<td>2 (2)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Musculoskeletal system</td>
<td>0</td>
<td>4</td>
<td>4 (4.1)</td>
<td>2</td>
<td>50</td>
</tr>
<tr>
<td>Nervous system</td>
<td>1</td>
<td>8</td>
<td>9 (9.2)</td>
<td>4</td>
<td>36.4</td>
</tr>
<tr>
<td>Respiratory system</td>
<td>0</td>
<td>3</td>
<td>3 (3.1)</td>
<td>1</td>
<td>33.3</td>
</tr>
<tr>
<td>Sensory organs</td>
<td>2</td>
<td>1</td>
<td>3 (3.1)</td>
<td>1</td>
<td>33.3</td>
</tr>
<tr>
<td>Systemic hormonal preparations, excluding sex hormones and insulins</td>
<td>1</td>
<td>2</td>
<td>3 (3.1)</td>
<td>1</td>
<td>33.3</td>
</tr>
<tr>
<td>Various</td>
<td>1</td>
<td>2</td>
<td>3 (3.1)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>82</td>
<td>98 (98.0)</td>
<td>33</td>
<td>33.7</td>
</tr>
</tbody>
</table>

*Two drugs, neither first-in-class nor with a post-market safety warning, were not listed in the World Health Organization Anatomical Therapeutic Chemical classification system.
Joel Lexchin

FIGURE 1. Kaplan–Meier curve showing time to first serious safety warning or removal from market for first-in-class and non-first-in-class drugs

No significant difference between curves, p = 0.0799, Log rank (Mantel–Cox) test.

FIGURE 2. Kaplan–Meier curve showing time to first serious safety warning or removal from market for innovation and not innovative first-in-class drugs

No significant difference between curves, p = 0.1734, Log rank (Mantel–Cox) test.

TABLE 2. Drugs withdrawn for safety reasons by first-in-class and innovation status

<table>
<thead>
<tr>
<th>Drug</th>
<th>First-in-class status</th>
<th>Innovation status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerivastatin</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Drotrecogin alfa</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Eflazumab</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Gatifloxacin</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Grepafloxacin</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Rofecoxib</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Sibutramine</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Tegaserod</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Tolcapone</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Trovafloxacin</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Valdecoxib</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
Discussion

Just over 16% of the drugs that were first-in-class were judged as therapeutically innovative compared to under 5% of those that were not-first-in-class. There was no difference in the safety of these two groups as judged by the marker used for safety in this study, that is, the time from approval to the first serious post-market safety warning. Therefore, overall, first-in-class drugs have a better benefit-to-harm ratio, as measured by post-market safety warnings, than drugs that were not-first-in-class. At the same time, it is also important to note that more than five in six of the drugs that were first-in-class were not innovative. Health Canada was much more likely to give a priority review to first-in-class drugs compared to those that were not-first-in-class, but its accuracy in predicting which first-in-class drugs are going to be therapeutically innovative is relatively weak, as only 16 out of 41 drugs with a priority review (39.0%) were rated as innovative.

Among the first-in-class drugs, there was no difference in safety between those that were and were not innovative as measured by the time to a first serious post-market safety warning. This finding reaffirms the conclusion that innovative first-in-class drugs do not have additional safety concerns because of their new mechanisms of action. In this subgroup, Health Canada made much better use of its priority review process, with almost 87.5% of the innovative group getting a priority review compared to 32.9% of the non-innovative group. Overall though, Health Canada is much more accurate in assigning first-in-class drugs to a standard review than it is to a priority review as shown by a negative predictive value of 91.2% versus a positive predictive value of 46.3% (Lexchin 2015). The positive predictive value measures the number of drugs evaluated as innovative by the PMPRB/Prescrire as a percentage of all drugs given a priority review by Health Canada, and the negative predictive value is the number of drugs rated as not therapeutically innovative as a percentage of all drugs given a standard review by Health Canada. This present study shows that, in addition to review status, the mechanism of action, i.e., being first-in-class, is also not a good indicator of significant therapeutic innovation. It reinforces the point that the ability to predict which products will turn out to be major therapeutic innovations needs to be determined by clinical trials and real-world experience, not based on surrogate measures such as review and first-in-class status.
The antineoplastic and immunomodulating group had the largest number of first-in-class drugs, although only 11.4% (4 of 35) were innovative. Drugs in this group, both first-in-class and non-first-in-class, were also the ones most likely to have a post-market serious safety warning, although the chances of this happening were higher in first-in-class drugs, 45.7% versus 34.3%.

As in the US (Lanthier et al. 2013), there is no trend, positive or negative, in the overall number of first-in-class drugs introduced into the Canadian market. Similarly, the number of innovative first-in-class drugs introduced is stable over time. The increasing amount of money being spent on research and development (Pharmaceutical Research and Manufacturers of America 2015a) does not seem to be leading to more therapeutic innovation.

The detection of safety problems with drugs may have improved over the period analyzed. Between 2004 and 2010, Health Canada increased the number of people and resources devoted to post-market safety monitoring (Wiktorowicz et al. 2010). However, better monitoring is likely to have affected the ability to detect safety problems for both first-in-class and non-first-in-class products and, therefore, should not have affected the results of this study.

This study has five significant limitations. First, because of data limitations, only 292 (68.5%) of the 426 approved new drugs could be analyzed. Whether the conclusions would be different if more of the drugs could have been included is unknown. Second is the assumption that the evaluations by PMPRB/Prescrire represent a gold standard in the evaluation of a drug’s therapeutic value. While there is always a legitimate debate about therapeutic value, the rigorous processes that these organizations use to arrive at their conclusions and their independence give strong face validity to their assessments. Third, the definition of a serious post-market safety warning was based on the way that Health Canada displayed the information (bold black print and/or boxed text), but the criteria that Health Canada used to develop its safety warnings and the emphasis that it placed on any particular safety issue are extremely vague. One Health Canada document states: “Regulatory actions … are taken according to the regulatory framework in place. This implies an evaluation of the signal and the appropriate benefit-risk review of the information available” (Marketed Health Products Directorate 2004). Fourth, the metric, serious safety warnings, is only an indirect measure of safety; it does not measure the number of people potentially affected by safety problems nor the seriousness of the harms that the drugs cause. Finally, previous work has shown that the median time between approval and a post-market safety warning or safety withdrawal is about 3 to 3.5 years (Lexchin 2014a, 2014b) and, therefore, some drugs may not have been on the market long enough for one of these events to have taken place.

In summary, there does not appear to be any greater concern about the safety of first-in-class drugs than with non-first-in-class ones despite their novel mechanism of action, and first-in-class drugs are more likely to be therapeutically innovative. However, only a minority of first-in-class drugs (16%) were found to be therapeutically innovative, and the improved benefit-to-harm ratio among first-in-class drugs only applies to this subgroup.

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References
Variation in Emergency Department Transfer Rates from Nursing Homes in Ontario, Canada

La variation dans les taux de transfert des foyers de soins infirmiers vers les services des urgences, en Ontario, Canada

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Variation in Emergency Department Transfer Rates from Nursing Homes in Ontario, Canada

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Abstract

Background: Nursing home (NH) residents are frequently transferred to the emergency department (ED) but there is little data on inter-facility variation, which has implications for intervention planning and implementation.

Objectives: To describe variation in ED transfer rates (TRs) across NHs and the association with NH characteristics.

Design/setting: Retrospective cohort study using linked administrative data from Ontario.

Participants: 71,780 residents of 604 NHs in 2010 and followed for one year.

Measurements: Funnel plots were used to identify high transfer NHs and logistic regression to test the association with NH location, size, ownership and historical ED transfer rate.

Results: One-year ED transfer rates ranged from 4.3% to 58.6% (mean 28.4%); 115 (19%) NHs were considered high. Being within five minutes of an ED, larger size and high historical ED transfer rate were associated with being a high ED transfer home.

Conclusion: There was substantial variation across NHs. Consideration of characteristics such as proximity to an ED may be important in the development and targeting of different interventions for NHs.

Résumé

Contexte : Les patients des foyers de soins infirmiers (FSI) sont souvent transférés aux services des urgences (SU), mais il existe peu de données sur les variations entre les établissements, ce qui entraîne des conséquences en matière de planification et de mise en place d’interventions.

Objectifs : Décrire les variations dans le taux de transfert des FSI vers les SU, relativement aux caractéristiques des FSI.


Participants : 71 780 patients suivis pendant une année, en 2010, provenant de 604 FSI.
Introduction

Emergency departments (EDs) are an important site of care for nursing home (NH) residents but the high rate of transfer has raised concerns about the provision of care in NHs. Few studies to date have examined variation across NHs in their ED transfer rates (TRs) or the extent to which this is associated with NH-level characteristics. Since the decision to transfer residents is made within the NH, through a combination of internal policies, resident and family preferences and documented care orders, variation in ED TRs may be a more direct measure of the influence of the NH than inpatient hospitalizations, which have been well-studied but are also a function of decision-making within the ED. Our previous research found that approximately 50% of residents who visited the ED were discharged back to the NH without hospitalization (Gruneir et al. 2010). Those findings illustrate that studying inpatient hospitalizations alone provide only partial information about acute care use by this population, while a broader focus on ED transfers more fully captures the transitions between the two sectors.

Without data on the extent to which ED transfers vary across NHs, it is difficult to know if current high rates result from sector-wide problems or from issues within specific NHs or specific types of NHs. This has implications for quality improvement implementation. Interventions to improve care for specific medical problems have been shown to reduce transfers without increasing the frequency of other adverse events (Loeb et al. 2006; McAiney et al. 2008) but they face barriers, including resource-intensity, to wider implementation. Facility-specific rates would allow for improved targeting of limited resources.

Given the paucity of data on variation in ED transfers across NHs, our intention is to provide population-based estimates to lay the groundwork for further study and intervention development. The objectives of this study are to quantify the extent of variation in ED TRs across NHs in Ontario, Canada, and to test the association of selected NH characteristics with observed variation in ED TRs.
Methods
This study was conducted in Ontario, Canada. In Ontario, NHs specifically refer to residential care settings intended for adults (aged ≥18 years) requiring round-the-clock nursing and/or support services and/or cannot live safely in a community setting; they typically do not provide post-acute services. There are three types of homes based on ownership: for-profit, non-profit and municipal. Both for-profit and non-profit homes are privately owned. Each municipality is required to maintain a certain number of NH beds, which operate in a non-profit manner. Regardless of ownership, all homes receive comparable per resident-day reimbursement from the provincial health insurance plan and are subject to the same restrictions on private fees for basic room-and-board reimbursement (McGrail et al. 2007; McGregor et al. 2005).

