HEALTHCARE

POLICY

Politiques de Santé

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

Volume 12 • Number 2

Data Matters • Discussion and Debate • Research Papers
Knowledge Translation, Linkage and Exchange

A LONGWOODS PUBLICATION Fonds WWW.HEALTHCAREPOLICY.NET

HEALTHCARE QUARTERLY: Best practices, policy and innovations in the administration of healthcare. For administrators, academics, insurers, suppliers and policy leaders. *Edited by* Dr. G. Ross Baker, University of Toronto, Toronto ✦ CANADIAN JOURNAL OF NURSING LEADERSHIP: Covering politics, policy, theory and innovations that contribute to leadership in nursing administration, practice, teaching and research. Peer reviewed. *Edited by* Dr. Lynn Nagle, University of Toronto, Toronto. ✦ HEALTHCARE PAPERS: Review of new models in healthcare. Bridging the gap between the world of academia and the world of healthcare management and policy. Authors explore the potential of new ideas. *Edited by* Prof. Adalsteinn Brown, University of Toronto, Toronto. ✦ HEALTHCARE POLICY: Healthcare policy research and translation. Peer reviewed. For health system managers, practitioners, politicians and their administrators, and educators and academics. Authors come from a broad range of disciplines including social sciences, humanities, ethics, law, management sciences and knowledge translation. *Edited by* Dr. Jennifer Zelmer, Adjunct Faculty, University of Victoria, Victoria. ✦ WORLD HEALTH & POPULATION: Best practices, policy and innovations in the administration of healthcare in developing communities and countries. For administrators, academics, researchers and policy leaders. Includes peer reviewed research papers. *Edited by* Dr. Judith Shamian, President, International Council of Nurses, Geneva, CH ✦ ELECTRONIC HEALTHCARE: Best practices, policy and innovations exploring e-models, e-practices and e-products for e-health. For administrators, academics, insurers, suppliers and policy pundits. ✦ LAW & GOVERNANCE: Within the framework of the law and the role of governance providing policies, programs, practices and opinions for the providers, administrators and insurers of healthcare services. *Editorial Chair,* Dr. Kevin Smith, McMaster University, Hamilton. ✦ HRRESOURCES: Cases, commentary and policy reviews for healthcare clinicians, human resources managers and the policy leaders, insurers, academics, administrators, boards and advisors of all healthcare organizations. ✦ LONGWOODS.COM: Enabling excellence in healthcare. Providing electronic access to news, information, career opportunities, conference schedules, research, case studies, policy reviews and commentary that cover politics, policy, theory, best practices and innovations in healthcare.

Longwoods Publishing | *Enabling Excellence*

HEALTHCARE
POLICY
Politiques de Santé

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

VOLUME 12 NUMBER 2 • NOVEMBER 2016

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

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

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

—

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

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

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

CONTENTS

From the Editor-in-Chief

Discussion and Debate

Research Papers

Online Exclusives

Peer Reviewed

TABLE DES MATIÈRES

De la rédactrice en chef

Discussions et débats

Rapports de recherche

Exclusivités en ligne

Examen par les pairs

HEALTHCARE
POLICY
Politiques de Santé

MANAGING EDITOR
ANIA BOGACKA
abogacka@longwoods.com

EDITORIAL DIRECTOR
DIANNE FOSTER-KENT
dkent@longwoods.com

COPY EDITING
CENVEO PUBLISHING SERVICES

TRANSLATOR
ÉRIC BERGERON

PROOFREADER
NATHALIE LEGROS

DESIGN AND PRODUCTION
ANTONY F. BICKENSON
abickenson@longwoods.com

PUBLISHER
ANTON HART
ahart@longwoods.com

ASSOCIATE PUBLISHER
REBECCA HART
rhart@longwoods.com

ASSOCIATE PUBLISHER
SUSAN HALE
shale@longwoods.com

ASSOCIATE PUBLISHER
MATTHEW HART
mhart@longwoods.com

ASSOCIATE PUBLISHER/ADMINISTRATION
BARBARA MARSHALL
bmarshall@longwoods.com

HOW TO REACH THE EDITORS AND PUBLISHER
Telephone: 416-864-9667 Fax: 416-368-4443

ADDRESSES
All mail should go to: Longwoods Publishing Corporation, 260 Adelaide Street East, No. 8, Toronto, Ontario M5A 1N1, Canada.

For deliveries to our studio: 54 Berkeley St., Suite 305, Toronto, Ontario M5A 2W4, Canada.

SUBSCRIPTIONS
Individual subscription rates for one year are [C] $122 for online only and [C] $195 for print + online. Institutional subscription rates are [C] $530 for online only and [C] $698 for print + online. For subscriptions contact Barbara Marshall at telephone 416-864-9667, ext. 100 or by e-mail at bmarshall@longwoods.com.

Subscriptions must be paid in advance. An additional tax (GST/HST) is payable on all Canadian transactions. Rates outside of Canada are in US dollars. Our GST/HST number is R138513668.

SUBSCRIBE ONLINE
Go to www.healthcarepolicy.net and click on "Subscribe."

REPRINTS
Reprints can be ordered in lots of 100 or more. For reprint information call Barbara Marshall at 416-864-9667 or fax 416-368-4443 or e-mail to bmarshall@longwoods.com.

Return undeliverable Canadian addresses to: Circulation Department, Longwoods Publishing Corporation, 260 Adelaide Street East, No. 8, Toronto, Ontario M5A 1N1, Canada.

EDITORIAL
To submit material or talk to our editors please contact Ania Bogacka at 416-864-9667 or by e-mail at abogacka@longwoods.com. Author guidelines are available online at http://www.longwoods.com/pages/hpl-for-authors.

ADVERTISING
For advertising rates and inquiries, please contact Matthew Hart at 416-864-9667, ext. 113 or by e-mail at mhart@longwoods.com.

PUBLISHING
To discuss supplements or other publishing issues contact Rebecca Hart at 416-864-9667, ext. 114 or by e-mail at rhart@longwoods.com.

Healthcare Policy/Politiques de Santé is published four times per year by Longwoods Publishing Corp., 260 Adelaide St. East, No. 8, Toronto, ON M5A 1N1, Canada. Manuscripts are reviewed by the editors and a panel of peers appointed by the editors. Information contained in this publication has been compiled from sources believed to be reliable. While every effort has been made to ensure accuracy and completeness, these are not guaranteed. The views and opinions expressed are those of the individual contributors and do not necessarily represent an official opinion of *Healthcare Policy* or Longwoods Publishing Corporation. Readers are urged to consult their professional advisers prior to acting on the basis of material in this journal.

Healthcare Policy/Politiques de Santé is indexed in the following: PubMed/Medline, CINAHL, CSA (Cambridge), Ulrich's, Embase, IndexCopernicus, Scopus, ProQuest, EBSCO Discovery Service, is archived in PubMed Central, and is a partner of HINARI.

ISSN No. 1715-6572
eISSN No. 1715-6580

Publications Mail Agreement No. 40069375

EDITORIAL

Better Science, Better Science Reporting

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

Canadian Institutes of Health Research (CIHR). 2016. *Sex, Gender and Health Research Guide: A Tool for CIHR Applicants*. Retrieved November 11, 2016. <http://www.cihr-irsc.gc.ca/e/32019.html>.

Equator Network. n.d. Retrieved November 11, 2016. <http://www.equator-network.org/>.

Heidari, S., T.F. Babor, P. De Castro, S. Tort and M. Curno. 2016. "Sex and Gender Equity in Research: Rationale for the SAGER Guidelines and Recommended Use." *Research Integrity and Peer Review* 1: 2. doi:10.1186/s41073-016-0007-6.

ÉDITORIAL

Meilleure science, meilleurs rapports de recherche

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

Equator Network. s.d. Consulté le 11 novembre 2016. <http://www.equator-network.org/>.

Heidari, S., T.F. Babor, P. De Castro, S. Tort et M. Curno. 2016. "Sex and Gender Equity in Research: Rationale for the SAGER Guidelines and Recommended Use." *Research Integrity and Peer Review* 1: 2. doi:10.1186/s41073-016-0007-6.

Instituts de recherche en santé du Canada (IRSC). 2016. *La recherche sur le sexe, le genre et la santé : un outil pour les candidats aux subventions des IRSC*. Consulté le 11 novembre 2016. <http://www.cihr-irsc.gc.ca/f/32019.html>.

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

NOLA M. RIES, JD, MPA, LLM
Associate Professor and Deputy Dean (Research), Newcastle Law School
University of Newcastle
Australia
External Research Fellow
Health Law Institute
University of Alberta
Edmonton, AB

MAUREEN DOUGLAS, BA, LLB
Senior Project Coordinator
Advance Care Planning CRIO Program
University of Alberta
Edmonton, AB

JESSICA SIMON, MD, FRCPC
Associate Professor and Division Head, Palliative Medicine
Faculty of Medicine, University of Calgary
Physician Consultant, Advance Care Planning and Goals of Care
Calgary Zone, Alberta Health Services
Calgary, AB

KONRAD FASSBENDER, PHD
Assistant Professor and Scientific Director, Covenant Health Palliative Institute
Faculty of Medicine and Dentistry
University of Alberta
Edmonton, AB

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.

Résumé

Les organismes de santé au Canada ont investi des ressources considérables dans des stratégies afin d'améliorer les connaissances sur la planification préalable de soins (PPS). Malgré tout, des obstacles demeurent et beaucoup de Canadiens n'ont pas encore totalement adopté les comportements reliés à la PPS, tels qu'écrire une directive médicale anticipée et nommer une personne légalement autorisée à prendre des décisions. Le manque d'efficacité de la PPS désavantage les patients, leurs proches et les prestataires de soins de santé. Cet article recommande une meilleure collaboration entre les professionnels de la santé et les avocats afin d'offrir un meilleur service de PPS aux clients, et présente un cadre d'intervention pour bâtir des liens entre ces deux professions habituellement cloisonnées.

The Canadian population is ageing, more people are living longer with chronic conditions and, importantly, many people say they want more control over their care, especially at the end of life. The recent report of the Advisory Panel on Healthcare Innovation (2015) urges more work to break down siloed professions and create person-centred teams. Doing so is necessary to find new ways to deal with the persistent inadequacies in healthcare systems, including in the delivery of chronic disease care, aged care and end-of-life care.

The call for change comes in well-researched reports, like that of the Advisory Panel, and also in personal stories, like Dr. Duncan Sinclair's essay (2015) on dignified care for the frail elderly and reflections on the deaths of two high-profile Canadian doctors, Dr. Donald Low and Dr. Larry Librach (Taylor and Martin 2014). Dr. Sinclair articulates his wishes – "respect for my continued dignity and personhood; staying in my home; no pain or suffering; and not being a burden to others" – that are described with remarkable consistency as what people want to prepare for a good death (Smith 2000). Dr. Sinclair also writes of his own sense of duty to "write those expectations down and put them on record" so others can meet their obligation "to follow my advance directive."

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.

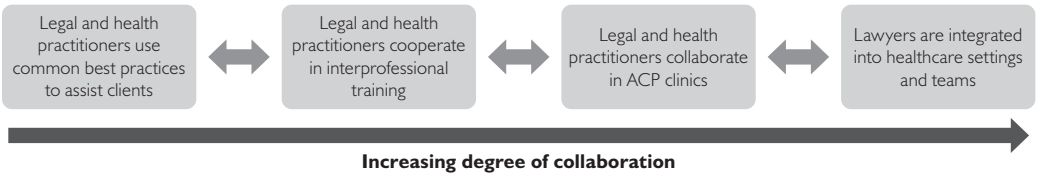
Second, some patients are more likely to talk to a lawyer than a physician about ACP. A Saskatchewan survey found that nearly half of people who had a written care plan had sought help from a lawyer to prepare the document, while only 5% had consulted with a doctor (Goodridge et al. 2013). Similarly, 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.