Data
This study was conducted using administrative data that were linked by unique, encoded identifiers and analyzed at the Institute for Clinical Evaluative Sciences (ICES) in Toronto, Ontario. Baseline resident data were obtained from the Resident Assessment Instrument Minimum Data Set version 2.0 (RAI-MDS 2.0), a comprehensive clinical assessment tool (Hirdes et al. 2003; Morris et al. 1994, 1999) mandated for use in Ontario. Assessments are completed at admission, three-month intervals and following major health changes. The RAI-MDS 2.0 is regularly used for research (Hawes et al. 1995). Information on ED transfers was obtained from the National Ambulatory Care Reporting System, a mandatory reporting requirement for all ED encounters in Ontario (CIHI 2007). Other administrative sources include the Registered Persons Database (RPDB) for demographics and the Occupancy Monitoring Database (OCCM) for NH descriptors. These data are regularly used for research and have been studied for their validity (Bronskill et al. 2004; Chan et al. 2001; Hux et al. 2002; Schull et al. 2007). The Research Ethics Board at Sunnybrook Health Sciences Centre reviewed this study.

Cohort
The cohort consists of all individuals 65 years and older who resided in an Ontario NH between January 1 and March 31, 2010. We excluded 23 NHs with fewer than 25 beds to reduce the likelihood of statistically unstable estimates (Intrator et al. 1999). Each resident was followed from baseline (the first assessment in the quarter) for one year until the first discharge from the NH, death or end of the 365-day follow-up period.

We described the cohort by demographics, diagnoses and functional ability. We used the MDS-embedded Cognitive Performance Scale (CPS) (Morris et al. 1994), Activities of Daily Living (ADL) Short Form Scale (Morris et al. 1994) and Changes in Health, End-Stage Disease, Signs and Symptoms (CHESS) Scale (Hirdes et al. 2003) to measure cognitive impairment, physical impairment and medical instability, respectively. All measures were obtained from the baseline RAI-MDS 2.0 assessment since some of our other work found limited changes in these measures over such a short follow-up period. We used only the first ED transfer after baseline since the incorporation of recurrent events was beyond the scope of this study.
We focused on four NH characteristics as available in our data: location, size, ownership and historical ED TR. Location was operationalized using two metrics. The first was urban versus rural setting based on community size. NHs in urban areas have better outcomes than those in rural areas, and it is thought that this may result from greater access to services (Temkin-Greener et al. 2012). The second metric was estimated travel time in minutes between the NH and the closest ED using ArcGIS 10 (ESRI) to map distances by postal code and posted speed limits on existing roadways. Based on preliminary analyses, travel time was dichotomized as <5 minutes or ≥5 minutes.

Facility size was based on the number of beds, dichotomized as <100 or ≥100 beds to be consistent with other studies (Zinn et al. 2007). Larger homes are thought to provide medical services more efficiently than smaller homes, resulting in lower hospitalization rates and better performance on other measures (Intrator et al. 1999, 2004). NH ownership was identified as one of for-profit, non-profit or municipal. Ownership type, most often measured as profit-status, has been well-studied with most research demonstrating better outcomes in non-profit homes (Hillmer et al. 2005; McGregor et al. 2006).

Lastly, we considered each NH's historical ED TR to assess the extent to which homes consistently have higher versus lower TRs over time. We estimated the three-month ED TR for each NH using residents identified between October 1 and December 31, 2009. We dichotomized this variable at the distribution mean (13%) based on preliminary analyses and because it was not normally distributed. We included historical ED TR as a means to test whether observed variation was random or persisted over time.

Analysis
The proportion of residents who experienced at least one ED transfer was estimated for each NH. We constructed a funnel plot to display variation in rates of ED transfer across NHs. The funnel plot was created by estimating a standardized transfer ratio for each NH (STR\textsubscript{NH}) that was plotted against the total number of residents in the NH. The STR\textsubscript{NH} is a ratio of the observed to the expected proportion of residents in the NH with an ED transfer. The provincial ED transfer rate was set as the expected value because no benchmark exists. The threshold of comparison was an STR\textsubscript{NH} of 1, meaning the observed and expected proportions are equal. We estimated 95% control bounds using binomial limits to characterize the degree of variation across NHs (Spiegelhalter 2005). The funnel plot allows for visual display of variation relative to pre-defined control bounds, so that deviation from the expected distribution can be easily observed (Rochon et al. 2007).

We divided NHs into three groups according to their position on the funnel plot. NHs were designated as having a high TR if they fell above the upper 95% control bound, an intermediate TR if they fell between the upper and lower 95% control bounds, and a low TR if they fell below the lower 95% control bound. Our intention was solely to describe NHs as high, intermediate or low relative to the provincial average – not that we anticipated that every NH in our study should have an expected ED TR equivalent to the provincial average.
We used logistic regression to estimate the association between each NH characteristic and the likelihood of being a high ED transfer facility relative to being an intermediate/low transfer facility. We collapsed the intermediate and low ED transfer facilities into a single category in order to be consistent with our original research objectives; this a priori decision was supported by interim analyses that included comparisons across the ED transfer groups on the NH characteristics and resident case-mix variables. We used a three-step process to develop our final model. First, we separately modelled each NH characteristic against the dichotomous outcome to determine “crude” estimates of association. Second, we simultaneously modelled all NH characteristics in a single model to assess for any changes in the odds ratio (OR) and collinearity. Third, we sequentially added select case-mix variables to the model described in Step 2 as a means to test for the presence of confounding. Based on observed changes to the ORs on the NH characteristics of interest, our final adjusted model controlled for the following: the proportion of residents in the NH with severe cognitive impairment, the proportion of residents in the NH with behavioural problems and the proportion in the NH with unstable medical conditions (CHESS >4). None of the other case-mix variables influenced the measures of association. We selected this approach, as opposed to a multilevel model, because our main interest was in characterizing NHs with high ED TRs as opposed to identifying resident risk factors for transfer. All analyses were conducted using SAS versions 9.2 and 9.3.

Results
We identified 71,780 residents in 604 NHs. Table 1 shows facility-level baseline characteristics for the full cohort as well as stratified by ED TR grouping. Across NHs, the mean age was 84.4 (SD = 1.7) years and the mean proportion of females was 71.9% (SD = 7.9) with little variation across facility groupings. The majority of residents in all NH groups had a length of stay of one year or more. There was a high burden of cognitive impairment, physical impairment and difficult behaviours with limited observable differences across NH types. Over one year, 20,829 (29%) residents were transferred to the ED at least once. The timing of the first ED transfers relative to the baseline assessment was 13.9% within 28 days, 49.7% between 28 and less than 180 days and 36.4% between 180 and 365 days. 12.5% of residents died within 30 days of their first ED transfer (data not shown). The facility-level mean proportion of residents with an ED transfer was 28.4% (SD 10.1) and ranged from 4.3% to 58.6% (interquartile range: 21.6–34.5%). Based on the STR\textsubscript{NH}, approximately 30 NHs (5%) were expected to each fall above and below the 95% control bounds. As Figure 1 illustrates, 115 (19%) NHs fell above the upper 95% control bound and 130 (21.5%) fell below the lower 95% control bound, suggesting greater variation than expected.

Differences in the distribution of NH characteristics according to ED TR groupings are shown in Table 2. NHs with high ED TRs were most often urban, within a 5-minute drive of an ED, and larger. There was little difference in ownership, although high TR homes were somewhat less likely to be municipally owned. The mean historical ED TR declined from 18.6 (SD 5.4) in the high TR group to 8.5 (SD 3.5) in the low group (not shown).
TABLE 1. Facility-level distribution of resident baseline characteristics for full cohort of NHs and stratified by relative ED transfer rate (71,780 residents at baseline)

<table>
<thead>
<tr>
<th>Facility average age, mean (SD)*</th>
<th>All NHs in cohort N = 604</th>
<th>“High” transfer NHs n = 115</th>
<th>“Intermediate” transfer NHs n = 359</th>
<th>“Low” transfer NHs n = 130</th>
</tr>
</thead>
<tbody>
<tr>
<td>84.8 (1.7)</td>
<td>84.2 (1.9)</td>
<td>84.8 (1.6)</td>
<td>85.1 (1.5)</td>
<td></td>
</tr>
<tr>
<td>Age groups, mean proportion (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65–74 years</td>
<td>10.6% (5.5%)</td>
<td>12.1% (6.3%)</td>
<td>10.3% (5.4%)</td>
<td>9.8% (4.7%)</td>
</tr>
<tr>
<td>75–84 years</td>
<td>34.1% (6.5%)</td>
<td>35.7% (6.4%)</td>
<td>34.1% (6.5%)</td>
<td>32.7% (6.1%)</td>
</tr>
<tr>
<td>85–94 years</td>
<td>46.2% (8.0%)</td>
<td>43.7% (8.4%)</td>
<td>46.4% (8.0%)</td>
<td>48.0% (7.2%)</td>
</tr>
<tr>
<td>95+ years</td>
<td>9.1% (4.0%)</td>
<td>8.4% (3.9%)</td>
<td>9.2% (3.8%)</td>
<td>9.5% (4.3%)</td>
</tr>
<tr>
<td>Women, mean proportion (SD)</td>
<td>71.9% (7.9%)</td>
<td>70.3% (7.6%)</td>
<td>71.9% (8.1%)</td>
<td>73.3% (7.4%)</td>
</tr>
<tr>
<td>Length of stay, mean proportion (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30 days</td>
<td>9.7% (6.2%)</td>
<td>10.5% (9.4%)</td>
<td>9.4% (5.2%)</td>
<td>9.9% (5.3%)</td>
</tr>
<tr>
<td>30–89 days</td>
<td>1.6% (2.0%)</td>
<td>1.6% (1.9%)</td>
<td>1.6% (2.2%)</td>
<td>1.4% (1.9%)</td>
</tr>
<tr>
<td>90–364 days</td>
<td>23.4% (6.7%)</td>
<td>22.8% (7.0%)</td>
<td>24.0% (7.0%)</td>
<td>22.3% (5.5%)</td>
</tr>
<tr>
<td>365 days or more</td>
<td>65.3% (9.4%)</td>
<td>65.1% (9.8%)</td>
<td>65.0% (9.6%)</td>
<td>66.4% (8.1%)</td>
</tr>
<tr>
<td>Cognitive performance scale score groups, mean proportion (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–2 (none to minimal)</td>
<td>42.0% (10.9%)</td>
<td>44.8% (11.0%)</td>
<td>41.4% (10.6%)</td>
<td>41.1% (11.3%)</td>
</tr>
<tr>
<td>3–4 (moderate)</td>
<td>34.3% (9.3%)</td>
<td>32.0% (8.5%)</td>
<td>34.6% (9.3%)</td>
<td>35.6% (9.5%)</td>
</tr>
<tr>
<td>5–6 (severe)</td>
<td>23.7% (9.3%)</td>
<td>23.2% (8.9%)</td>
<td>24.0% (9.5%)</td>
<td>23.3% (9.0%)</td>
</tr>
<tr>
<td>Facility average cognitive performance scale score, mean (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.8 (0.4)</td>
<td>2.7 (0.5)</td>
<td>2.8 (0.4)</td>
<td>2.8 (0.4)</td>
<td></td>
</tr>
<tr>
<td>Activities of daily living short-form scale groups, mean proportion (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–1 (minimal)</td>
<td>14.7% (7.7%)</td>
<td>16.0% (8.0%)</td>
<td>14.7% (7.8%)</td>
<td>13.4% (7.0%)</td>
</tr>
<tr>
<td>2–3 (moderate)</td>
<td>37.6% (8.8%)</td>
<td>37.1% (8.1%)</td>
<td>37.5% (8.7%)</td>
<td>38.2% (9.5%)</td>
</tr>
<tr>
<td>4–5 (dependent)</td>
<td>47.8% (10.3%)</td>
<td>46.9% (10.5%)</td>
<td>47.8% (10.3%)</td>
<td>48.5% (10.4%)</td>
</tr>
<tr>
<td>Facility average ADL short-form scale, mean (SD)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.5 (0.4)</td>
<td>3.4 (0.4)</td>
<td>3.5 (0.4)</td>
<td>3.5 (0.4)</td>
<td></td>
</tr>
<tr>
<td>Problem behaviours, mean proportion (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inappropriate</td>
<td>18.4% (10.1%)</td>
<td>15.8% (8.6%)</td>
<td>18.1% (9.4%)</td>
<td>21.5% (12.2%)</td>
</tr>
<tr>
<td>Verbally abusive</td>
<td>19.3% (7.9%)</td>
<td>18.8% (7.9%)</td>
<td>19.2% (7.9%)</td>
<td>19.8% (7.8%)</td>
</tr>
<tr>
<td>Physically abusive</td>
<td>12.1% (5.7%)</td>
<td>10.9% (4.7%)</td>
<td>12.2% (6.1%)</td>
<td>13.0% (5.6%)</td>
</tr>
<tr>
<td>Wandering</td>
<td>17.2% (7.2%)</td>
<td>15.9% (6.8%)</td>
<td>17.3% (7.2%)</td>
<td>18.2% (7.4%)</td>
</tr>
<tr>
<td>Resists care</td>
<td>36.2% (14.0%)</td>
<td>33.4% (12.3%)</td>
<td>36.1% (14.1%)</td>
<td>38.8% (14.6%)</td>
</tr>
</tbody>
</table>
## Variation in Emergency Department Transfer Rates from Nursing Homes in Ontario, Canada

<table>
<thead>
<tr>
<th>CHESS scale score</th>
<th>All NHs in cohort N = 604</th>
<th>“High” transfer NHs n = 115</th>
<th>“Intermediate” transfer NHs n = 359</th>
<th>“Low” transfer NHs n = 130</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>46.9% (14.7%)</td>
<td>50.9% (14.0%)</td>
<td>46.9% (14.4%)</td>
<td>42.3% (15.2%)</td>
</tr>
<tr>
<td>1</td>
<td>31.7% (7.8%)</td>
<td>31.0% (7.6%)</td>
<td>31.6% (7.8%)</td>
<td>32.5% (7.9%)</td>
</tr>
<tr>
<td>2</td>
<td>14.8% (7.4%)</td>
<td>12.9% (6.1%)</td>
<td>14.9% (7.4%)</td>
<td>16.1% (8.2%)</td>
</tr>
<tr>
<td>3</td>
<td>4.5% (3.7%)</td>
<td>3.6% (2.8%)</td>
<td>4.5% (3.5%)</td>
<td>5.5% (4.5%)</td>
</tr>
<tr>
<td>4</td>
<td>1.7% (1.8%)</td>
<td>1.4% (1.5%)</td>
<td>1.6% (1.6%)</td>
<td>2.1% (2.3%)</td>
</tr>
<tr>
<td>5</td>
<td>0.4% (0.9%)</td>
<td>0.2% (0.5%)</td>
<td>0.4% (0.9%)</td>
<td>0.5% (1.1%)</td>
</tr>
<tr>
<td>Facility average CHESS score, mean (SD)</td>
<td>0.8 (0.3)</td>
<td>0.7 (0.3)</td>
<td>0.8 (0.3)</td>
<td>0.9 (0.4)</td>
</tr>
</tbody>
</table>

### Major diagnoses – mean proportion (SD)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>All NHs in cohort N = 604</th>
<th>“High” transfer NHs n = 115</th>
<th>“Intermediate” transfer NHs n = 359</th>
<th>“Low” transfer NHs n = 130</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes mellitus</td>
<td>24.7% (6.2%)</td>
<td>26.4% (6.8%)</td>
<td>24.9% (6.1%)</td>
<td>22.7% (5.5%)</td>
</tr>
<tr>
<td>Arteriosclerotic heart disease</td>
<td>12.9% (10.5%)</td>
<td>11.9% (10.4%)</td>
<td>12.9% (10.8%)</td>
<td>13.6% (10.0%)</td>
</tr>
<tr>
<td>Cardiac dysrhythm</td>
<td>7.0% (5.7%)</td>
<td>6.0% (4.8%)</td>
<td>7.2% (6.0%)</td>
<td>7.4% (5.6%)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>12.5% (5.2%)</td>
<td>11.8% (4.7%)</td>
<td>12.5% (5.1%)</td>
<td>13.2% (5.8%)</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>5.3% (3.9%)</td>
<td>5.5% (3.8%)</td>
<td>5.2% (3.7%)</td>
<td>5.4% (4.7%)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>39.3% (12.8%)</td>
<td>35.7% (12.3%)</td>
<td>39.2% (12.1%)</td>
<td>42.9% (14.1%)</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>25.7% (10.3%)</td>
<td>24.4% (8.1%)</td>
<td>25.3% (9.8%)</td>
<td>28.1% (12.6%)</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>18.6% (9.1%)</td>
<td>17.0% (8.6%)</td>
<td>18.8% (9.2%)</td>
<td>19.7% (8.9%)</td>
</tr>
<tr>
<td>Dementia (other than Alzheimer’s)</td>
<td>44.1% (11.2%)</td>
<td>44.3% (11.8%)</td>
<td>44.2% (11.2%)</td>
<td>43.6% (11.0%)</td>
</tr>
<tr>
<td>Stroke (cerebrovascular accident)</td>
<td>21.5% (6.5%)</td>
<td>21.8% (6.7%)</td>
<td>21.5% (6.5%)</td>
<td>21.2% (6.7%)</td>
</tr>
<tr>
<td>Parkinson disease</td>
<td>6.9% (3.0%)</td>
<td>6.5% (3.0%)</td>
<td>7.0% (3.1%)</td>
<td>7.1% (3.0%)</td>
</tr>
<tr>
<td>Anxiety disorder</td>
<td>7.8% (5.3%)</td>
<td>7.1% (5.3%)</td>
<td>7.7% (5.5%)</td>
<td>8.6% (4.7%)</td>
</tr>
<tr>
<td>Depression</td>
<td>28.5% (11.1%)</td>
<td>25.7% (9.6%)</td>
<td>28.2% (10.9%)</td>
<td>31.6% (12.3%)</td>
</tr>
<tr>
<td>Emphysema/Chronic obstructive pulmonary disease</td>
<td>14.8% (6.5%)</td>
<td>14.4% (6.3%)</td>
<td>14.8% (6.6%)</td>
<td>15.1% (6.4%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>8.5% (4.9%)</td>
<td>8.3% (4.7%)</td>
<td>8.6% (5.0%)</td>
<td>8.5% (5.1%)</td>
</tr>
<tr>
<td>Renal failure</td>
<td>8.1% (6.2%)</td>
<td>8.1% (6.4%)</td>
<td>8.1% (6.2%)</td>
<td>7.9% (5.9%)</td>
</tr>
</tbody>
</table>

### Accidents, mean proportion (SD)

<table>
<thead>
<tr>
<th>Accident</th>
<th>All NHs in cohort N = 604</th>
<th>“High” transfer NHs n = 115</th>
<th>“Intermediate” transfer NHs n = 359</th>
<th>“Low” transfer NHs n = 130</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fell in past 30 days</td>
<td>13.2% (4.9%)</td>
<td>12.6% (5.1%)</td>
<td>13.4% (4.8%)</td>
<td>13.3% (4.9%)</td>
</tr>
<tr>
<td>Fell in past 180 days</td>
<td>25.3% (8.9%)</td>
<td>24.0% (9.0%)</td>
<td>25.3% (8.8%)</td>
<td>26.3% (9.0%)</td>
</tr>
<tr>
<td>Fracture in past 180 days (hip or other)</td>
<td>2.8% (2.0%)</td>
<td>2.5% (1.9%)</td>
<td>2.9% (2.1%)</td>
<td>2.6% (2.0%)</td>
</tr>
</tbody>
</table>

CHESS = Changes in Health, End-Stage Disease, Signs and Symptoms Scale; ED = emergency department; NH = nursing home; SD = standard deviation. *Average means across all facilities in the category. §Average proportion across all facilities in the category.
TABLE 2. Distribution of NH characteristics by ED transfer rate

<table>
<thead>
<tr>
<th>NH-specific rates of ED transfer</th>
<th>High rate</th>
<th>Intermediate rate</th>
<th>Low rate</th>
<th>Total</th>
<th>Adjusted OR(^1) (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ED transfer rate range*</td>
<td>35.5–58.6%</td>
<td>17.7–41.2%</td>
<td>4.3–23.1%</td>
<td>4.3–58.6%</td>
<td>–</td>
</tr>
</tbody>
</table>

Location, \(n\) (%)

<table>
<thead>
<tr>
<th>Rural</th>
<th>20 (17.4%)</th>
<th>111 (30.9%)</th>
<th>35 (26.9%)</th>
<th>166 (27.5%)</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>95 (82.6%)</td>
<td>248 (69.1%)</td>
<td>95 (73.1%)</td>
<td>438 (72.5%)</td>
<td>1.41 (0.76, 2.61)</td>
</tr>
</tbody>
</table>

≥5 minutes to closest ED

<table>
<thead>
<tr>
<th>Rural</th>
<th>37 (31.6%)</th>
<th>171 (47.3%)</th>
<th>60 (46.2%)</th>
<th>268 (44.1%)</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>78 (68.4%)</td>
<td>188 (52.7%)</td>
<td>70 (53.8%)</td>
<td>336 (55.9%)</td>
<td>1.77 (1.09, 2.86)</td>
</tr>
</tbody>
</table>

Size, \(n\) (%)

<table>
<thead>
<tr>
<th>&lt; 100 beds</th>
<th>28 (24.4%)</th>
<th>161 (44.8%)</th>
<th>56 (43.1%)</th>
<th>245 (40.6%)</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥100 beds</td>
<td>87 (75.6%)</td>
<td>198 (55.2%)</td>
<td>74 (56.9%)</td>
<td>359 (59.4%)</td>
<td>1.91 (1.13, 3.23)</td>
</tr>
</tbody>
</table>

Ownership,\(^\d\) \(n\) (%)