FIGURE 1. Framework for health–legal collaboration



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 (Hallarman et al. 2014). Hallarman 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.

Correspondence may be directed to: Nola M. Ries, Associate Professor and Deputy Dean (Research), Newcastle Law School, University of Newcastle, Australia; e-mail: nola.ries@newcastle.edu.au.

References

Advisory Panel on Healthcare Innovation. 2015. *Unleashing Innovation: Excellent Healthcare for Canada*. Ottawa, ON: Health Canada. Retrieved March 1, 2016. <www.healthycanadians.gc.ca/publications/health-system-systeme-sante/report-healthcare-innovation-rapport-soins/alt/report-healthcare-innovation-rapport-soins-eng.pdf>.

Allison, T.A. and R.L. Sudore. 2013. "Disregard of Patients' Preferences Is a Medical Error: Comment on 'Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning'." *JAMA Internal Medicine* 173(9): 787. doi:10.1001/jamainternmed.2013.203.

Castillo L.S., B.A. Williams, S.M. Hooper, C.P. Sabatino, L.A. Weithorn and R.L. Sudore. 2011. "Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care." *Annals of Internal Medicine* 154(2): 121–28. doi:10.7326/0003-4819-154-2-201101180-00012.

Goodridge D., E. Quinlan, R. Venne, P. Hunter and D. Surtees. 2013. "Planning for Serious Illness by the General Public: A Population-Based Survey." *ISRN Family Medicine* 2013: 483673. doi:10.5402/2013/483673.

Hagen N., J. Howlett, N.C. Sharma, P. Biondo, J. Holroyd-Leduc, K. Fassbender et al. 2015. "Advance Care Planning: Identifying System-Specific Barriers and Facilitators." *Current Oncology* 22(4): e237–45. doi:10.3747/co.22.2488.

Hallarman, L., D. Snow, M. Kapoor, C. Brown, K. Rodabaugh and E. Lawton. 2014. "Blueprint for Success: Translating Innovations from the Field of Palliative Medicine to the Medical-Legal Partnership." *Journal of Legal Medicine* 35(1): 179–94. doi:10.1080/01947648.2014.885330.

Heyland, D., D. Barwich, D. Pichora, P. Dodek, F. Lamontagne, J.J. You et al. 2013. "Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning." *JAMA Internal Medicine* 173(9): 778–87. doi:10.1001/jamainternmed.2013.180.

Lovell, A. and P. Yates. 2014. "Advance Care Planning in Palliative Care: A Systematic Literature Review of the Contextual Factors Influencing Its Uptake 2008–2012." *Palliative Medicine* 28(8): 1026–35. doi:10.1177/0269216314531313.

Lum, H.D., R.L. Sudore and D.B. Bekelman. 2015. "Advance Care Planning in the Elderly." *The Medical Clinics of North America* 99(2): 391–403. doi:10.1016/j.mcna.2014.11.010.

Lund, S., A. Richardson and C. May. 2015. "Barriers to Advance Care Planning at the End of Life: An Exploratory Systematic Review of Implementation Studies." *PLoS ONE* 10(2): e0116629. doi:10.1371/journal.pone.0116629.

O'Sullivan, R., K. Mailo, R. Angeles and G. Agarwal. 2015. "Advance Directives: Survey of Primary Care Patients." *Canadian Family Physician* 61(4): 353–56.

Russell, S. 2014. "Advance Care Planning: Whose Agenda Is It Anyway?" *Palliative Medicine* 28(8): 997–99. doi:10.1177/0269216314543426.

Shalowitz, D.I., E. Garrett-Mayer and D. Wendler. 2006. "The Accuracy of Surrogate Decision Makers: A Systematic Review." *Archives of Internal Medicine* 166(5): 493–97.

Sinclair, D. 2015. "Advance Directives, Dignity and Care-Giving: A Voice for Frail Elderly Canadians." *Longwoods.com Essays*. Retrieved March 1, 2016. <www.longwoods.com/content/24226>.

Smith, R. 2000. "A Good Death." *BMJ* 320: 129. doi:10.1136/bmj.320.7228.129.

Sudore, R.L. and T.R. Fried. 2010. "Redefining the 'Planning' in Advance Care Planning: Preparing for End-of-Life Decision Making." *Annals of Internal Medicine* 153(4): 256–61. doi:10.7326/0003-4819-153-4-201008170-00008.

Suter, E., N.D. Oelke, C.E. Adair and G.D. Armitage. 2009. "Ten Key Principles for Successful Health Systems Integration." *Healthcare Quarterly* 13(Sp.): 16–23.

Taylor, M. and S. Martin. 2014. "Whose Death Is It Anyway? Perspectives on End-of-Life in Canada." *Healthcare Papers* 14(1): 7–15. doi:10.12927/hcpap.2014.23963.

Teixeira, A.A., L. Hanvey, C. Tayler, D. Barwich, S. Baxter and D.K. Heyland. 2013. "What Do Canadians Think of Advanced Care Planning? Findings from an Online Opinion Poll." *BMJ Supportive & Palliative Care* 5(1): 40–47. doi:10.1136/bmjspcare-2013-000473.

Wendler, D. and A. Rid. 2011. "Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others." *Annals of Internal Medicine* 154(5): 336–36. doi:10.7326/0003-4819-154-5-201103010-00008.

Zelmer, J. 2015. "Beyond Pilots: Scaling and Spreading Innovation in Healthcare." *Healthcare Policy* 11(2): 8–12.

RESEARCH PAPER

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

AMANDA L. TERRY, PHD
Assistant Professor, Department of Family Medicine, Department of Epidemiology & Biostatistics
Schulich Interfaculty Program in Public Health
The University of Western Ontario
London, ON

MOIRA STEWART, PHD
Distinguished University Professor
Department of Family Medicine, Department of Epidemiology & Biostatistics
Schulich School of Medicine & Dentistry
The University of Western Ontario
London, ON

MARTIN FORTIN, MD, MSC, CMFC(F)
Professor, Department of Family Medicine
Université de Sherbrooke
Sherbrooke, QC

SABRINA T. WONG, RN, PHD
Professor, UBC School of Nursing and Centre for Health Services and Policy Research
University of British Columbia
Vancouver, BC

INESE GRAVA-GUBINS, MA
Research Consultant
Toronto, ON

LISA ASHLEY, RN, CCHN(C), MEd
Senior Nurse Advisor, Canadian Nurses Association
Academic Consultant Level 2, School of Nursing
University of Ottawa
Ottawa, ON

PATRICIA SULLIVAN-TAYLOR, BScN, MPA, PMP
Director, Health System Funding Policy
Ontario Ministry of Health and Long-Term Care
Toronto, ON

FRANK SULLIVAN, FRSE, FRCP, FRCGP, CCFP
Gordon F. Cheesbrough Research Chair and Director of UTOPIAN,
Professor, Department of Family & Community Medicine
Dalla Lana School of Public Health
University of Toronto
Toronto, ON

LYNNE ZUCKER, BASc, MASc
Vice President, Clinical Systems Integration, Canada Health Infoway
Toronto, ON

AMARDEEP THIND, MD, PhD
Professor, Department of Family Medicine, Department of Epidemiology & Biostatistics
Director, Schulich Interfaculty Program in Public Health
The University of Western Ontario
London, ON

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).

TABLE 1. Summary of actions to address knowledge and research gaps

Gap in knowledge and research	Summary of action points
1. Value of EMRs	• Explore connection between maturity of use and accrued value • Understand trade-off: effort of adoption versus value • Create a value map/matrix (stakeholders on one axis, value EMR brings on other axis)
2. EMR implementation and adoption	• Supply basic and advanced training, support and education for users • Understand value of implementation and adoption • Identify non-adopters – identify barriers to adoption and how to overcome them • Identify best practices of advanced users – success and supports, conduct economic analysis • Synthesize existing data and research reports
3. Data entry and extraction procedures	• Create unified standards and capabilities across EMRs • Deliver incentives for data quality • Use improved data search technology • Test data entry interventions • Understand best practices leading to high optimization and data entry
4. Data sharing	• Define standardized data sets and determine sharing rules • Work towards interprovincial consistency • Understand public attitudes
5. Overarching framework for interoperability	• Implement overarching framework across Canada • Create a communication strategy for framework
6. Define data elements	• Expand data collected in EMR, e.g., quality of life • Include data elements from different sources, e.g., patients • Design a data completeness score function
7. Develop ideal EMR design	• Design needs to match PHC context • Include multiple disciplines • Research – inform existing and new EMR designs

EMR = electronic medical record; PHC = primary healthcare research.

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

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.

Acknowledgements

The authors thank the conference attendees. This study was funded by the Canadian Institutes of Health Research (CIHR) (#239664). Dr. Stewart is funded by the Dr. Brian W. Gilbert Canada Research Chair in Primary Health Care Research. Dr. Fortin holds a Chair in Chronic Diseases in Primary Care. Dr. Thind is a Canada Research Chair in Health Services Research. The authors acknowledge the contributions of Francis Lau to the conference and this paper.

Correspondence may be directed to: Amanda L. Terry, PhD, Assistant Professor, Schulich School of Medicine & Dentistry, The University of Western Ontario, Western Centre for Public Health and Family Medicine, 1151 Richmond Street, London, ON N6A 3K7; tel.: 519-661-2111 ext. 20049; e-mail: aterry4@uwo.ca.

References

Adler, N.E. and W.W. Stead. 2015. "Patients in Context–EHR Capture of Social and Behavioral Determinants of Health." *New England Journal of Medicine* 372 (8): 698–701.

Angus Reid Public Opinion. 2013. *Canadians Comfortable with the Public Sector Using Private Data. News Release. Toronto, Ontario, Angus Reid Public Opinion*. Retrieved June 6, 2016. <http://angusreidglobal.com/wp-content/uploads/2008/11/2013.04.08_CityAge.pdf>.

Archer, N. and M. Cocosila. 2011. "A Comparison of Physician Pre-Adoption and Adoption Views on Electronic Health Records in Canadian Medical Practices." *Journal of Medical Internet Research* 13 (3): e57.

Bassi, J. and F. Lau. 2013. "Measuring Value for Money: A Scoping Review on Economic Evaluation of Health Information Systems." *Journal of the American Medical Informatics Association* 20 (4): 792–801.

Bassi, J., F. Lau and M. Lesperance. 2012. "Perceived Impact of Electronic Medical Records in Physician Office Practices: A Review of Survey-Based Research." *Interactive Journal of Medical Research* 1(2): e3.

Beasley, J.W., R.J. Holden and F. Sullivan. 2011. "Electronic Health Records: Research into Design and Implementation." *British Journal of General Practice* 61(591): 604–05.

Birtwhistle, R. and T. Williamson. 2015. "Primary Care Electronic Medical Records: A New Data Source for Research in Canada." *Canadian Medical Association Journal* 187(4): 239–40.

Boonstra, A. and M. Broekhuis. 2010. "Barriers to the Acceptance of Electronic Medical Records by Physicians from Systematic Review to Taxonomy and Interventions." *BMC Health Services Research* 10: 231.

Brouwer, H.J., P.J.E. Bindels and H. Van Weert. 2006. "Data Quality Improvement in General Practice." *Family Practice* 23: 529–36.

Canada Health Infoway. 2007. "White Paper on the Information Governance of the Interoperable Electronic Health Record." Retrieved June 6, 2016. <www.ehealthinformation.ca/wp-content/uploads/2014/08/govern.pdf>.