<table>
<thead>
<tr>
<th>Municipal</th>
<th>14 (12.3%)</th>
<th>61 (17.2%)</th>
<th>27 (20.9%)</th>
<th>102 (17.1%)</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-profit</td>
<td>27 (23.7%)</td>
<td>80 (22.5%)</td>
<td>36 (27.9%)</td>
<td>143 (23.9%)</td>
<td>1.64 (0.76, 3.56)</td>
</tr>
<tr>
<td>For-profit</td>
<td>73 (64.0%)</td>
<td>214 (60.3%)</td>
<td>66 (51.2%)</td>
<td>353 (59.0%)</td>
<td>1.57 (0.79, 3.12)</td>
</tr>
</tbody>
</table>

Historical transfer rate, \(n\) (%)

<table>
<thead>
<tr>
<th>&lt; 13%</th>
<th>96 (84.2%)</th>
<th>183 (51.0%)</th>
<th>12 (9.2%)</th>
<th>291 (48.3%)</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥13%</td>
<td>19 (15.8%)</td>
<td>176 (49%)</td>
<td>118 (90.8%)</td>
<td>313 (51.7%)</td>
<td>7.03 (4.04, 12.24)</td>
</tr>
</tbody>
</table>

\(\text{CI} = \text{confidence interval}; \text{ED} = \text{emergency department}; \text{NH} = \text{nursing home}; \text{OR} = \text{odds ratio}.\)

*Transfer rates overlap owing to funnel shape of control bounds. \(^\d\)All NH factors modelled simultaneously and adjusted for NH case-mix variables (proportion of residents with each behavioural problem, cognitive impairment and high levels of instability). \(^\d\)Not available for all NHs.
For all NH characteristics, except ownership, there was some attenuation of the OR in the simultaneous model relative to the independent models but little additional change following case-mix adjustment (results of the fully adjusted model only are shown in Table 2). Being within a 5-minute drive of an ED (OR 1.8, 95% CI: [1.1, 2.9]) and large size (OR 1.9, 95% CI: [1.1, 3.2]) were both associated with a high ED TR. Historical ED TR demonstrated the strongest association (OR 7.0, 95% CI: [4.0, 12.2]). Urban location showed an association with high ED TR in the independent model but this did not persist after adding distance. Ownership type was not associated with ED TR.

Discussion
We found that almost one-third of NH residents were transferred to the ED at least once over one year but that this varied 13-fold across homes. Nearly 20% of all NHs were identified as having high rates of ED transfer – substantially more than the expected 5%. We further found that high ED TR was associated with home characteristics even after controlling for case-mix.

Research on antipsychotics, physical restraints, feeding tubes and hospitalizations has shown that facility-level variation across NH is a complex issue with multiple and multi-layered inputs. Our results suggest that the same is true for ED transfers. Building on our previous work, we found that proximity to an ED was associated with a high ED TR, independent of urban–rural setting, which itself was not predictive. Our preliminary analyses did show that NHs within close proximity of an ED were more likely to be in urban settings, but not exclusively so, suggesting that physical proximity and urban-rural setting are related, yet different, issues. Although research on other quality metrics has generally found better outcomes among urban NHs, the relationship with hospitalization has been less clear and there is little research looking specifically at ED transfers (Gessert et al. 2006; Kang et al. 2011; Phillips et al. 2004). Research from non-NH populations shows that proximity is associated with ED use and hospitalizations (Goodman et al. 1997; Ludwick et al. 2009). Our findings suggest that ease of access may be an important driver of ED transfer but whether it contributes to higher levels of “inappropriate” use remains unclear.

We also found that larger homes were more likely to have high ED TRs. This is contradictory to other evidence, which has shown better performance among larger homes (Intrator et al. 1999, 2004; Mor et al. 2011). Our preliminary analyses found that larger homes were more likely to be in urban areas and have a higher historical ED TR. It may be that larger NHs are more likely to share other characteristics, such as more stringent policies around ED transfers, that we were unable to measure here.

Although the point estimates on for-profit and non-profit nursing homes indicated higher odds of being a high ED TR home relative to municipal facilities, the confidence intervals were wide and crossed 1.0, indicating no significant association. Research from British Columbia, another Canadian province, found the impact of profit-status was modified by other aspects of ownership; specifically, only certain types of non-profit NHs,
including those amalgamated to a health authority, had lower hospitalization rates than for-profit homes, and that there was no difference between single-site non-profit and for-profit homes (McGregor et al. 2006). In Ontario, all NHs are subject to the same provincial legislation on reimbursement, private fees and spending allocations, which may explain why we did not observe differences by profit status.

Even after controlling for case-mix, NHs with a higher historical TR had sevenfold greater odds of being in the high ED transfer group than those homes with lower historical rates. This likely represents the influence of time-invariant factors that we were unable to examine. For example, we lacked data on staffing, which is likely both invariant over the period studied and associated with ED TRs. It also likely reflects an NH’s underlying culture, which is typically difficult to operationalize in studies such as ours. Others have shown that homes do exhibit an internal set of shared values that can have important implications for care practices. For example, a recent study of hospital transfers found that staff perceptions of what constituted “avoidable” varied greatly across homes even when similar reasons for transfer were identified (Lamb et al. 2011).

Safe reductions in ED TRs will likely require a multi-pronged approach that addresses issues with the resident and family, care providers, NH practice and the local environment. Finding such stark variation in facility TRs suggests that different NHs will likely require different strategies to improve outcomes. While this study does not elucidate how such interventions should be targeted, it does identify issues for future research. For example, our findings on location suggest that a more nuanced approach than urban–rural dichotomy may be more appropriate for studying regional effects. As well, there is a need for data on staff perceptions of the role of the ED in resident care and the extent to which it varies across NHs. This type of data opens up opportunities for discussion with high and low TR NHs on their perceptions of contributing factors and practices.

Limitations
There are limitations to this study. There are a number of NH characteristics that we could not measure such as staffing. Evidence from Ontario suggests that there is limited variation in nurse staffing; however, this and other staff types cannot be ruled out as important factors. Other NH characteristics that we could not consider include engagement in quality improvement, cultural affiliation and access to medical consultants. Resident and family insistence for ED transfer are frequently cited as a significant factor but there is little data on how these preferences vary across NHs. The historical ED TR was based on the quarter prior to study baseline because the RAI-MDS was not fully implemented in Ontario until 2009. Future work would benefit from a longer time span on ED transfer trends. Finally, we excluded very small NHs which were likely concentrated in rural areas; however, given the small number \( n = 23; 3.7\% \) of all NHs we do not anticipate that this had any influence on our findings.
Conclusion
We observed 13-fold variation in ED TRs across Ontario NHs, and that far more NHs than expected were identified as having high TRs. There is no standard “appropriate” rate of ED transfer, but the rates reported here appear high and the wide variation suggests that there are opportunities to reduce them. While our findings suggest that certain types of NHs could benefit from intervention, they also demonstrate the need for a comprehensive approach to understanding the impact of location, facility structure and other characteristics, such as staffing and culture, on transfer decisions and related outcomes.

Acknowledgements
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References


Designing Integrated Approaches to Support People with Multimorbidity: Key Messages from Systematic Reviews, Health System Leaders and Citizens
Concevoir des approches intégrées pour aider les personnes souffrant de multimorbidité : messages clés de revues systématiques, de dirigeants de systèmes de santé et de citoyens
MICHAEL G. WILSON, JOHN N. LAVIS AND FRANCOIS-PIERRE GAUVIN

Abstract
Background: Living with multiple chronic conditions (multimorbidity) – and facing complex, uncoordinated and fragmented care – is part of the daily life of a growing number of Canadians.

Methods: We undertook: a knowledge synthesis; a “gap analysis” of existing systematic reviews; an issue brief that synthesized the available evidence about the problem, three options for addressing it and implementation considerations; a stakeholder dialogue involving key health-system leaders; and a citizen panel.

Results: We identified several recommendations for actions that can be taken, including: developing evidence-based guidance that providers can use to help achieve goals set by patients; embracing approaches to supporting self-management; supporting greater communication and collaboration across healthcare providers as well as between healthcare providers and patients; and investing more efforts in health promotion and disease prevention.

Conclusions: Our results point to the need for health system decision-makers to support bottom-up, person-centred approaches to developing models of care that are tailored for people with multimorbidity and support a research agenda to address the identified priorities.

To view the full article, please visit http://www.longwoods.com/content/24853.
A Review of Discharge-Prediction Processes in Acute Care Hospitals

Abstract

Aims and Objectives: Discharge prediction is designed to streamline inpatient flow and reduce hospital overcrowding without adding capacity. This study’s objective was to describe the literature on discharge prediction and assess its usefulness in evaluating the implementation and outcomes of discharge prediction projects.

Methods: The authors reviewed the current peer-reviewed and grey literature on discharge prediction projects in acute care hospitals. Project descriptions were analyzed using Donabedian’s structure–process–outcome model for evaluating complex healthcare innovations.

Results: The review revealed a paucity of literature on the use and effectiveness of discharge prediction. There is high variation in its use and generally poor reporting of both implementation and outcomes.

Conclusions: The literature on discharge prediction generally lacks the descriptive detail that would be useful to parties considering or planning a discharge prediction initiative. Further study is required to determine how best to integrate these prediction tools into acute care hospitals.

To view the full article, please visit http://www.longwoods.com/content/24854.

Résumé

Objectifs : La prédiction de congés est conçue pour rationaliser la venue de patients et réduire l’engorgement dans les hôpitaux sans ajouter de nouveaux lits. L’objectif de cette étude était de faire un survol de la littérature, et de vérifier son utilité dans l’évaluation de projets de prédictions de congés et de résultats.

Méthodes : Nous avons revu la littérature scientifique et la littérature grise sur les projets de prédiction de congés dans les hôpitaux de soins de courte durée. Les descriptions de projets ont été analysées en utilisant le modèle structure–processus–résultat de Donabedian, qui évalue la complexité des innovations en soins de santé.

Résultats : L’étude a révélé la rareté de la littérature sur l’utilisation et l’efficacité des prédictions de congés. Il existe une variation élevée dans son utilisation, et en général, la documentation sur l’implantation et les résultats est plutôt incomplète.

Conclusions : La littérature sur la prédiction de congés manque habituellement d’explications qui pourraient être utiles à ceux qui considèrent ou planifient des projets de prédictions de congés. Davantage de recherches sont nécessaires pour déterminer comment mieux intégrer ces outils de prédictions dans les hôpitaux de soins de courte durée.
Designing Integrated Approaches to Support People with Multimorbidity: Key Messages from Systematic Reviews, Health System Leaders and Citizens

Concevoir des approches intégrées pour aider les personnes souffrant de multimorbidity : messages clés de revues systématiques, de dirigeants de systèmes de santé et de citoyens

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Hamilton, ON
Abstract

**Background:** Living with multiple chronic conditions (multimorbidity) – and facing complex, uncoordinated and fragmented care – is part of the daily life of a growing number of Canadians.

**Methods:** We undertook: a knowledge synthesis; a “gap analysis” of existing systematic reviews; an issue brief that synthesized the available evidence about the problem, three options for addressing it and implementation considerations; a stakeholder dialogue involving key health-system leaders; and a citizen panel.