Canada Health Infoway. 2013. "The Emerging Benefits of Electronic Medical Record Use in Community-Based Care." Retrieved June 6, 2016. <www.infoway-inforoute.ca/en/component/edocman/resources/reports/benefits-evaluation/1224-the-emerging-benefits-of-electronic-medical-record-use-in-community-based-care-full-report>.

Canadian Institute for Health Information (CIHI). 2012. "Implementing Primary Health Care EMR Content Standards Supports Improving Patient Care and Health System Management." Retrieved August 20, 2015. <www.cihi.ca/en/emr_cs_exben_infosheet_en.pdf>.

Canadian Medical Association (CMA). 2015. "How Can Canada Achieve Enhanced Use of Electronic Medical Records?" Retrieved June 6, 2016. <www.cma.ca/Assets/assets-library/document/en/advocacy/Enhanced-Use-of-EMRs-Discussion-Paper-Final-May-2014.pdf>.

Castillo, V.H., A.I Martinez-Garcia and J.R. Pulido. 2010. "A Knowledge-Based Taxonomy of Critical Factors for Adopting Electronic Health Record Systems by Physicians: A Systematic Literature Review." *BMC Medical Informatics and Decision Making* 10: 60.

Chang, F. and N. Gupta. 2015. "Progress in Electronic Medical Record Adoption in Canada." *Canadian Family Physician* 61: 1076–84.

College of Family Physicians of Canada, Canadian Medical Association, and Royal College of Physicians and Surgeons of Canada. 2014. "2014 National Physician Survey." Retrieved June 6, 2016. <http://nationalphysiciansurvey.ca/surveys/2014-survey/>.

Cresswell, K.M., D.W. Bates and A. Sheikh. 2013. "Ten Key Considerations for the Successful Implementation and Adoption of Large-Scale Health Information Technology." *Journal of the American Medical Informatics Association* 20: e9–e13.

Friedberg, M.W., K.L. Coltin, D.G. Safran, M. Dresser, A.M. Zaslavsky and E.C. Schneider. 2009. "Associations between Structural Capabilities of Primary Care Practices and Performance on Selected Quality Measures." *Annals of Internal Medicine* 151 (7): 456–63.

Green, L.A., G. Potworowski, A. Day, R. May-Gentile, D. Vibbert, B. Maki. et al. 2015. "Sustaining 'Meaningful Use' of Health Information Technology in Low-Resource Practices." *Annals of Family Medicine* 13(1): 17–22.

Greiver, M., J. Barnsley, B. Aliarzadeh, P. Krueger, R. Moineddin, D.A. Butt et al. 2011a. "Using a Data Entry Clerk to Improve Data Quality in Primary Care Electronic Medical Records: A Pilot Study." *Informatics in Primary Care* 19 (4): 241–50.

Greiver, M., J. Barnsley, R.H. Glazier, R. Moineddin and B.J. Harvey. 2011b. "Implementation of Electronic Medical Records: Theory-Informed Qualitative Study." *Canadian Family Physician* 57: e390–97.

Greiver, M., N. Drummond, R. Birtwhistle, J. Queenan, A. Lambert-Lanning and D. Jackson. 2015. "Using EMRs to Fuel Quality Improvement." *Canadian Family Physician* 61: 92.

Horsky, J., G.D. Schiff, D. Johnston, L. Mercincavage, D. Bell and B. Middleton. 2012. "Interface Design Principles for Usable Decision Support: A Targeted Review of Best Practices for Clinical Prescribing Interventions." *Journal of Biomedical Informatics* 45: 1202–16.

Ipsos Reid. 2012. "Electronic Health Information and Privacy Survey 2012: What Canadians Think Toronto: Ipsos Reid." Retrieved June 6, 2016. <www.infoway-inforoute.ca/en/component/edocman/resources/reports/privacy/461-ipsos-reid-survey-on-electronic-health-information-and-privacy>.

Jang, Y., M.A. Lortie and S. Sanche. 2014. "Return on Investment in Electronic Health Records in Primary Care Practices: A Mixed-Methods Study." *JMIR Medical Informatics* 2(2): e25.

Jones, E. and M. Wittie. 2015. "Accelerated Adoption of Advanced Health Information Technology in Beacon Community Health Centers." *Journal of the American Board of Family Medicine* 28: 565–75.

King, J., V. Patel, E.W. Jamoom and M.F. Furukawa. 2014. "Clinical Benefits of Electronic Health Record Use: National Findings." *Health Services Research* 49(1 Pt2): 392–404.

Krist, A.H., J.W. Beasley, J.C. Crosson, D.C. Kibbe, M.S. Klinkman, C.U. Lehmann et al. 2014. "Electronic Health Record Functionality Needed to Better Support Primary Care." J*ournal of the American Medical Informatics Association* 21 (5): 764–71.

Lai, J.K., F. Lau and N. Shaw. 2009. "A Study of Information Technology Use and Implementation of Electronic Medical Record Systems in BC Medical Practices." *BC Medical Journal* 51(3): 114–21.

Lau, F., M. Price and J. Bassi. 2014. "Toward A Coordinated EHR Strategy for Canada – A White Paper." Toronto, ON: Queen's School of Business, The Monieson Centre for Business Research in Healthcare. Retrieved June 6, 2016. <https://smith.queensu.ca/centres/monieson/knowledge_articles/toward-a-coordinated-electronic-health-record-ehr-strategy-for-canada.php>.

Lau, F., M. Price, J. Boyd, C. Partridge, H. Bell and R. Raworth. 2012. "Impact of Electronic Medical Record on Physician Practice in Office Settings: A Systematic Review." *BMC Medical Informatics and Decision Making* 12: 10.

McAlearney, A.S., P.H. Song, J. Robbins, A. Hirsch, M. Jorina, N. Kowalczyk et al. 2010. "Moving from Good to Great in Ambulatory Electronic Health Record Implementation." *Journal of Healthcare Quality* 32(5): 41–50.

McGinn, C.A., M.P. Gagnon, N. Shaw, C. Sicotte, L. Mathieu, Y. Leduc et al. 2012. "Users' Perspectives of Key Factors to Implementing Electronic Health Records in Canada: A Delphi Study." *BMC Medical Informatics and Decision Making* 12: 105.

McGinn, C.A., S. Grenier, J. Duplantie, N. Shaw, C. Sicotte, L. Mathieu et al. 2011. "Comparison of User Groups' Perspectives of Barriers and Facilitators to Implementing Electronic Health Records: A Systematic Review." *BMC Medicine* 9: 46.

Motulsky, A., L. Lamothe and C. Sicotte. 2013. "Impacts of Second-Generation Electronic Prescriptions on the Medication Management Process in Primary Care: A Systematic Review." *International Journal of Medical Informatics* 82(6): 473–91.

Motulsky, A., C. Sicotte, M.P. Gagnon, J. Payne-Gagnon, J.A. Langue-Dube, C.M. Rochefort et al. 2015. "Challenges to the Implementation of a Nationwide Electronic Prescribing Network in Primary Care: A Qualitative Study of Users' Perceptions." *Journal of the American Medical Informatics Association* 22(4): 838–48.

Ornstein, S.M., L.S. Nemeth, P.J. Nieter, R.G. Jenkins, A.M. Wessell and C.B. Litvin. 2015. "Learning from Primary Care Meaningful Use Exemplars." *Journal of the American Board of Family Medicine* 28(3): 360–70.

Pandhi, N., W.L. Yang, Z. Karp, A. Young, J.W. Beasley, S. Kraft et al. 2014. "Approaches and Challenges to Optimising Primary Care Teams' Electronic Health Record Usage." *Informatics in Primary Care* 21(3): 142–51.

Pare, G., L. Raymond, A.O. de Guinea, P. Poba-Nzaou, M.C. Trudel, J. Marsan et al. 2014. "Barriers to Organizational Adoption of EMR Systems in Family Physician Practices: A Mixed-Methods Study in Canada." *International Journal of Medical Informatics* 83(8): 548–58.

Paterson, G., N. Shaw, A. Grant, E. Delisle, K. Leonard, S. Mitchell Corley et al. 2011. "Cross-Canada EMR Case Studies: Analysis of Physicians' Perspectives on Benefits and Barriers." *Electronic Journal of Health Informatics* 6(4): e34.

Payne, T.H., D.W. Bates, E.S. Berner, E.V. Bernstam, H.D. Covvey, M.E. Frisse et al. 2013. "Healthcare Information Technology and Economics." *Journal of the American Medical Informatics Association* 20(2): 212–17.

Pearce, C., M. Arnold, C. Phillips, S. Trumble and K. Dwan. 2011. "The Patient and the Computer in the Primary Care Consultation." *Journal of the American Medical Informatics Association* 18(2): 138–42.

Perera, G., A. Holbrook, L. Thabane, G. Foster and D.J. Willison. 2011. "Views on Health Information Sharing and Privacy from Primary Care Practices Using Electronic Medical Records." *International Journal of Medical Informatics* 80(2): 94–101.

Phoenix Strategic Perspectives Inc. 2013. *Final Report Survey of Canadians on Privacy-Related Issues, Prepared for the Office of the Privacy Commissioner of Canada*. Ottawa, ON: Phoenix Strategic Perspectives Inc. Retrieved June 6, 2016. <www.priv.gc.ca/information/por-rop/2013/por_2013_01_e.asp>.

Price, M., A. Singer and J. Kim 2013. "Adopting Electronic Medical Records or Just Electronic Paper Records." *Canadian Family Physician* 59(7): e322–29.

Randhawa, G.K., F. Lau and M. Price. 2013. "Evaluating the Adoption of e-Prescribing in Primary Care." *Healthcare Quarterly* 16(4): 55–60.

Raymond, L., G. Pare, G.A. de Ortiz, P. Poba-Nzaou, M.C. Trudel, J. Marsan et al. 2015. "Improving Performance in Medical Practices through the Extended Use of Electronic Medical Record Systems: A Survey of Canadian Family Physicians." *BMC Medical Informatics and Decision Making* 15: 27.

Report of the Advisory Panel on Healthcare Innovation. 2015. U*nleashing Innovation: Excellent Healthcare for Canada*. Ottawa, ON: Health Canada. Retrieved June 6, 2016. <www.healthycanadians.gc.ca/publications/health-system-systeme-sante/report-healthcare-innovation-rapport-soins/alt/report-healthcare-innovation-rapport-soins-eng.pdf>.

Rich, P. 2015. "Edging Toward the Digital Future: National Physician Survey Findings Reveal Progress – But Also Gaps." *Future Practice* (March 2015): 3–7.

Rimmer, C., S. Hagens, A. Baldwin and C.J. Anderson 2015. "Measuring Maturity of Use for Electronic Medical Records in British Columbia: The Physician Information Technology Office." *Healthcare Quarterly* 17(4): 75–80.

Rubinowicz, A., I. Vedel, S. Sanche, M. Lortie, S. Law, J. Hughes et al. 2016. "A Portrait of Electronic Medical Record Use in Primary Care across Canada." *Health Reform Observer* 4(2): Article 1.

Ryan, M.S., S.C. Shih, C.H. Winther and J.J. Wang. 2014. "Does It Get Easier to Use an EHR? Report from an Urban Regional Extension Center." *Journal of General Internal Medicine* 29(10): 1341–48.

Schoen, C., R. Osborn, D. Squires, M. Doty, P. Rasmussen, R. Pierson et al. 2012. "A Survey of Primary Care Doctors in Ten Countries Shows Progress in Use of Health Information Technology, Less in Other Areas". *Health Affairs (Millwood)* 31(12): 2805–16.

Sicotte, C., L. Taylor and R. Tamblyn. 2013. "Predicting the Use of Electronic Prescribing Among Early Adopters in Primary Care." *Canadian Family Physician* 59: e312–21.

Sittig, D.F. and A. Wright. 2015. "What Makes an EHR 'Open' Or Interoperable?" *Journal of the American Medical Informatics Association* 22: 1099–101.

Terry, A.L., M. Stewart, M. Fortin, S.T. Wong, M. Kennedy, F. Burge et al. 2014. "Gaps in Primary Healthcare Electronic Medical Record Research and Knowledge: Findings of a Pan-Canadian Study." *Healthcare Policy* 10(1): 46–59.

Terry, A.L., J.B. Brown, L.D. Bestard, A. Thind and M. Stewart. 2012. "Perspectives on Electronic Medical Record Implementation after Two Years of Use in Primary Health Care Practice." *Journal of the American Board of Family Medicine* 25(4): 522–27.

Terry, A.L., G. Giles, J.B. Brown, A. Thind and M. Stewart. 2009. "Adoption of Electronic Medical Records in Family Practice: The Providers' Perspective." *Family Medicine* 41(7): 248–52.

Unertl, K.M., M.B. Weinger, K.B. Johnson and N.M. Lorenzi. 2009. "Describing and Modeling Workflow and Information Flow in Chronic Disease Care." *Journal of the American Medical Informatics Association* 16(6): 826–36.

Vedel, I., L. Lapointe, M.T. Lussier, C. Richard, J. Goudreau, L. Lalonde et al. 2012. "Healthcare Professionals' Adoption and Use of a Clinical Information System (CIS) in Primary Care: Insights from the Da Vinci Study." *International Journal of Medical Informatics* 81(2): 73–87.

Willison, D.J., K. Keshavjee, K. Nair, C. Goldsmith and A. Holbrook. M. 2003. "Patient Consent Preferences for Research Uses of Information in Electronic Medical Records: Interview and Survey Data." *BMJ* 326(7385): 373.

Willison, D.J., L. Schwartz, J. Abelson, C. Charles, M. Swinton, D. Northrup et al. 2007. "Alternatives to Project-Specific Consent for Access to Personal Information for Health Research: What Is the Opinion of the Canadian Public?" *Journal of the American Medical Informatics Association* 14(6): 706–12.

Willison, D.J., V. Steeves, C. Charles, L. Schwartz, J. Ranford, G. Agarwal et al. 2009. "Consent for Use of Personal Information for Health Research: Do People with Potentially Stigmatizing Health Conditions and the General Public Differ in Their Opinions?" *BMC Medical Ethics* 10: 10.

RESEARCH PAPER

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?

JULIA M. LANGTON, PHD
Research Associate
Centre for Health Services and Policy Research, University of British Columbia
Vancouver, BC

SABRINA T. WONG, RN, PHD
Professor
Centre for Health Services and Policy Research & School of Nursing, University of British Columbia
Vancouver, BC

SHARON JOHNSTON, MD, LLM, CCFP
Associate Professor
Department of Family Medicine, University of Ottawa & Bruyere Research Institute
Ottawa, ON

JULIA ABELSON, BA&SC (HONS), MSC, PHD
Professor
Department of Clinical Epidemiology & Biostatistics, Centre for Health Economics and Policy Analysis, McMaster University
Hamilton, ON

MEHDI AMMI, PhD
Assistant Professor
School of Public Policy & Administration
Carleton University
Ottawa, ON

FRED BURGE, MD, MSc, FCFP
Professor
Faculty of Medicine, Dalhousie University
Halifax, NS

JOHN CAMPBELL, PhD
Professor
Primary Care Research Group, University of Exeter Medical School
Exeter, UK

JEANNIE HAGGERTY, PhD
Professor
Faculty of Medicine, McGill University
Montréal, QC

WILLIAM HOGG, HONS BSc, MSc, MClSc, MD, CCFP, FCFP
Professor
Department of Family Medicine, University of Ottawa & Bruyere Research Institute
Ottawa, ON

WALTER P. WODCHIS, BMath, MA, MAE, PhD
Associate Professor
Institute of Health Policy, Management and Evaluation, University of Toronto
Toronto, ON

KIMBERLYN McGRAIL, PhD
Associate Professor
Centre for Health Services and Policy Research, University of British Columbia
Vancouver, BC

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 specialities (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

Organizations reporting on primary care	Description	Reporting format	Framework: performance domains	Website
Australia				
MyHealthy Communities, National Health Performance Authority	National independent agency, reports local-level health information. Many of the MyHealthyCommunities measures focus on primary care.	Public reports and interactive website.	Whole of health system: Equity, effectiveness, efficiency and population health outcome measures.	<www.myhealthycommunities.gov.au/>
Canada				
Your Health System, Canadian Institute for Health Information (CIHI) Performance Measurement Framework	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.	Public reports and interactive website.	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.	<www.cihi.ca/cihi-ext-portal/internet/en/tabbedcontent/health+system+performance/our+health+system/cihi013620>
CIHI Pan-Canadian Primary Care Indicators	A suite of indicators developed specifically for pan-Canadian reporting.	Public report detailing indicators. No current pan-Canadian reporting.	Primary care specific (indicator groupings): acceptability, accessibility, appropriateness, comprehensiveness, coordination, effectiveness, efficiency, expenditure, governance, health status, information technology infrastructure and workforce.	<www.cihi.ca/CIHI-ext-portal/internet/EN/TabbedContent/types+of+care/primary+health/cihi006583>
England				
National Health Service (NHS) Outcomes Framework	A small number of primary care indicators reported with other healthcare indicators; detailed in a report.	Public reports and interactive website.	Premature mortality, quality of life (long-term conditions), recovery from illness, patient experience, patient safety.	<www.gov.uk/government/publications/nhs-outcomes-framework-2014-to-2015>
Quality and Outcomes Framework (QOF), NHS	Primary care indicators developed for pay-for-performance (physician incentives to improve care quality).	Public reports and interactive website.	Primary care specific: clinical, public health, quality and productivity (previously organizational), patient experience.	<http://qof.hscic.gov.uk/>
Care Quality Commission (CQC)	Monitoring system for general practices to help monitor the quality of care (e.g., used to plan inspection activities and also publicly available).	Public reports and interactive website.	Primary care specific: effectiveness, responsiveness and care.	<www.cqc.org.uk/>
NHS Choices	Launched to support the public become active consumers of healthcare and to make healthcare decisions.	Interactive website.	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.	<www.nhs.uk/pages/home.aspx>

TABLE 1. Continued

Organizations reporting on primary care	Description	Reporting format	Framework: performance domains	Website
GP Patient Survey (on behalf of NHS)	GP patient survey sent to over 1 million people across the UK.	Public reports and interactive website.	No specific framework. Questions are in relation to access and experiences with primary care and dental care.	<https://gp-patient.co.uk/about>
New Zealand				
Atlas of Variation in Health Care, Health Quality and Safety Commission	National and local-level reporting. Several measures related to primary care contained in the online interactive Atlas.	Public reports and interactive website.	Indicator groupings by clinical areas.	<www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/quality-accounts/>
Norway – Limited information available in English				
Sweden				
Quality and Efficiency in Swedish Health Care, Swedish Association of Local Authorities and Regions	National and local-level reporting. Several measures related to primary care in the report.	Public report.	Whole of health system: overall indicators (e.g., mortality) and indicators by 12 clinical areas.	<www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19072/2013-5-7.pdf>
Switzerland – Limited information available in English				
US				
Healthcare Effectiveness and Data Information Set (HEDIS)	A collection of indicators focused on primary care performance. Indicator specifications developed for health plans; designed to assist consumers in health plan selection.	Public report.	Indicators groupings: effectiveness, access, patient experience, utilization/resource use, health plan descriptive.	<www.ncqa.org/HEDISQualityMeasurement/WhatisHEDIS.aspx>
Physician Quality Reporting System (PQRS)	Government-run (Centres for Medicare and Medicaid) voluntary program collecting data on healthcare performance including primary care.	Indicators available online. Results not publicly reported; direct to physicians.	Indicator groupings: effectiveness, safety, communication/coordination, person-centred, efficiency, community/population health.	<www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/>
Physician Consortium Performance Improvement (PCPI)	Physician-led (American Medical Association) effort to drive improvement and support healthcare professionals.	Indicators available online. Results not publicly reported; direct to physicians.	Primary care: Indicators in 47 clinical areas.	<https://www.ama-assn.org/about/improving-health-outcomes>
Quality Indicators, Agency for Healthcare Research and Quality (AHRQ)	Indicator specifications for providers and clinicians: the prevention quality indicators relate to primary care.	Indicators available online, results not publicly reported.	Whole of health system: prevention quality and safety indicators related to primary care.	<www.qualityindicators.ahrq.gov/Modules/pqi_resources.aspx>

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.

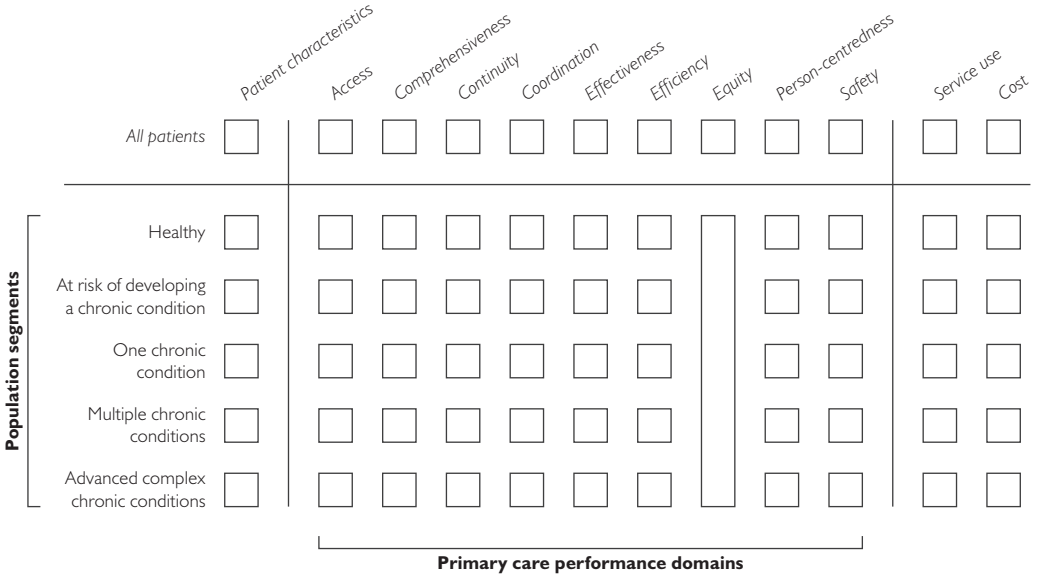
There was a range in the level of focus on primary care, for example, the US HEDIS indicator set was developed specifically for primary care. And while there is currently no national primary care reporting system in Canada outside of the work produced by the Commonwealth Fund, the Canadian Institute 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*



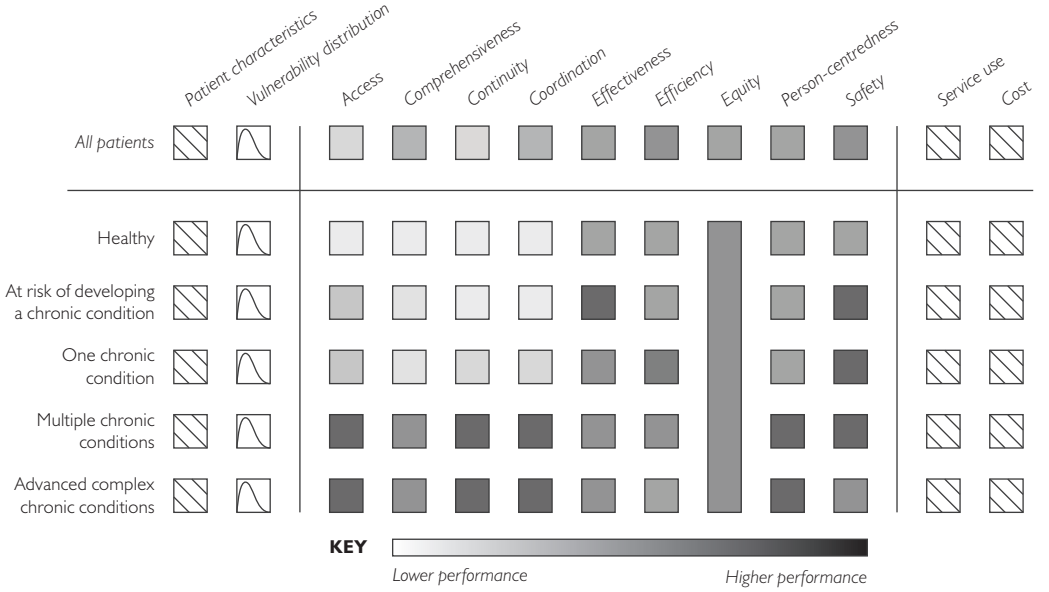
*This framework is a matrix structure of domains of primary care performance by patient population segments. The selection of performance domains and population segments can be modified depending on the intended use of the framework or the specific jurisdiction.