**Results:** We identified several recommendations for actions that can be taken, including: developing evidence-based guidance that providers can use to help achieve goals set by patients; embracing approaches to supporting self-management; supporting greater communication and collaboration across healthcare providers as well as between healthcare providers and patients; and investing more efforts in health promotion and disease prevention.

**Conclusions:** Our results point to the need for health system decision-makers to support bottom-up, person-centred approaches to developing models of care that are tailored for people with multimorbidity and support a research agenda to address the identified priorities.

Résumé

**Contexte :** Vivre avec des maladies chroniques multiples (multimorbidité), et faire face à des soins complexes, non coordonnés et fragmentés, fait partie du quotidien d’un nombre croissant de Canadiens.

**Méthodes :** Nous avons entrepris : une synthèse des connaissances; une « analyse de l’écart » des revues systématiques actuelles; une synthèse des données probantes disponibles concernant le problème, trois options pour l’évaluer et mettre en place les correctifs; un débat entre les personnes intéressées, impliquant les dirigeants du système de santé; et un panel de citoyens.

**Résultats :** Nous avons cerné plusieurs recommandations concernant les mesures à prendre, notamment : élaborer des directives fondées sur des données probantes que les intervenants peuvent utiliser pour aider les patients à atteindre leurs objectifs; adopter des approches favorisant l’autogestion; encourager de meilleures communications et collaborations parmi les intervenants de la santé, ainsi qu’entre les intervenants et les patients; investir davantage d’efforts dans la promotion de la santé et la prévention des maladies.

**Conclusions :** Nos résultats soulèvent la nécessité pour les dirigeants du système de santé d’encourager des approches « du bas vers le haut », centrées sur la personne, afin de développer des modèles de soins qui sont adaptés aux personnes souffrant de multimorbidité, et d’encourager des programmes de recherche qui abordent les priorités identifiées.
Background
Living with multiple chronic conditions (or multimorbidity as defined below) is part of the daily life of a growing number of Canadians. Recent estimates indicate that 12.9% of Canadian adults were living with two or more chronic conditions and that 3.9% were living with three or more chronic conditions (Roberts et al. 2015). Data from Ontario indicate a significant upward trend with the number of Ontarians living with multimorbidity having increased from 17.4% in 2003 to 24.3% in 2009, which is a 40% increase (Pefoyo et al. 2015). Another study found that rates of multimorbidity vary widely across primary care settings (the central point of contact for many with chronic diseases), but similarly indicated that the overall picture is one of high levels of multimorbidity (Stewart et al. 2013). Moreover, multimorbidity disproportionately affects some groups more than others as rates grow steadily with age, and they are higher among the more vulnerable groups in society (e.g., people who are less educated and have lower incomes) (CIHI 2011; Fortin et al. 2006; Health Council of Canada 2007, 2011; Roberts et al. 2015; Stewart et al. 2013). Their objectives and key methodological features are shown in Table 1.

Multimorbidity has been defined as “the co-existence of two or more chronic conditions, where one is not necessarily more central than the others” (Boyd and Fortin 2010). Boyd and Fortin (2010) further indicate that the concept of multimorbidity means that multiple diseases, syndromes and conditions may overlap and potentially interact, as compared to comorbidity where one index disease is the focus in relation to other comorbid conditions. Moreover, the management of multiple chronic conditions can overlap in unique ways for each individual (Boyd and Fortin 2010), thereby making clinical management complex (e.g., due to the need to prescribe and manage several medications). A recent qualitative study conducted in Ontario found that people with multimorbidity face several challenges such as a lack of decision-making support, poor communication and uncoordinated health services (Gill et al. 2014), and others have noted that the care for people with multimorbidity is “fragmented, incomplete, inefficient, and ineffective” (Boyd and Fortin 2010). Also, high-needs users of the health system, many of whom are adults with multimorbidity, account for a disproportionately high share of costs – more than two-thirds in Ontario (Wodchis et al. 2012). Accordingly, there have been growing calls for changes to health systems and clinical decision-making processes to provide the complex and integrated care required by those with multimorbidity (OECD 2011; Tinetti et al. 2012).

To contribute to addressing this pressing health system issue, we undertook a series of projects focused on evidence synthesis and on stakeholder and citizen engagement. Our overall objective was to use these projects to support the actions of those involved in addressing the challenges associated with providing care for people with multimorbidity. In this paper, we provide an overview of the approach we used for each project and the key messages we derived from them.
### TABLE 1. Summary of our approach to evidence synthesis and stakeholder and citizen engagement

<table>
<thead>
<tr>
<th>Project</th>
<th>Objective</th>
<th>Key methodological features</th>
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| Knowledge synthesis         | Synthesize the available research evidence about optimal treatment approaches for people with multimorbidity                                 | • Included four types of documents: (1) systematic reviews evaluating the health risks faced by people with multimorbidity and/or programs and models for their treatment; (2) guidelines (or approaches to developing guidelines) outlining approaches for treating people with multimorbidity; (3) effectiveness studies evaluating programs and models for treating people with multimorbidity; and (4) process evaluations of programs and models for treating people with multimorbidity  
  • Conducted database searches, hand-searched websites of relevant Canadian and international organizations, and asked key informants for literature  
  • Two independent reviewers assessed all literature for inclusion  
  • Extracted the focus and key findings from each document, and appraised the methodological quality of all systematic reviews (using the AMSTAR tool) (Shea et al. 2007) |
| ‘Gap analysis’              | Identify key knowledge gaps that could be the focus for future research                                                                  | • Updated all of the literature searches (in March 2014)  
  • Developed a ‘gap map’ by organizing the included reviews and economic evaluations in a matrix by mapping each review according to the level of intervention in the system (at the level of patients or individuals, providers, teams, organizations, sectors or systems) and to outcomes included within the Institute for Healthcare Improvement’s Triple Aim Initiative (Improving the patient experience of care, improving the health of populations and reducing the per capita cost of care) (Institute for Healthcare Improvement 2014) |
| Issue and citizen brief    | Package the available evidence for stakeholders and citizens                                                                            | • Convened a steering committee and conducted key informant interviews to inform the development of the brief  
  • Updated searches from the knowledge synthesis and synthesized the findings related to the problem, three elements of a potentially comprehensive approach to address the problem, and implementation considerations |
| Stakeholder dialogue       | Identify shared ground, divergences of opinion and possible next steps to address the issue                                                | • Convened health system stakeholders (policy makers, managers of health organizations, professional and community leaders, patients/citizens/groups representing them, and researchers) for deliberations to support participants to champion creative efforts to design integrated approaches to support people with multimorbidity  
  • Participants were identified in collaboration with a steering committee and selected based on their ability to: (1) bring unique views, experiences and tacit knowledge to bear on the challenge and learn from the research evidence and from others’ views, experiences and tacit knowledge; and (2) champion within their respective constituencies the actions that will address the challenge creatively  
  • Deliberations were facilitated by one of us (JNL) and followed the structure of the issue brief, with a final deliberation focused on next steps that could be taken for different constituencies  
  • Followed the Chatham House Rule (i.e., “the information used during the meeting can be used, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed”) (Chatham House 2014)  
  • Conducted a thematic analysis of the deliberations |
| Citizen panel              | Identify the values and preferences that citizens believe should guide next steps                                                          | • Sought to recruit a panel of 10–14 citizens* in Ontario that was balanced in terms of gender, age, socioeconomic status and lived experience (i.e., balance between those with one chronic disease, with two or more chronic diseases, and those caring for someone with a chronic disease)  
  • Participants were recruited through an organization that maintains a panel of approximately 250,000 Canadians who participate in loyalty programs  
  • The deliberations were facilitated by one of us (FPG) and followed the structure of the citizen brief  
  • Prepared a thematic summary of the deliberations, with specific focus on identifying underlying values and preferences expressed by participants |

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*We conducted a related articles search of PubMed in June 2012 using each of the 10 studies included in a recent systematic review (Smith et al. 2012) and a hand search of the excluded references in the review. The PubMed search was limited to articles published in 2011 or later (the year the search was last conducted in the review). We also searched Medline in September 2012 using the ‘co-morbidity’ MeSH term (as the focus of the document) and limiting the search to the last 10 years (2002 to 24 September 2012).

*We used the approach developed by the International Initiative for Impact Evaluation (International Initiative for Impact Evaluation 2014).

*We excluded employees of healthcare organizations or healthcare professionals, elected officials, and individuals working for market research, advertising, public media or public relations firms.
Methods
Each of the five projects used distinct methods, which we describe in detail in each of the full reports that are published elsewhere (Gauvin et al. 2013, 2014a, 2014b; Wilson and Lavis 2013, 2014; Wilson et al. 2013). We provide an overview of the projects, their objectives and key methodological features in Table 1.

Results

Findings from the evidence syntheses

Knowledge synthesis
For the knowledge synthesis, we identified six systematic reviews, eight randomized controlled trials, eight qualitative studies, four cross-sectional studies, six overviews of the applicability of existing guidelines to multimorbidity (each found few or no guidelines addressing treatment for multimorbidity), five guidelines that provide implications or recommendations for treatment (but none that focused exclusively on multimorbidity) and two consensus documents and 10 papers that we classified as “supplementary literature” (document/descriptive analyses, non-systematic reviews and discussion papers/comments/editorials) that provided examples of sets of principles that had been developed for the creation of multimorbidity guidelines.

Key findings from systematic reviews relate to: (1) consequences of and risk and protective factors for multimorbidity; (2) programs and models for treating people with multimorbidity; and (3) guidelines for treating people with multimorbidity. The most commonly identified consequences of multimorbidity include functional impairment and disability, poor quality of life, increased risk of early death (although findings are inconsistent), high healthcare utilization, high out-of-pocket costs and the significant burden placed on patients and their families (France et al. 2012; Marengoni et al. 2011). In terms of risk factors, long-term care residents are at high risk for mental–physical multimorbidity (van den Brink et al. 2012). Certain combinations of chronic conditions (e.g., chronic respiratory disease, congestive heart failure and diabetes) present a greater risk for physical decline than other combinations; however, there is inconsistent evidence of the impact of patients’ income, sex, age and ethnicity on multimorbidity (France et al. 2012). A large social network has been found to be a protective factor for the consequences of multimorbidity (Marengoni et al. 2011).

For multimorbidity programs and models, we found three systematic reviews, which found that:

- patient-oriented interventions that focus on specific risk factors or impairments (e.g., functional ability or medication management) and are linked with relevant providers have been found to be more effective than interventions with a general focus (Smith et al. 2012);
• organizational interventions such as integrated treatment programs coordinated by care managers or individualized medication care plans have been found to improve prescribing, medication use and adherence (Smith et al. 2012);
• the effectiveness of comprehensive care programs that are built around the Chronic Care Model is inconsistent across studies, but the effects are either comparable to or better than standard care (de Bruin et al. 2012); and
• inappropriate medication use has been found to be reduced by computerized decision support and pharmaceutical care interventions (Patterson et al. 2012).

Promising interventions evaluated in primary studies that we identified include nurse-led interventions (Ishani et al. 2011; Williams et al. 2012), pharmacist-led shared medical appointments (Taveira et al. 2011), guided care teams (Boult et al. 2011; Boyd et al. 2007) and patient-centred, team-based collaborative care management (Katon et al. 2012; Lin et al. 2012; McGregor et al. 2011; Von et al. 2011).

Finally, we found several overviews focused on the applicability of existing guidelines to multimorbidity, examples of guidelines that included recommendations related to multimorbidity and principles that have been suggested for the creation of multimorbidity guidelines. The overviews of the applicability of existing guidelines to multimorbidity found inconsistent attention paid to multimorbidity. The overviews also found that many guidelines identify considerations about comorbidity (but not multimorbidity) and considered it in treatment, and some provided information about the burden of treatment on the patient, but none actually specified preferred actions for patients with more than one concurrent condition (Boyd et al. 2005; Fortin et al. 2011; Hughes et al. 2012; Lugtenberg et al. 2011; Mutasingwa et al. 2011; Vitry and Zhang 2008).

While not focused on managing multimorbidity, several guidelines that we identified either included recommendations related to multimorbidity or undertook a development process that may be informative for efforts to develop a multimorbidity guideline. Examples of this include ensuring consistency with guidelines for the major risk factors for the disease focused on in the guideline and providing advice about what to prescribe based on possible physical comorbidities and co-prescribing scenarios (NICE 2009, 2012).

The most frequently cited principles/recommendations (see the knowledge synthesis for the full list of 15 principles/recommendations) that have been suggested for the creation of multimorbidity guidelines are to:

• include information on the most common multimorbidity disease clusters along with the main chronic condition (Boyd et al. 2005; Fabbri et al. 2012; US Department of Health and Human Services 2010);
• develop a patient-centred approach to guideline development (Boyd et al. 2012a; Eddy et al. 2011; Lugtenberg et al. 2011; Mutasingwa et al. 2011; Tinetti et al. 2004; US Department of Health and Human Services 2010; van Weel and Schellevis 2006);
cross-reference guidelines with each other (Guthrie et al. 2012; Hughes et al. 2012);
• use patient-friendly language (Boyd et al. 2005, 2012b; Cox et al. 2011; Fabbri et al. 2012; Guthrie et al. 2012; Hughes et al. 2012; Mutasingwa et al. 2011; Tinetti et al. 2004);
• consider the feasibility of implementation (Boyd et al. 2012a; Fabbri et al. 2012); and
• include older adults and patients with comorbid conditions in randomized trials
and include the results in the development of guidelines (Boyd et al. 2005, 2012a; Lugtenberg et al. 2011; Tinetti et al. 2004; US Department of Health and Human Services 2010; van Weel and Schellevis 2006).

GAP ANALYSIS
We included 26 systematic reviews (six high-quality, 17 medium-quality and three low-quality) and four economic evaluations in the “gap analysis” (the full matrix is available in the original report). Many of the systematic reviews address several intervention levels and/or types of outcomes but most address interventions at the level of providers or teams and disease-focused outcomes. Moreover, while three reviews addressed prevention/upstream interventions, all exclusively addressed disease-focused outcomes and none addressed any of the other seven outcomes relevant to the three outcome domains (improving the patient experience of care, improving the health of populations and reducing the per capita cost of care) included in the Triple Aim Initiative. Further, almost half of the reviews (n = 12) did not include a study that was conducted in Canada, and those that did contained very few, pointing to a lack of Canada-specific evidence available about interventions for people with complex-care needs.
In addition, four broad priority areas for future research emerged from our “gap analysis” (and from key informant interviews that we conducted to inform the analysis): (1) identifying complex-care patients and paying particular attention to those with the most complex needs; (2) taking a balanced approach to evaluating interventions and ensuring coverage of program-, system- and societal-level interventions; (3) adopting a patient-centred approach to measuring outcomes; and (4) developing guidance for patients/individuals and for providers.

ISSUE BRIEF AND CITIZEN BRIEF
The issue brief drew on the same systematic reviews that we identified in the knowledge synthesis and supplemented them with additional local evidence about the problem and systematic reviews related to specific components of the three elements of a potentially comprehensive approach to address the problem. The three elements broadly related to: (1) developing integrated models of care that improve the patient experience, improve health and keep per capita costs manageable; (2) enabling primary care, community care and other providers to identify and use guidelines (or care pathways) that meet the needs of people living with multimorbidity; and (3) enabling primary care, community care and other providers to efficiently support self-management by patients with multimorbidity. In addition to the systematic reviews included in the knowledge synthesis that focused on elements 1 and 2,
we identified additional reviews that found improvements in physical and mental health outcomes for patient education and family interventions designed to help patients with multimorbidity use self-management resources, and for information and communication technology, home-based support and a range of interventions aimed at supporting appropriate medicine use by consumers.

Findings from Citizen and Stakeholder Engagement

Stakeholder dialogue

The stakeholder dialogue brought together 21 participants, which included three policy makers, nine managers (a number of which are involved with Health Links in Ontario), three providers, five researchers and one from a disease-based society. Participants agreed with the framing of the problem in the issue brief, but raised three several additional considerations. First, many identified a lack of clarity about the target population of integrated approaches (e.g., is the target: people with or at-risk for multimorbidity, low-income people with multimorbidity, complex and vulnerable patients and/or high-needs patients in relation to both healthcare and the full spectrum of the social determinants of health?). Building on this, the second consideration raised was the need to determine what the goal is for addressing the “problem” of multimorbidity (e.g., is it a goal in itself, a mechanism for strengthening primary care more generally or a way of improving the patient journey for those with and without multimorbidity?). Finally, many emphasized that the full trajectory or journey for a patient (not just those living with multimorbidity) is not always the focus of care, which was seen as a missed opportunity for prevention and providing person-centred care.

In deliberating about the elements of a potentially comprehensive approach to address the problem, participants agreed that the status quo is not an option and identified three areas of focus in relation to the elements, which include:

1. focusing on person-centred care, identifying how to scale up successful approaches and building the capacity of health professionals that would be involved in new models of care;
2. developing an optimal approach for producing care guidelines or guidance for people with multimorbidity that is person-centred and focuses on identifying patients’, caregivers’ and families’ goals; and
3. developing tools and resources for self-management through partnerships between providers and citizen groups that include proactive approaches and use social media/technology to reach more people.

Towards implementing these approaches, participants emphasized the need for collaborating within teams and across silos, engaging patients, caregivers and families, funding approaches that support models of care for people with multimorbidity and making better use of technology (e.g., electronic medical records and computerized clinical decision support). Moreover, participants identified several next steps that they thought should be taken. These
included “staying the course” and not prematurely abandoning current support for bottom-up, person-centred approaches to developing models of care; develop evidence-based guidance that providers can use to help achieve goals set by patients; embracing approaches to supporting self-management that are innovative and prioritize collaboration; and developing a research agenda to address the many unanswered questions in this domain.

Citizen panel
The citizen panel brought together an ethnoculturally and socioeconomically diverse group of 11 citizens. Based on their lived experience, panel participants identified several factors they saw as driving the challenge, which included an ageing population with increasingly complex care needs, fragmentation of care, the psychosocial and economic burden on informal/family caregivers, lack of informational support and lack of focus on health promotion and disease prevention to curb the burden of chronic health conditions. When asked to deliberate about the elements of an approach to address the problem, participants identified six values that they viewed as being important to underpin future actions, which include:

1. patient- and caregiver-centredness (care and support must be attuned to the complex needs of people with multiple chronic health conditions, as well as the needs of their informal/family caregivers);
2. access (to reliable and timely information, as well as coordination support);
3. collaboration (to mobilize all those who can provide needed support and services beyond what is provided by the health system);
4. solidarity (to ensure we do not leave the most vulnerable to fend for themselves);
5. empowerment (to equip people to engage in conversations with healthcare providers and manage their own care); and
6. trust (between patients and providers).

Panel participants also generally agreed about the need to focus efforts on the key components of the Chronic Care Model (Wagner et al. 1996) as a viable approach to improve how care is organized and delivered, but identified three priorities for its use. First, participants emphasized the need to adapt the model to people with multimorbidity, who often suffer from mental health problems and addictions, or from Alzheimer’s and other dementias, as they may be unable to self-manage or make informed decisions. Second, many identified the need to offer tools, resources and coaching for informal/family caregivers who must navigate the complex legal system to provide care and support for someone with multimorbidity who is unable to self-manage or make informed decisions. Finally, participants strongly emphasized the need to implement long-awaited electronic health records and other e-health initiatives that could provide informational support and coordination support to people with multimorbidity and their informal/family caregivers.
Discussion

Key findings across projects
While much of the evidence is mixed and inconclusive or lacking (e.g., in the case of guidelines), several key messages emerged from the literature we identified: (1) the main consequences of multimorbidity (functional impairment, poor quality of life, high healthcare utilization, high out-of-pocket costs and increased burden on the patient for their care); (2) interventions that are more targeted (e.g., integrated treatment programs coordinated by care managers) are more effective than those with a broader or more generic approach (e.g., case management or changes in care delivery); (3) “complex and multifaceted pharmaceutical care” can reduce inappropriate medication use and adverse drug events; and (4) recommendations exist for developing multimorbidity-specific guidelines. Our findings also suggest strong alignment between stakeholders’ priorities and citizens’ values and preferences, which point to several actions that can be taken, including: (1) developing evidence-based guidance that providers can use to help achieve goals set by patients; (2) embracing approaches to supporting self-management; (3) supporting greater communication and collaboration across healthcare providers as well as between healthcare providers and patients; and (4) investing more efforts in health promotion and prevention.

Strengths and limitations
The primary strength of our approach is the power of combining the best available research evidence from systematic reviews with tacit knowledge and real-world views and experiences of those involved in or affected by the issue to derive a more holistic understanding of it and to identify actions that can be taken by health system decision-makers to address it. The main limitation of our approach is that the stakeholder dialogue and citizen panel were convened with participants from Ontario (although the stakeholder dialogue had one participant from Quebec and another from the US). This could mean that the key themes identified in each are not representative of those from other provinces in Canada.

Implications for research
While we identified many systematic reviews that were at least somewhat relevant to multimorbidity, there was consensus among the stakeholder dialogue participants that there is a need to develop a clearly articulated research agenda. Such an agenda could be shaped around the four priorities that emerged from our mapping of the literature and key informant interviews, which included identifying complex-care patients; taking a balanced approach to evaluating a range of program-, system- and societal-level interventions; measuring patient-relevant outcomes; and developing evidence-based guidance that can be used by health providers to help achieve the goals set by people with multimorbidity and their families and caregivers. A logical first step would therefore be to engage in a priority-setting process to build on these areas and identify more specific research priorities that need to be addressed in the short, medium and long term, and the gap analysis, as well as themes from
the stakeholder dialogue and citizen panel, can provide important insight into setting future research priorities.