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

service delivery (Lynn et al. 2007) and specifically, primary care service delivery (BC Ministry of Health 2014; Dow et al. 2013; Hewner et al. 2014; Porter et al. 2013; Zhou et al. 2014) but with little discussion about the potential implications for performance measurement.

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

We considered principles used in examples of population segmentation with a focus on the work of Lynn et al. (2007), Porter et al. (2013) and others (BC Ministry of Health 2014; Dow et al. 2013; Hewner et al. 2014; Zhou et al. 2014) to provide some guidance on optimal features of population segments. We have established the following criteria:

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

Population group	Description	Rationale for inclusion in a primary performance measurement framework
Healthy	No ongoing medical conditions or behavioural risk factors. Possible acute conditions that require time-limited treatment (e.g., pregnancy, accidental injury).	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.
At risk of developing a chronic condition	Presence of medical risk factors for developing a chronic disease (e.g., overweight or obese, smoking, excessive alcohol consumption, recreational drug use, sedentary lifestyle).	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).
One chronic condition	One ongoing chronic condition with impact on functional status (e.g., diabetes mellitus, hypertension).	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).
Multiple chronic conditions	Two or more ongoing chronic conditions with impact on functional status.	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).
Advanced complex chronic conditions	Multiple advanced chronic conditions with complications or patient approaching the end of life.	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).

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

This research was funded by the Canadian Institutes of Health Research (CIHR) and Michael Smith Foundation for Health Research (Agreement number 01247-000) through a Community-Based Primary Health Care (CBPHC) Innovation Team grant.

Correspondence may be directed to: Kimberlyn McGrail, PhD, Centre for Health Services and Policy Research, University of British Columbia, 211–2206 East Mall, Vancouver, BC V6T 1Z3; e-mail kim.mcgrail@ubc.ca.

References

Adair, C.E., E. Simpson, A.L. Casebeer, J.M. Birdsell, K.A. Hayden and S. Lewis. 2006a. "Performance Measurement in Healthcare: Part I – Concepts and Trends from a State of the Science Review." *Healthcare Policy* 1(4): 85–104. doi:10.12927/hcpol.2006.18248.

Adair, C.E., E. Simpson, A.L. Casebeer, J.M. Birdsell, K.A. Hayden and S. Lewis. 2006b. "Performance Measurement in Healthcare: Part II – State of the Science Findings by Stage of the Performance Measurement Process." *Healthcare Policy* 2(1): 56–78. doi:10.12927/hcpol.2006.18338.

Arksey, H. and L. O'Malley. 2005. "Scoping Studies: Towards a Methodological Framework." *International Journal of Social Research Methodology* 8(1): 19–32. doi:10.1080/1364557032000119616.

Ashman, J.J. and V. Beresovsky. 2013. "Multiple Chronic Conditions among US Adults Who Visited Physician Offices: Data from the National Ambulatory Medical Care Survey, 2009." *Preventing Chronic Disease* 10: E64. doi:10.5888/pcd10.120308.

Banerjee, S. 2014. "Multimorbidity – Older Adults Need Health Care that Can Count Past One." *Lancet* 385(9968): 587–89. doi:10.1016/S0140-6736(14)61596-8.

Barnett, K., S.W. Mercer, M. Norbury, G. Watt, S. Wyke and B. Guthrie. 2012. "Epidemiology of Multimorbidity and Implications for Health Care, Research, and Medical Education: A Cross-Sectional Study." *Lancet* 380(9836): 37–43. doi:10.1016/S0140-6736(12)60240-2.

Bayliss, E.A., D.E. Bonds, C.M. Boyd, M.M. Davis, B. Finke, M.H. Fox et al. 2014. "Understanding the Context of Health for Persons with Multiple Chronic Conditions: Moving from What Is the Matter to What Matters." *Annals of Family Medicine* 12(3): 260–69. doi:10.1370/afm.1643.

Bayliss, E.A., J.L. Ellis, J.A. Shoup, C. Zeng, D.B. McQuillan and J.F. Steiner. 2015. "Effect of Continuity of Care on Hospital Utilization for Seniors with Multiple Medical Conditions in an Integrated Health Care System." *The Annals of Family Medicine* 13(2): 123–29. doi:10.1370/afm.1739.

BC Ministry of Health. 2014. *The Blue Matrix: How Big Data Provides Insight into the Health of the Population and their Use of Health Care in British Columbia | ihdlnconference2014.org*. Retrieved October 14, 2014. <www.ihdlnconference2014.org/abstract/Burd>.

Berwick, D.M., T.W. Nolan and J. Whittington. 2008. "The Triple Aim: Care, Health, and Cost." *Health Affairs (Project Hope)* 27(3): 759–69. doi:10.1377/hlthaff.27.3.759.

Burge, F., B. Lawson and G. Johnston. 2003. "Family Physician Continuity of Care and Emergency Department Use in End-of-Life Cancer Care." *Medical Care* 41(8): 992–1001. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med4&AN=12886178>.

Caminiti, C., T. Meschi, L. Braglia, F. Diodati, E. Iezzi, B. Marcomini et al. 2013. "Reducing Unnecessary Hospital Days to Improve Quality of Care Through Physician Accountability: A Cluster Randomised Trial." *BMC Health Services Research* 13: 14. doi:10.1186/1472-6963-13-14.

Canadian Institute for Health Information (CIHI). 2012. *Pan-Canadian Primary Health Care Indicator Update Report*. Retrieved June 17, 2016. <https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC2000&lang=en>.

Cunningham, C.T., P. Cai, D. Topps, L.W. Svenson, N. Jetté and H. Quan. 2014. "Mining Rich Health Data from Canadian Physician Claims: Features and Face Validity." *BMC Research Notes* 7(1): 682. doi:10.1186/1756-0500-7-682.

Davis, K., K. Stremikis, D. Squires and S. Cathy. 2014. "Mirror, Mirror on the Wall, 2014 Update: How the U.S. Health Care System Compares Internationally, The Commonwealth Fund." <www.commonwealthfund.org/publications/fund-reports/2014/jun/mirror-mirror>.

Doggen, K., A. Lavens and V. Van Casteren. 2014. "The Right Indicator for the Job: Different Levels of Rigor may be Appropriate for the Development of Quality Indicators. Comment on Stelfox and Straus." *Journal of Clinical Epidemiology* 67(9): 963–64. doi:10.1016/j.jclinepi.2014.03.001.

Dow, A.W., A. Bohannon, S. Garland, P.E. Mazmanian and S.M. Retchin. 2013. "The Effects of Expanding Primary Care Access for the Uninsured: Implications for the Health Care Workforce Under Health Reform." *Academic Medicine: Journal of the Association of American Medical Colleges* 88(12): 1855–61. doi:10.1097/ACM.0000000000000032.

Emeche, U. 2015. "Is a Strategy Focused on Super-Utilizers Equal to the Task of Health Care System Transformation? Yes." *Annals of Family Medicine* 13(1): 6–7. doi:10.1370/afm.1746.

Etheredge, L.M. 2014. "Rapid Learning: A Breakthrough Agenda." *Health Affairs (Project Hope)* 33(7): 1155–62. doi:10.1377/hlthaff.2014.0043.

Evans, R.G., K.M. McGrail, S.G. Morgan, M.L. Barer and C. Hertzman. 2010. "APOCALYPSE NO: Population Aging and the Future of Health Care Systems." *Canadian Journal on Aging* 20(S1): 160–91. doi:10.1017/S0714980800015282.

Fortin, M., M. Stewart, M.-E. Poitras, J. Almirall and H. Maddocks. 2012. "A Systematic Review of Prevalence Studies on Multimorbidity: Toward a More Uniform Methodology." *Annals of Family Medicine* 10(2): 142–51. doi:10.1370/afm.1337.

Haggerty, J.L. 2012. "Ordering the Chaos for Patients with Multimorbidity." *BMJ (Clinical Research Ed.)* 345(sep07_1): e5915. doi:10.1136/bmj.e5915.

Haggerty, J.L., R.J. Reid, G.K. Freeman, B.H. Starfield, C.E. Adair and R. McKendry. 2003. "Continuity of Care: A Multidisciplinary Review." *BMJ (Clinical Research Ed.)* 327(7425): 1219–21. doi:10.1136/bmj.327.7425.1219.

Health Quality Ontario. 2014. *A Primary Care Performance Measurement Framework for Ontario*. Toronto, ON: Author.

Hewner, S., J.Y. Seo, S.E. Gothard and B.J. Johnson. 2014. "Aligning Population-Based Care Management with Chronic Disease Complexity." *Nursing Outlook* 62(4): 250–8. doi:10.1016/j.outlook.2014.03.003.

Higgins, A., G. Veselovskiy and L. McKown. 2013. "Provider Performance Measures in Private and Public Programs: Achieving Meaningful Alignment with Flexibility to Innovate." *Health Affairs* 32(8): 1453–61. doi:/10.1377/hlthaff.2013.0007.

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

Hutchison, B. and R. Glazier. 2013. "Ontario's Primary Care Reforms Have Transformed the Local Care Landscape, but a Plan is Needed for Ongoing Improvement." *Health Affairs (Project Hope)* 32(4): 695–703. doi:10.1377/hlthaff.2012.1087.

Hutchison, B., J.-F. Levesque, E. Strumpf and N. Coyle. 2011. "Primary Health Care in Canada: Systems in Motion." *The Milbank Quarterly* 89: 256–88. doi:10.1111/j.1468-0009.2011.00628.x.

Institute of Medicine (IOM). 2001. *Crossing the Quality Chasm: A New Health System for the 21st Century, Committee on Quality Health Care in America*. Washington, DC: National Academy Press.

Institute of Medicine (IOM). 2006. *Performance Measurement: Accelerating Improvement. Performance Measurement: Accelerating Improvement*. Washington, DC: National Academy Press. <www.iom.edu/Reports/2005/Performance-Measurement-Accelerating-Improvement.aspx>.

Ionescu-Ittu, R., J. McCusker, A. McCusker, A.-M. Vadeboncoeur, D. Roberge, D. Larouche et al. 2007. "Continuity of Primary Care and Emergency Department Utilization Among Elderly People." *Canadian Medical Association Journal* 177(11): 1362–68. doi:10.1503/cmaj.061615.