**Implications for policy**
Our findings provide several insights that can be used by health system decision-makers in Canada, who are grappling with how to design integrated approaches to support people with multimorbidity. The most fundamental actionable message from our findings is the need to move forward with efforts to support bottom-up, person-centred approaches to developing models of care. Critical to this is thinking beyond our historical focus on physicians and hospitals to develop integrated approaches for providing the range of supports that people with multimorbidity require, regardless of who provides them or where they are provided. In particular, this will likely require considering reforms, such as Ontario is now doing through its proposal to strengthen patient-centred care through bundled payments (Government of Ontario 2015) that would allow provincial and territorial health systems to provide accessible, comprehensive, coordinated and continuing care to people with multimorbidity across home and community, primary and acute care. Moreover, efforts to this end will need to consider a number of additional factors, including how best to identify those at risk for multimorbidity (particularly in vulnerable and hard-to-reach populations), monitor and evaluate models of care using meaningful indicators of success, scaling up successful approaches and building the capacity of providers to effectively provide care within these models.

**Acknowledgements**
The authors would like to thank those involved with each of the projects that we present in this paper, who are formally acknowledged in each of the documents that are available on the McMaster Health Forum website (www.mcmasterhealthforum.org). Funding for the issue brief and stakeholder dialogue was provided by the Canadian Institutes of Health Research through an Expedited Knowledge Synthesis Grant (grant #267895), the Government of Ontario (through a Ministry of Health and Long-Term Care Health System Research Fund grant entitled Harnessing Evidence and Values for Health System Excellence) and McMaster University’s Labarge Optimal Aging Initiative.

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Designing Integrated Approaches to Support People with Multimorbidity


A Review of Discharge-Prediction Processes in Acute Care Hospitals

Une étude sur les processus de prédiction de congés de patients des hôpitaux de soins de courte durée

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Abstract

Aims and Objectives: Discharge prediction is designed to streamline inpatient flow and reduce hospital overcrowding without adding capacity. This study’s objective was to describe the literature on discharge prediction and assess its usefulness in evaluating the implementation and outcomes of discharge prediction projects.

Methods: The authors reviewed the current peer-reviewed and grey literature on discharge prediction projects in acute care hospitals. Project descriptions were analyzed using Donabedian’s structure–process–outcome model for evaluating complex healthcare innovations.

Results: The review revealed a paucity of literature on the use and effectiveness of discharge prediction. There is high variation in its use and generally poor reporting of both implementation and outcomes.
Conclusions: The literature on discharge prediction generally lacks the descriptive detail that would be useful to parties considering or planning a discharge prediction initiative. Further study is required to determine how best to integrate these prediction tools into acute care hospitals.

Résumé
Objectifs : La prédiction de congés est conçue pour rationaliser la venue de patients et réduire l’engorgement dans les hôpitaux sans ajouter de nouveaux lits. L’objectif de cette étude était de faire un survol de la littérature, et de vérifier son utilité dans l’évaluation de projets de prédictions de congés et de résultats.
Méthodes : Nous avons revu la littérature scientifique et la littérature grise sur les projets de prédiction de congés dans les hôpitaux de soins de courte durée. Les descriptions de projets ont été analysées en utilisant le modèle structure–processus–résultat de Donabedian, qui évalue la complexité des innovations en soins de santé.
Résultats : L’étude a révélé la rareté de la littérature sur l’utilisation et l’efficacité des prédictions de congés. Il existe une variation élevée dans son utilisation, et en général, la documentation sur l’implantation et les résultats est plutôt incomplète.
Conclusions : La littérature sur la prédiction de congés manque habituellement d’explications qui pourraient être utiles à ceux qui considèrent ou planifient des projets de prédictions de congés. Davantage de recherches sont nécessaires pour déterminer comment mieux intégrer ces outils de prédictions dans les hôpitaux de soins de courte durée.

Introduction
We use the term “discharge prediction” (DP) to refer to a family of operational techniques, which involve assigning a predicted date of discharge to patients upon their admission to hospital. These predictions are made by the medical team based on the patient’s clinical status at time of admission and are typically updated throughout the hospital stay. Patient care services and operations can then be aligned around this date, with the goal of minimizing delays and inefficiencies during the patient’s stay (Rodi et al. 2006), reducing their length of stay (LOS) (Li et al. 2012) and helping to alleviate overcrowding through improved patient flow (Carratalà et al. 2012).

There are many reasons why hospital administrators and other decision-makers might find DP attractive. Hospital overcrowding is a common problem, with adverse consequences for both the quality of patient care and for healthcare costs, where shorter lengths of stay have been associated with reductions in the total cost of a hospital admission (Clancy 2009; Clarke et al. 1996). Overcrowding has been associated with decreased patient satisfaction, as well as a higher risk of in-hospital complications and mortality (Clements et al. 2008; Fatovich et al. 2005; Ospina et al. 2007; Virtanen et al. 2011; Welch 2010). Overcrowding occurs when the demand for admissions exceeds inpatient bed capacity; capacity in turn is a function of the number of inpatients and their average length of stay (ALOS).
Hospital overcrowding is a complex phenomenon, involving factors relating to admission (input), efficiency of care delivery during hospital stay (throughput) and discharge (output). Many of these factors, such as emergency department demand or patient complexity, are not under a hospital’s control. By contrast, DP potentially offers greater control over the efficiency of the discharge process. It can theoretically improve both throughput and output by aligning clinical and operational services during a patient’s hospital stay and during discharge planning. The intent is that the resulting efficiencies will reduce LOS, thereby increasing the bed capacity available to meet admission demands and improving overcrowding. In this way, DP may also offer the potential to mitigate hospital overcrowding without the increased operating costs incurred by adding staff and beds.

While improving the discharge process may lead to reduced LOS and reduced acute care costs (Greenwald et al. 2007; Li et al. 2012; Walters et al. 2007), the specific contribution of DP itself remains unclear. Moreover, although it is in use in many hospitals, the most effective way to use DP is unknown. Decision-makers who have heard of DP and are contemplating adopting it therefore face two questions: does it really work? And how is it implemented? Many of them will turn to the literature for answers. Thus, we sought to examine literature that describes actual DP initiatives, and we assess how useful these reports are in addressing these two questions.

Methods
We realized early in the study that a traditional systematic review was unlikely to yield a meaningful synthesis of study results. Initial exploratory searches of several databases (PubMed, Scopus, Cumulative Index to Nursing and Allied Health Literature [CINAHL], Cochrane), which we conducted to refine our search terms, suggested there was a very small body of literature on the topic. Discussions with a quality improvement consultant who specializes in discharge planning reinforced this impression and further indicated that quality of reporting would be inconsistent. Therefore, we chose not to conduct a systematic review.

We decided instead to produce a high-level overview of the current reporting on DP. Our goal was to identify and describe any apparent trends or patterns in DP practices, which seemed to us a reasonable way to assess the utility of this literature from the standpoint of hospital administrators interested in DP, or of a planning committee or implementation team interested in DP’s practicalities. Indeed, we think it important to offer such high-level commentary not only to document any detectable trends but also to draw attention to this literature’s current state: a synthesis of study results via traditional systematic review will be useful to decision-makers only if the quality of reporting improves.

With this objective in mind, we searched PubMed and Google. For completeness, we performed similar searches of CINAHL, Cochrane and Scopus, which did not return additional records. However, these databases are specialized and/or have a strong academic focus. Some hospitals (e.g., small, rural, non-academic) may not subscribe to these databases, so even if relevant records were present, they would be inaccessible to project staff. Therefore, we limited ourselves to publicly available sources to which any hospital can reasonably be assumed to have access.
We used PubMed for peer-reviewed literature and Google to access grey literature. We used Google’s standard search engine as opposed to Google Scholar to maximize our chances of returning reports from the websites of individual hospitals, health authorities and related organizations. Our search terms were refined over the course of several exploratory searches and discussions with the quality improvement consultant. The final set of terms includes the one relevant MeSH term (“discharge planning”), terms recommended by the consultant and terms that appeared in the grey literature sources. This process helped ensure we adequately accounted for synonymous or related terms (e.g., “anticipated,” “expected” and “estimated date of discharge”). Our search terms and search results are outlined in Figure 1.

**FIGURE 1.** Search terms and search strategy

<table>
<thead>
<tr>
<th>Peer-reviewed literature</th>
<th>Grey literature</th>
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<tr>
<td><strong>Search terms</strong></td>
<td><strong>Search terms</strong></td>
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<tr>
<td>“expected date of discharge”</td>
<td>“anticipated date of discharge”</td>
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<tr>
<td>“anticipated date of discharge”</td>
<td>“patient discharge” + “anticipated date of discharge”</td>
</tr>
<tr>
<td>“discharge appointment”</td>
<td>“estimated discharge date”</td>
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<tr>
<td>“estimated date of discharge”</td>
<td>“expected discharge date”</td>
</tr>
</tbody>
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(n = 196)  (n = 23)

Records screened  (N = 410)

Records excluded*  (n = 375)

Records included in analysis  (n = 35)

*Records were excluded for one of two reasons (see text for details):
(a) on review, they did not actually describe a DP project;
(b) they did not contain a description of the project which could be analyzed.

Based on title-review, peer-reviewed articles that discussed a DP process were selected for full-text review. Google search results were scanned sequentially until the items became repetitive or irrelevant (typically about 6–10 pages into the results). Additional resources were obtained from the quality improvement consultant. Any articles that did not elaborate upon the use of DP as it related to discharge planning in an acute care setting were excluded. The authors collectively developed a standardized system to guide the process of record selection and the extraction of descriptive data from the included records. One author (A. de G.) performed the review of titles and abstracts, and then conducted the descriptive review of each included article to obtain details of the discharge initiatives they discussed. The other authors consulted on the selection and review process, and all authors reviewed the resulting descriptive data.
We organized the selected articles using Donabedian’s (1988) structure–process–outcome framework for evaluating complex interventions. Structural elements included hospital demographic information, such as size (based on number of beds), geographic location (urban or rural, as well as country) and type of hospital (academic or community). Process elements included details of the DP initiative such as where DP planning information was recorded, who determined the predicted discharge date, who was allowed to change it and how often it was reviewed. Outcomes included LOS, re-admissions, patient satisfaction and any other clinical or operational outcomes.

Results
Our search resulted in 196 peer-reviewed articles and 214 non-peer-reviewed papers, pamphlets or information booklets. After excluding materials without an actual DP component, or lacking a detailed project description as described above, 35 items were included in the study: 12 peer-reviewed and 23 non-peer-reviewed. Publication dates ranged from 1992 through 2014, with 54% of the materials reporting on initiatives that had occurred since 2009. Several of the grey literature sources did not report a project date or timeline. Tables 1 and 2 describe the 35 included DP projects.

### TABLE 1. Peer-reviewed literature: Descriptive details

<table>
<thead>
<tr>
<th>Country</th>
<th>Setting*</th>
<th>Hospital type§</th>
<th>Hospital size¶</th>
<th>Who assigns predicted date</th>
<th>Prediction method</th>
<th>Location of DP date</th>
<th>Outcomes reported</th>
</tr>
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<tbody>
<tr>
<td>1</td>
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<td>Staff compliance</td>
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</tr>
<tr>
<td>3</td>
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<td>Large</td>
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<td>Algorithm</td>
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</tr>
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</tr>
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<td>Nurses</td>
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</tr>
<tr>
<td>8</td>
<td>England</td>
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<td>Large</td>
<td>Team</td>
<td>–</td>
<td>Staff satisfaction, compliance</td>
</tr>
<tr>
<td>9</td>
<td>England</td>
<td>Urban</td>
<td>Community</td>
<td>Large</td>
<td>Team</td>
<td>Algorithm</td>
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</tr>
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<td>–</td>
<td>–</td>
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</tr>
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<td>Large</td>
<td>–</td>
<td>–</td>
<td>Patient satisfaction</td>
</tr>
<tr>
<td>12</td>
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<td>Academic</td>
<td>Medium</td>
<td>–</td>
<td>–</td>
<td>Staff communication</td>
</tr>
</tbody>
</table>

ALOS = average length of stay; DP = discharge prediction. *Urban vs. rural distinction is based on the given hospital’s website. Totals given in text may not sum to 100% as some projects incorporated both urban and rural hospitals. §Academic vs. community distinction is based on the given hospital’s website. Totals given in text may not sum to 100% as some projects included both academic and community hospitals. ¶Small (<200 beds), medium (200–400 beds), large (>400 beds). Size definitions are based on those of the Canadian Institute for Health Information (CIHI 2016) and Yergens et al. (2014).
## TABLE 2. Grey literature: Descriptive details

<table>
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<th></th>
<th>Country</th>
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<th>Hospital type§</th>
<th>Hospital size¶</th>
<th>Who assigns predicted date</th>
<th>Prediction method</th>
<th>Location of DP date</th>
<th>Outcomes reported</th>
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<td>–</td>
<td>–</td>
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<td>Team</td>
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<td>–</td>
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<td>Large</td>
<td>Physician</td>
<td>–</td>
<td>Patient chart, whiteboard</td>
<td>–</td>
</tr>
<tr>
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<td>All</td>
<td>Team</td>
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<tr>
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<td>Both</td>
<td>All</td>
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<td>Algorithm</td>
<td>Patient chart</td>
<td>–</td>
</tr>
<tr>
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<td>All</td>
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<td>–</td>
<td>–</td>
<td>–</td>
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<td>Senior medical staff</td>
<td>–</td>
<td>Patient satisfaction</td>
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<td>All</td>
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<td>Unit benchmarks</td>
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<td>Physician</td>
<td>Clinical judgment</td>
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<td>Staff compliance, patient satisfaction</td>
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<td>–</td>
<td>Staff compliance, patient satisfaction</td>
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<td>Large</td>
<td>Team</td>
<td>–</td>
<td>Patient chart</td>
<td>–</td>
</tr>
</tbody>
</table>

† Denotes more than one hospital involved in the DP project.

DP = discharge prediction. *Urban vs. rural distinction is based on the given hospital’s website. Totals given in text may not sum to 100% as some projects incorporated both urban and rural hospitals. §Academic vs. community distinction is based on the given hospital’s website. Totals given in text may not sum to 100% as some projects included both academic and community hospitals. ¶Small (<200 beds), medium (200–400 beds), large (>400 beds). Size definitions are based on those of the Canadian Institute for Health Information (CIHI 2016) and Yergens et al. (2015).
Structure
Geographically, these DP projects occurred in large, developed nations: the UK (34%), the US (29%), Australia (20%) and Canada (17%). Large hospitals (more than 400 beds) were more likely to be reporting on the use of DP initiatives (80%). DP initiatives were more commonly reported by academic centres (80%) and urban hospitals (94%).

Process
The reporting of DP use was highly variable in that many of the core aspects that make up a DP initiative (e.g., who assigns the date, how it is predicted) were not documented or were documented inconsistently across projects.

There were many different individuals and/or groups who determined these dates: physicians (44%), a multidisciplinary team (41%), nurses (7%) and a project-specific consultant or manager (7%). Twenty-eight of the 35 projects (80%) reported where the predicted date was recorded and 27 (77%) reported who determined the DP date. But none of the projects reported on whether these or other individuals were allowed to change the initially predicted date, nor did they report how frequently it was reviewed or updated.

Sixteen projects (46%) reported how the DP date was determined: 11 relied upon clinical judgment, while four used an algorithm or similar decision tool to predict a discharge date. Of those latter four projects, none used a validated LOS prediction tool.

Seven projects (20%) reported on the accuracy of their DP, ranging from 28–88% of patients discharged on or before their predicted date. Of these, one project distinguished between different patient populations, noting lower prediction accuracy for patients admitted through the emergency department (44%) as compared to elective admissions (55%). Two projects reported how many patients were assigned a predicted date (61% in both cases).

Five projects (14%) brought in additional staff to assist with DP implementation, while 22 projects (63%) made implementation the responsibility of existing staff. Eight projects (23%) adopted a phased implementation or roll-out strategy, while 18 projects (51%) did not and nine projects (26%) did not report.

Outcomes
Seventeen projects (49%) recorded patient care or operational outcomes associated with the use of DP as follows: four projects reported on LOS, ranging from a 13–19% reduction in ALOS. But this reporting was inconsistent, as some compared DP and non-DP hospital units, others the same unit pre- and post-adoption of DP and others did not specify. One project reported ALOS in days, one in percentages only, one in an inconsistent mix of days and percentages and one did not quantify the ALOS reduction.

One project reported reduced costs – a 20% reduction in the use of items per patient. Ten projects reported anecdotal improvements such as “noticeably fewer complaints,” “improved staff communication” or greater compliance, confidence or knowledge of DP use by providers. Another five projects reported improved patient satisfaction, also measured
anecdotally. Fourteen projects reported time frames for their outcomes, ranging from a few weeks to a few years. No studies reported on re-admissions.

Discussion
Our results suggest there are large gaps in reporting on the design and outcomes of DP projects. As a result, this literature is far less useful for decision-makers and project staff than it could be. To make an informed decision, hospital administrators considering the adoption of a DP initiative would benefit from clear reporting about: (a) how other DP initiatives operate and (b) what their outcomes have been. Unfortunately, the reports found in our search have a very limited utility when it comes to these two areas of interest.

For the first area – reporting on structure and process – the literature is not well-suited to a readership looking for information on how to design and plan a DP initiative. Implementing such a project requires decisions about who will assign a DP date, how they will determine it, who can access it, who can change it, how often it is re-assessed or updated and where the date will be stored. In most reports, this basic information was vague, and for many projects it was absent altogether. There was similarly scant reporting on the operational quality of the initiatives themselves: very few reports mentioned the consistency with which discharge dates were assigned, how many patients were actually assigned a date or how accurate the predicted date was.

Looking at what the projects did report, there was high variability in the way discharge dates were predicted, reviewed and recorded. Such variability could potentially benefit hospitals searching for DP ideas by providing them a menu of different approaches to choose from when designing their own approach, but only if each approach is adequately described. Most are not.

For the second area, reporting on outcomes (of any kind) was also sparse. Projects typically reported on patient or staff satisfaction, with a small minority reporting on LOS. Satisfaction was assessed anecdotally, and, while some projects noted LOS reductions, the inconsistency of reporting and lack of descriptive detail made it difficult to interpret and compare the results.

There are some potential reasons why the literature on the use and effectiveness of DP is sparse. First, DP is often one piece of larger quality improvement projects, making it challenging to separate the DP’s contribution from the project’s other aspects, and to determine whether an outcome is due to the project itself or to how well the project was implemented (Campbell et al. 2007; Groene 2011; Shojania and Grimshaw 2005). Second, many of the discharge initiatives identified in our search were reported as in progress, so publishable results may not have been available if an evaluation had not yet been conducted. Third, there is the possibility of publication bias: quality improvement projects are not often published (Davidoff and Batalden 2005; Ross et al. 2010), nor is work reporting negative results (Dickersin 1990). Thus, while there is a general lack of evidence around the use and effectiveness of DP, this may be due to the nature of its implementation or to other factors that are separate from the quality of DP initiatives.
Some limitations to our review exist. First is the nature of the literature itself. There was little peer-reviewed material available and only a small amount of grey literature, which we included as quality improvement projects are often reported in non-peer-reviewed sources (Crawford et al. 2002; Davidoff et al. 2008). The projects did not all report on similar aspects of DP, making it difficult to get a comprehensive view of different DP processes and how they are used. Many DP initiatives could go unreported and this may reflect in our results; for example, while we found that large, urban hospitals were more likely to report on DP use, it may be that small rural hospitals are frequent DP users but may have different infrastructure or motivation to disseminate reports on their projects.

Second, we did not adopt a systematic review methodology – though our results suggest that a systematic review is unlikely to be fruitful given the size of the literature and the poor reporting. Instead, we have provided a high-level review of discharge initiatives: the sort of initial search for recommendations and best practices that a hospital might conduct in preparation for adopting a DP project of its own. This approach allowed us to observe the variability among discharge initiatives and the state of the literature that healthcare practitioners interested in DP are likely to encounter.

Future studies could enrich these results by directly contacting hospitals that use DP, though we cannot say whether this approach would glean information beyond what those hospitals have already chosen to report. What readers who are trying to decide whether – and how – to adopt DP really deserve is a literature of a much higher reporting quality, with close analysis of both process and outcomes. Once the DP literature has grown in both size and quality, a systematic review would be a logical and useful next step. By drawing attention to the current level of reporting, we hope to encourage those who undertake DP projects to publish their reports with a view to contributing to a rich and detailed literature, which would make informed decisions about DP possible.

Conclusion
Discharge prediction has an intuitive appeal: the possibility of improving patient flow by improving efficiency without adding staff or beds. But there is a paucity of evidence regarding its use and effectiveness. The recency of publication of the majority of our included materials suggests a current interest in DP, but its use is variable. And while variable use is not necessarily a problem in itself (any care practice will need to be tailored to its local context somewhat), the pattern of reporting is less useful than it could be. The current literature, both grey and peer-reviewed, that is most readily available to decision-makers, provides neither the level of detail nor the kind of outcomes data that would help when making decisions about the adoption of a method of DP.

Our review of the available sources paints a picture of an enticing idea being explored in diverse ways. Further studies are needed to investigate the actual use of DP and its effects. A higher quality of reporting will better guide decision-makers towards informed choices regarding DP use and will help determine the role of this promising idea in efforts to improve patient care and operational outcomes.
Acknowledgements
The authors would like to thank Chris Roach for sharing his knowledge of DP practices and for assisting in the search for materials. This study was funded by an operating grant from the Canadian Institutes of Health Research (CIHR, #130487).

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References


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