Ivers, N.M., A. Sales, H. Colquhoun, S. Michie, R. Foy, J.J. Francis and J.M. Grimshaw. 2014. "No More 'Business as Usual' with Audit and Feedback Interventions: Towards an Agenda for a Reinvigorated Intervention." *Implementation Science* 9(1): 14. doi:10.1186/1748-5908-9-14.

Johnston, S. and M. Hogel. 2016. "A Decade Lost: Primary Healthcare Performance Reporting Across Canada under the Action Plan for Health System Renewal." *Healthcare Policy* 11(4): 95–110. doi:10.12927/hcpol.2016.24593.

Koller, D., G. Schön, I. Schäfer, G. Glaeske, H. van den Bussche and H. Hansen. 2014. "Multimorbidity and Long-Term Care Dependency–A Five-Year Follow-Up." *BMC Geriatrics* 14: 70. doi:10.1186/1471-2318-14-70>.

Kontopantelis, E., D.A. Springate, M. Ashworth, R.T. Webb, I.E. Buchan and T. Doran. 2015. "Investigating the Relationship Between Quality of Primary Care and Premature Mortality in England: A Spatial Whole-Population Study." *BMJ* 350(mar02 1): h904–h904. doi:10.1136/bmj.h904.

Kringos, D.S., W.G.W. Boerma, A. Hutchinson, J. Hutchinson and P.P. Groenewegen. 2010. "The Breadth of Primary Care: A Systematic Literature Review of Its Core Dimensions." *BMC Health Services Research* 10(1): 65. doi:10.1186/1472-6963-10-65.

Kringos, D.S., W. Boerma, J. van der Zee and P. Groenewegen. 2013. "Europe's Strong Primary Care Systems Are Linked to Better Population Health but Also to Higher Health Spending." *Health Affairs (Project Hope)* 32(4): 686–94. doi:10.1377/hlthaff.2012.1242.

Lane, N.E., C.J. Maxwell, A. Gruneir, S.E. Bronskill and W.P. Wodchis. 2015. "Absence of a Socioeconomic Gradient in Older Adults' Survival with Multiple Chronic Conditions." *EBioMedicine* 2(12): 2094–100. doi:10.1016/j.ebiom.2015.11.018.

Levac, D., H. Colquhoun and K.K. O'Brien. 2010. "Scoping Studies: Advancing the Methodology." *Implementation Science* 5(1): 69. doi:10.1186/1748-5908-5-69.

Lunney, J.R., J. Lynn and C. Hogan. 2002. "Profiles of Older Medicare Decedents." *Journal of the American Geriatrics Society* 50: 1108–12. doi:10.1046/j.1532-5415.2002.50268.x.

Lynn, J., B.M. Straube, K.M. Bell, S.F. Jencks and R.T. Kambic. 2007. "Using Population Segmentation to Provide Better Health Care for All: The 'Bridges to Health' model." *Milbank Quarterly* 85(2): 185–208; discussion 209–212. doi:10.1111/j.1468-0009.2007.00483.x.

Martin-Misener, R., R. Valaitis, S.T. Wong, M. MacDonald, D. Meagher-Stewart, J. Kaczorowski et al. 2012. "A Scoping Literature of Collaboration between Primary Care and Public Health." *Primary Health Care Research and Development* 13(4): 327–46.

Milani, R.V. and C.J. Lavie. 2014. "Healthcare 2020: Reengineering Healthcare Delivery to Combat Chronic Disease." *The American Journal of Medicine* 128(4): 337–43. doi:10.1016/j.amjmed.2014.10.047.

Morgan, S. and C. Cunningham. 2011. "Population Aging and the Determinants of Healthcare Expenditures: The Case of Hospital, Medical and Pharmaceutical Care in British Columbia, 1996 to 2006." *Healthcare Policy* 7(1): 68–79. doi:10.12927/hcpol.2011.22525.

Mukhi, S., J. Barnsley and R.D. Deber. 2014. "Accountability and Primary Healthcare." *Healthcare Policy* 10(SP): 90–98. doi:10.12927/hcpol.2014.23849.

Newton, W.P. and A. Lefebvre. 2015. "Is a Strategy Focused on Super-Utilizers Equal to the Task of Health Care System Transformation?" *Annals of Internal Medicine* 13(1): 8–9. doi:10.1370/afm.1747.

Oliver, K., S. Innvar, T. Lorenc, J. Woodman and J. Thomas. 2014. "A Systematic Review of Barriers to and Facilitators of the Use of Evidence by Policymakers." *BMC Health Services Research* 14(1): 2. doi:10.1186/1472-6963-14-2.

Panzer, R.J., R.S. Gitomer, W.H. Greene, P.R. Webster, K.R. Landry and C.A. Riccobono. 2013. "Increasing Demands for Quality Measurement." *JAMA* 310(18): 1971–80. doi:10.1001/jama.2013.282047.

Porter, M. 2010. "What Is Value in Health Care?" *New England Journal of Medicine* 363: 2477–81. doi:10.1056/NEJMp1011024.

Porter, M.E., E.A. Pabo and T.H. Lee. 2013. "Redesigning Primary Care: A Strategic Vision to Improve Value by Organizing Around Patients' Needs." *Health Affairs (Project Hope)* 32(3): 516–25. doi:10.1377/hlthaff.2012.0961.

Ricci-Cabello, I., S. Stevens, E. Kontopantelis, A.R.H. Dalton, R.I. Griffiths, J.L. Campbell et al. 2015. "Impact of the Prevalence of Concordant and Discordant Conditions on the Quality of Diabetes Care in Family Practices in England." *The Annals of Family Medicine* 13(6): 514–22. doi:10.1370/afm.1848.

Russell, G. 2015. "Does Paying for Performance in Primary Care Save Lives?" *BMJ (Clinical Research Ed.)* 350: h1051. doi:10.1136/bmj.h1051.

Schoen, C., R. Osborn, M.M. Doty, D. Squires, J. Peugh and S. Applebaum. 2009. "A Survey of Primary Care Physicians in Eleven Countries, 2009: Perspectives on Care, Costs, and Experiences." *Health Affairs (Project Hope)* 28(6): w1171–83. doi:10.1377/hlthaff.28.6.w1171.

Senn, N., M. Breton, S. Ebert and J.-F. Levesque. 2014. "Comparative Analysis of Primary Care Organizational Frameworks." in *North American Primary Care Research Group Conference*. New York, NY.

Smith, P.C., E. Mossialos, I. Papanicolas and S. Leatherman. 2009. "Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects." in S.L. Peter, C. Smith, E. Mossialos and I. Papanicolas, (Ed.), *The Cambridge Health Economics, Policy and Management Series*. Cambridge: Cambridge University Press. <www.euro.who.int/en/about-us/partners/observatory/publications/studies/performance-measurement-for-health-system-improvement-experiences,-challenges-and-prospects>.

Stange, K.C., R.S. Etz, H. Gullett, S.A. Sweeney, W.L. Miller, C.R. Jaén et al. 2014. "Metrics for Assessing Improvements in Primary Health Care." *Annual Review of Public Health* 35: 423–42. doi:10.1146/annurev-publhealth-032013-182438.

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

Starfield, B., L. Shi and J. Macinko. 2005. "Contribution of Primary Care to Health Systems and Health." *Milbank Quarterly* 83(3): 457–502. doi:10.1111/j.1468-0009.2005.00409.x.

The Commonwealth Fund. 2014. *International Profiles of Health Care Systems: Australia, Canada, Denmark, England, France, Germany, Italy, Japan, The Netherlands, New Zealand, Norway, Singapore, Sweden, Switzerland, and the United States – The Commonwealth Fund*. Retrieved February 17, 2016. <www.commonwealthfund.org/publications/fund-reports/2015/jan/international-profiles-2014>.

The Health Foundation. 2015. *Indicators of Quality of Care in General Practices in England*. Retrieved October 19, 2016. <www.health.org.uk/publication/indicators-quality-care-general-practices-england>.

Thorpe, K.E. 2005. "The Rise in Health Care Spending and What to Do About It." *Health Affairs (Project Hope)* 24(6): 1436–45. doi:10.1377/hlthaff.24.6.1436.

Venkatesh, A., K. Goodrich and P.H. Conway. 2014. "Opportunities for Quality Measurement to Improve the Value of Care for Patients with Multiple Chronic Conditions." *Annals of Internal Medicine* 161(10 Suppl.): S76–80. doi:10.7326/M13-3014.

Vogel, L. 2015. "Provinces Optimistic for Health Accord Talks." *Canadian Medical Association Journal* 188(2): E27–E28. doi:10.1503/cmaj.109-5206.

Vuik, S.I., E.K. Mayer and A. Darzi. 2016. "Patient Segmentation Analysis Offers Significant Benefits for Integrated Care and Support." *Health Affairs* 35(5): 769–75. doi:10.1377/hlthaff.2015.1311.

Watson, D.E., A.M. Broemeling, R.J. Reid and C. Black. 2004. *A Results-Based Logic Model for Primary Health Care: Laying an Evidence-Based Foundation to Guide Performance Measurement, Monitoring, and Evaluation*. Vancouver, BC: Centre for Health Services and Policy Research.

Zhou, Y.Y., W. Wong and H. Li. 2014. "Improving Care for Older Adults: A Model to Segment the Senior." *The Permanente Journal* 18(3): 18–21.

RESEARCH PAPER

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

RAISA DEBER, PhD
Professor, Institute of Health Policy, Management and Evaluation
Dalla Lana School of Public Health, University of Toronto
Toronto, ON

ROBERT SCHWARTZ, PhD, IHPME
Professor, Institute of Health Policy, Management and Evaluation,
Dalla Lana School of Public Health
Executive Director and Principal Investigator, Ontario Tobacco Research Unit
University of Toronto
Toronto, ON

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/resourcestools/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) distinguish 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 associated with balancing the number of indicators needed to provide enough information, with usability and costs associated with having too many indicators. Developing and running 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 enrolment, 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 different 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 relevant 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 clinical 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.

Acknowledgements

This review has been drawn from a Canadian Institutes for Health Research (CIHR)-funded Expedited Synthesis, in partnership with the Ontario Ministry of Health and Long-Term Care, Public Health Practice Branch. The authors appreciate the contributions of their research partners and of the research team: Professors Ross Baker, Jan Barnsley, Andrea Baumann, Whitney Berta, Brenda Gamble, Audrey Laporte, Fiona Miller, Tina Smith and Walter Wodchis; students Kathleen Gamble, Corrine Davies-Schinkel, Tim Walker; Project Manager Kanecy Onate; and Administrative Support Christine Day.

Correspondence may be directed to: Raisa Deber, PhD, Institute of Health Policy, Management and Evaluation, Health Sciences Building, 155 College Street, Suite 425, Toronto, ON M5T 3M6; tel.: 416-978-8366; e-mail: raisa.deber@utoronto.ca.

References

Abernethy, M.A., M. Horne, A.M. Lillis, M.A. Malina and F.H. Selto. 2005. "A Multi-Method Approach to Building Causal Performance Maps from Expert Knowledge." *Management Accounting Research* 16(2): 135–55.

Adair, C.E., L. Simpson, J.M. Birdsell, K. Omelchuk, A.L., Casebeer, H.P. Gardiner et al. 2003 (January 17). *Performance Measurement Systems in Health and Mental Health Services: Models, Practices and Effectiveness. A State of the Science Review*. Retrieved October 31, 2016. <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.195.2219&rep=rep1&type=pdf>.

Adair, C.E., E. Simpson, A.L. Casebeer, J.M. Birdsell, K.A. Hayden and S. Lewis. 2006a. "Performance Measurement in Healthcare: Part 1 – Concepts and Trends from a State of the Science Review." *Healthcare Policy* 1(4): 85–104. doi:10.12927/hcpol.2006.18248.

Adair, C.E., E. Simpson, A.L. Casebeer, J.M. Birdsell, K.A. Hayden and S. Lewis. 2006b. "Performance Measurement in Healthcare: Part II – State of the Science Findings by Stage of the Performance." *Healthcare Policy* 2(1): 56–78. doi:10.12927/hcpol.2006.18338.

Aitken, J.-M. 1994. "Voices from the Inside: Managing District Health Services in Nepal." *International Journal of Health Planning and Management* 9(4): 309–40.

Alexander, J.A., B.J. Weiner, S.M. Shortell, L.C. Baker and M.P. Becker. 2006. "The Role of Organizational Infrastructure in Implementation of Hospitals' Quality Improvement." *Hospital Topics* 84(1): 11–20.

Ammons, D.N. 1995. "Overcoming the Inadequacies of Performance Measurement in Local Government: The Case of Libraries and Leisure Services." *Public Administration Review* 55(1): 37–47.

Arah, O.A., N.S. Klazinga, D.M.J. Delnoij, A.H.A. Ten Asbroek and T. Custers. 2003. "Conceptual Frameworks for Health Systems Performance: A Quest for Effectiveness, Quality, and Improvement." *International Journal for Quality in Health Care* 15(5): 377–98. doi:10.1093/intqhc/mzg049.

Arah, O.A., G.P. Westert, J. Hurst and N.S. Klazinga. 2006. "A Conceptual Framework for the OECD Health Care Quality Indicators Project." *International Journal for Quality in Health Care* 18(Suppl. 1): 5–13.

Armstrong, R., E. Waters, L. Moore, E. Riggs, L.G. Cuervo, P. Lumbiganon and P. Hawe. 2008. "Improving the Reporting of Public Health Intervention Research: Advancing Trend and Consort." *Journal of Public Health* 30(1): 103–09.

Baker, G.R., N. Brooks, G. Anderson, A. Brown, I. McKillop, M. Murray and G. Pink. 1998. "Healthcare Performance Measurement in Canada: Who's Doing What?". *Healthcare Quarterly* 2(2): 22–26. doi:10.12927/hcq.16555.

Baker, G.R., A. MacIntosh-Murray, C. Porcellato, L. Dionne, K. Stelmacovich and K. Born. 2008. *High Performing Healthcare Systems: Delivering Quality by Design*. Toronto, ON: Longwoods Publishing.

Baker, G.R., P.G. Norton, V. Flintoft, R. Blais, A.D. Brown, J. Cox et al. 2004. "The Canadian Adverse Events Study: The Incidence of Adverse Events among Hospital Patients in Canada." *Canadian Medical Association Journal* 170(11): 1678–86. doi:10.1503/cmaj.1040498.

Baker, G.R. and G.H. Pink. 1995. "A Balanced Scorecard for Canadian Hospitals." *Healthcare Management Forum* 8(4): 7–13.

Barnsley, J., L. Lemieux-Charles and R. Baker. 1996. "Selecting Clinical Outcome Indicators for Monitoring Quality of Care." *Healthcare Management Forum* 9(1): 5–21.

Behn, R. 2001. *Rethinking Democratic Accountability*. Washington DC: Brookings Institution Press.

Bevan, G. 2010. "If Neither Altruism Nor Markets Have Improved NHS Performance, What Might?" *Eurohealth* 16(3): 20–22.

Bevan, G. and C. Hood. 2006. "What's Measured Is What Matters: Targets and Gaming in the English Public Health Care System." *Public Administration* 84(3): 517–38.

Black, N. 2015. "To Do the Service No Harm: The Dangers of Quality Assessment." *Journal of Health Services Research and Policy* 20(2): 65–66. doi:10.1177/1355819615570922.

Bouckaert, G. 1993. "Measurement and Meaningful Management." *Public Productivity and Management Review* 17(1): 31–43.

Brinkerhoff, D.W. 2004. "Accountability and Health Systems: Toward Conceptual Clarity and Policy Relevance." *Health Policy and Planning* 19(6): 371–79. doi:10.1093/heapol/czh052.

Campbell, S.M., J. Braspenning, A. Hutchinson and M. Marshall. 2003. "Research Methods Used in Developing and Applying Quality Indicators in Primary Care." *BMJ* 326: 816–19.

Canadian Institute for Health Information (CIHI). 2012. *A Performance Measurement Framework for the Canadian Health System*. Ottawa, ON: Author. <https://secure.cihi.ca/free_products/HSP-Framework-ENweb.pdf>.

Chassin, M.R., R.W. Galvin and National Roundtable on Health Care Quality. 1998. "The Urgent Need to Improve Health Care Quality: Institute of Medicine National Roundtable on Health Care Quality." *JAMA* 280(11): 1000–05. doi:10.1001/jama.280.11.1000.

Deber, R., A. Topp and D. Zakus. 2004. *Private Delivery and Public Goals: Mechanisms for Ensuring That Hospitals Meet Public Objectives*. Washington, DC: World Bank. <http://siteresources.worldbank.org/INTHSD/Resources/376278-1202320704235/GuidingPrivHospitalsDeberetal.pdf>.

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

Dixon-Woods, M., S. Agarwal, D. Jones, B. Young and A. Sutton. 2005. "Synthesizing Qualitative and Quantitative Evidence: A Review of Possible Methods." *Journal of Health Services Research and Policy* 10(1): 45–53.

Dobrow, M.J., T. Sullivan and C. Sawka. 2008. "Shifting Clinical Accountability and the Pursuit of Quality: Aligning Clinical and Administrative Approaches." *Healthcare Management Forum* 21(3): 6–12. doi:10.1016/S0840-4704(10)60269-4.

Donabedian, A. 1966. "Evaluating the Quality of Medical Care." *Milbank Quarterly* 44(3, Part 2): 166–203.

Donabedian, A. 1980. *The Definition of Quality and Approaches to Assessment*. Ann Arbor, MI: Health Administration Press.

Donabedian, A. 1988. "The Quality of Care: How Can It Be Assessed?" *JAMA* 260(12): 1743–48.

Emanuel, E.J. and L.L. Emanuel. 1996. "What Is Accountability in Health Care?" *Annals of Internal Medicine* 124(2): 229–39. doi:10.7326/0003-4819-124-2-199601150-00007.

Exworthy, M. 2010. "The Performance Paradigm in the English NHS: Potential, Pitfalls, and Prospects." *Eurohealth* 16(3): 16–19.

Folan, P. and J. Browne. 2005. "A Review of Performance Measurement: Towards Performance Management." *Computers in Industry* 56(7): 663–80.

Fooks, C. and L. Maslove. 2004. *Rhetoric, Fallacy or Dream? Examining the Accountability of Canadian Health Care to Citizens*. Ottawa, ON: Canadian Policy Research Networks. <www.cprn.org/documents/27403_en.pdf>.

Freeman, T. 2002. "Using Performance Indicators to Improve Health Care Quality in the Public Sector: A Review of the Literature." *Health Services Management Research* 15(2): 126–37. doi:10.1258/0951484021912897.

Gibberd, R. 2005. "Performance Measurement: Is It Now More Scientific?" *International Journal for Quality in Health Care* 17(3): 185–86.

Grayson, L. and A. Gomersall. 2003. *A Difficult Business: Finding the Evidence for Social Science Reviews. Working Paper 19*. London, UK: ESRC UK Centre for Evidence Based Policy and Practice, University of London. <www.evidencenetwork.org/Documents/wp19.pdf>.

Ham, C. 2010. "Improving Performance in the English National Health Service." *Eurohealth* 16(3): 23–25.

Hamblin, R. 2008. "Regulation, Measurements and Incentives. The Experience in the US and the UK: Does Context Matter?" *Journal of the Royal Society for the Promotion of Health* 128(6): 291–98.

Hurst, J. 2002. "Performance Measurement and Improvement in Health Systems: Overview of Issues and Challenges." In P. Smith (Ed.), *Measuring Up: Improving Health System Performance in OECD Countries* (pp. 35–54). Paris, FR: Organisation for Economic Co-operation and Development.

Hurst, J. and M. Jee-Hughes. 2001. *Performance Measurement and Performance Management in OECD Health Systems*. Paris, FR: Organisation for Economic Co-operation and Development. <http://search.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DEELSA/ELSA/WD(2000)8&docLanguage=En>.

Irwin, R. 2010. "Managing Performance: An Introduction." *Eurohealth* 16(3): 15–16.

Julnes, P.D.L. 2009. *Performance-Based Management Systems: Effective Implementation and Maintenance*. Boca Raton, FL: CRC Press.

Kaplan, R.S. and D.P. Norton. 1996. "Using the Balanced Scorecard as a Strategic Management System." *Harvard Business Review* 74(1): 75–85.

Kelley, E. and J. Hurst. 2006. "Health Care Quality Indicators Project: Conceptual Framework Paper." OECD Health Working Papers No. 23. Paris, FR: Organisation for Economic Co-operation and Development. <www.oecd.org/dataoecd/1/36/36262363.pdf>.

Klazinga, N. 2010. "Health System Performance Management." *Eurohealth* 16(3): 26–28.

Klazinga, N., K. Stronks, D. Delnoij and A. Verhoeff. 2001. "Indicators Without a Cause: Reflections on the Development and Use of Indicators in Health Care from a Public Health Perspective." *International Journal for Quality in Health Care* 13(6): 433–38.

Kuhlmann, S. 2010. "Performance Measurement in European Local Governments: A Comparative Analysis of Reform Experiences in Great Britain, France, Sweden and Germany." *International Review of Administrative Sciences* 76(2): 331–45.

Lebas, M.J. 1995. "Performance Measurement and Performance Management." *International Journal of Production Economics* 41(1/3): 23–35.

Leggat, S.G., L. Narine, L. Lemieux-Charles, J. Barnsley, G.R. Baker, C. Sicotte et al. 1998. "A Review of Organizational Performance Assessment in Health Care." *Health Services Management Research* 11(1): 3–18.

Linder, J.A., E.O. Kaleba and K.S. Kmetik. 2009. "Using Electronic Health Records to Measure Physician Performance for Acute Conditions in Primary Care: Empirical Evaluation of the Community-Acquired Pneumonia Clinical Quality Measure Set." *Medical Care* 47(2): 208–16.

Lindsay, P., M. Schull, S. Bronskill and G. Anderson. 2002. "The Development of Indicators to Measure the Quality of Clinical Care in Emergency Departments Following a Modified-Delphi Approach." *Academic Emergency Medicine* 9(11): 1131–39.

Lipsky, M. 1980. *Street-Level Bureaucracy: Dilemmas of the Individual in Public Services*. New York, NY: Russell-Sage Foundation Publications.

Loeb, J.M. 2004. "The Current State of Performance Measurement in Health Care." *International Journal for Quality in Health Care* 16(Suppl. 1), i5–i9. doi:10.1093/intqhc/mzh007.

Marmor, T.R. and J.A. Morone. 1980. "Representing Consumer Interests: Imbalanced Markets, Health Planning and the HSAs." *Milbank Memorial Fund Quarterly, Health and Society* 58(1): 125–65. doi:10.1111/j.1468-0009.2005.00431.x.

Mattke, S., E. Kelley, P. Scherer, J. Hurst, M.L.G. Lapetra and HCQI Expert Group Members. 2006. *Health Care Quality Indicators Project: Initial Indicators Report*. Paris, FR: Organisation for Economic Co-operation and Development. <www.oecd.org/dataoecd/1/34/36262514.pdf>.

Mays, N., C. Pope and J. Popay. 2005. "Systematically Reviewing Quantitative and Qualitative Evidence to Inform Management and Policy-Making in the Health Field." *Journal of Health Services Research and Policy* 10(1): 6–20.

McGlynn, E.A. 2009. "Measuring Clinical Quality and Appropriateness." In P.C. Smith, E. Mossialos, I. Papanicolas and S. Leatherman (Eds.), *Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects* (pp. 87–113). Cambridge, MA: Cambridge University Press.

McGlynn, E.A. and S.M. Asch. 1998. "Developing a Clinical Performance Measure." *American Journal of Preventive Medicine* 14(Suppl. 3): 14–21.

Monahan, P.J. 2006. *Chaoulli V Quebec and the Future of Canadian Healthcare: Patient Accountability as the "Sixth Principle" of the Canada Health Act*. Toronto, ON: C.D. Howe Institute, ISPCO Inc. <www.cdhowe.org/pdf/benefactors_lecture_2006.pdf>.

Myers, R. and R. Lacey. 1996. "Consumer Satisfaction, Performance and Accountability in the Public Sector." *International Review of Administrative Sciences* 62(3): 331–50.

Nolte, E., C. Bain and M. McKee. 2009. "Population Health." In P.C. Smith, E. Mossialos, I. Papanicolas and S. Leatherman (Eds.), *Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects* (pp. 27–62). Cambridge, MA: Cambridge University Press.

Pawson, R. 2002. "Evidence-Based Policy: The Promise of 'Realist Synthesis'." *Evaluation* 8(3): 340–58.

Pawson, R., T. Greenhalgh, G. Harvey and K. Walshe. 2005. "Realist Review – A New Method of Systematic Review Designed for Complex Policy Interventions." *Journal of Health Services Research and Policy* 10(Suppl. 1): 21–34. doi:10.1258/1355819054308530.

Phillips, C.D., M. Chen and M. Sherman. 2008. "To What Degree Does Provider Performance Affect a Quality Indicator? The Case of Nursing Homes and ADL Change." *Gerontologist* 48(3): 330–37.

Pink, G.H., I. McKillop, E.G. Schraa, C. Preyra, C. Montgomery and G.R. Baker. 2001. "Creating a Balanced Scorecard for a Hospital System." *Journal of Health Care Finance* 27(3): 1–20.

Poister, T.H. and G. Streib. 1999. "Performance Measurement in Municipal Government: Assessing the State of the Practice." *Public Administration Review* 59(4): 325–35.

Pope, C., N. Mays and J. Popay. 2006. "Informing Policy Making and Management in Healthcare: The Place for Synthesis." *Healthcare Policy* 1(2): 43–48.

Propper, C., M. Sutton, C. Whitnall and F. Windmeijer. 2008. "Did 'Targets and Terror' Reduce Waiting Times in England for Hospital Care?" *B.E. Journal of Economic Analysis & Policy* 8(2): 1935–1682. doi:10.2202/1935-1682.1863.

Provincial Auditor of Ontario. 2003. *Annual Report of the Office of the Provincial Auditor of Ontario*. Toronto, ON: Office of the Provincial Auditor of Ontario. <www.auditor.on.ca/en/reports_2003_en.htm>.

Public Health Foundation. 2009. *Performance Management in Public Health: A Literature Review*. Seattle, WA: Turning Point. <www.phf.org/resourcestools/Documents/PMCliteraturereview.pdf>.

Schwartz, R. 2011. "Bridging the Performance Measurement-Management Divide? Editor's Introduction." *Public Performance & Management Review* 35(1): 103–107. doi:10.2753/PMR1530-9576350105.

Schwartz, R. and R. Deber. 2016. "The Performance Measurement – Management Divide in Public Health." *Health Policy* 120(3): 273–80. doi:org/10.1016/j.healthpol.2016.02.003.

Shortt, S.E.D. and J.K. Macdonald. 2002. "Toward an Accountability Framework for Canadian Healthcare." *Healthcare Management Forum* 15(4): 24–32.

Smith, P.C. 2002. "Performance Management in British Health Care: Will It Deliver?" *Health Affairs* 21(3): 103–15. doi:10.1377/hlthaff.21.3.103.

Smith, P.C., E. Mossialos, I. Papanicolas and S. Leatherman (Eds). 2009. *Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects*. Cambridge, MA: Cambridge University Press.

Solberg, L.I., G. Mosser and S. McDonald. 1997. "The Three Faces of Performance Measurement: Improvement, Accountability, and Research." *International Journal for Quality in Health Care* 23(3): 135–47.

Stoto, M.A. 2014. "Population Health Measurement: Applying Performance Measurement Concepts in Population Health Settings." *eGEMs* 2(4): 1132. doi:10.13063/2327-9214.1132.

Ten Asbroek, A.H., O.A. Arah, J. Geelhoed, T. Custers, D.M. Delnoij and N.S. Klazinga. 2004. "Developing a National Performance Indicator Framework for the Dutch Health System." *International Journal for Quality in Health Care* 16(Suppl. 1): i65–i75.

Townley, B. 2005. "Critical Views of Performance Measurement." In K. Kempf-Leonard (Ed.), *Encyclopedia of Social Measurement* (Vol. 1, pp. 565–71). Amsterdam, The Netherlands: Elsevier Academic Press.

Tregunno, D., R. Baker, J. Barnsley and M. Murray. 2004. "Competing Values of Emergency Department Performance: Balancing Multiple Stakeholder Perspectives." *Health Services Research* 39(4): 771–92.

US Government Accountability Office. 2005. *Performance Measurement and Evaluation: Definitions and Relationships*. Washington, DC: Author.

Veillard, J.H.M. 2012. "Performance Management in Health Systems and Services: Studies on Its Development and Use at International, National/Jurisdictional, and Hospital Levels." (PhD), University of Amsterdam, Amsterdam, Netherlands. Retrieved October 31, 2016. <http://jeremyveillardresearch.com/thesis/Veillard_PhD_Thesis.pdf>.

Weir, E., N. d'Entremont, S. Stalker, K. Kurji and V. Robinson. 2009. "Applying the Balanced Scorecard to Local Public Health Performance Measurement: Deliberations and Decisions." *BMC Public Health* 9(127). doi:10.1186/1471-2458-9-127.

Zimmerman, S.V. 2005. *Mapping Legislative Accountabilities. Health Care Accountability Papers – No.5, Health Network*. Ottawa, ON: Canadian Policy Research Networks. Ottawa, ON: Canadian Policy Research Networks. <www.cprn.org/documents/35190_en.pdf>.

RESEARCH PAPER

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

JOEL LEXCHIN, MSc, MD
Professor Emeritus, School of Health Policy and Management
York University
Emergency Physician, University Health Network
Associate Professor, Department of Family and Community Medicine
University of Toronto
Toronto, ON

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

Introduction : Les nouvelles classes de médicaments utilisent des mécanismes d'action uniques. Cette étude évalue l'aspect innovant et l'innocuité de ces médicaments approuvés par Santé Canada entre 1997–2012.

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 brevetés (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.

Résultats : En tout, 462 médicaments ont été approuvés par Santé Canada pendant la période soumise à l'étude. Parmi ceux-ci, 345 ont été évalués par le CEPMB et Prescrire International, ou l'un des deux, et des données pour de nouvelles classes de médicament étaient disponibles pour 292 d'entre eux. Quatre-vingt-dix-huit de ces 292 médicaments appartenaient à de nouvelles classes et 16 de ceux-ci étaient innovants, comparés aux 9 des 194 médicaments qui n'appartenaient pas à de nouvelles classes. Il n'y avait pas de différence sur le plan de l'innocuité entre les deux groupes.

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://webprod3.hc-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

292. 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 ($p < 0.0002$).

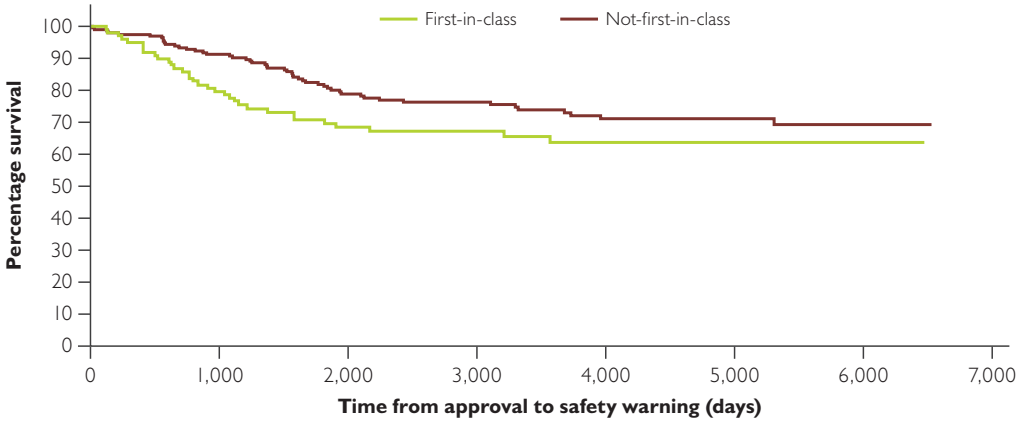
Figure 3 plots the total number of first-in-class drugs and the number of those that were innovative introduced from 1997 to 2012. Linear regression analysis shows no time trend for either group.

TABLE 1. First-in-class and non-first-in-class drugs grouped by innovation status and Anatomic Therapeutic Chemical classification*

Anatomic Therapeutic Chemical classification (first level)	First-in-class						Non-first-in-class					
				Post-market safety warning/withdrawal						Post-market safety warning/withdrawal		
	Innovative	Not innovative	Total number in group and per cent of total first-in-class	Number	Per cent of drugs in group (%)	Per cent of all post-market safety warnings/withdrawals (%)	Innovative	Not innovative	Total number in group and per cent of total not-first-in-class	Number	Per cent of drugs in group (%)	Per cent of all post-market safety warnings/withdrawals (%)
Alimentary tract and metabolism	4	10	14 (14.3)	4	28.6	12.1	1	14	15 (7.8)	4	26.7	8.2
Anti-infectives for systemic use	1	11	12 (12.2)	2	16.7	6.1	1	31	32 (16.7)	12	37.5	24.5
Antineoplastic and immunomodulating agents	4	31	35 (35.7)	16	45.7	48.5	5	30	35 (18.2)	12	34.3	24.5
Blood and blood-forming agents	1	3	4 (4.1)	1	25	3.0	0	12	12 (6.3)	4	33.3	8.2
Cardiovascular system	0	3	3 (3.1)	1	33.3	3.0	0	16	16 (8.3)	6	37.5	12.2
Dermatologicals	0	3	3 (3.1)	0	0	0	0	2	2 (1)	0	0	0
Genitourinary system and sex hormones	1	1	2 (2)	0	0	0	0	14	14 (7.3)	1	7.1	2.0
Musculoskeletal system	0	4	4 (4.1)	2	50	6.1	0	8	8 (4.2)	3	37.5	6.1
Nervous system	1	8	9 (9.2)	4	36.4	12.1	1	33	34 (17.7)	5	14.7	10.2
Respiratory system	0	3	3 (3.1)	1	33.3	3.0	0	8	8 (4.2)	1	12.5	2.0
Sensory organs	2	1	3 (3.1)	1	33.3	3.0	1	8	9 (4.7)	0	0	0
Systemic hormonal preparations, excluding sex hormones and insulins	1	2	3 (3.1)	1	33.3	3.0	0	4	4 (2.1)	0	0	0
Various	1	2	3 (3.1)	0	0	0	0	3	3 (1.6)	1	33.3	2.0
Total	*16*	*82*	*98*	*33*	*33.7*	*100.0*	*9*	*183*	*192*	*49*	*25.5*	*100.0*

*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.

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

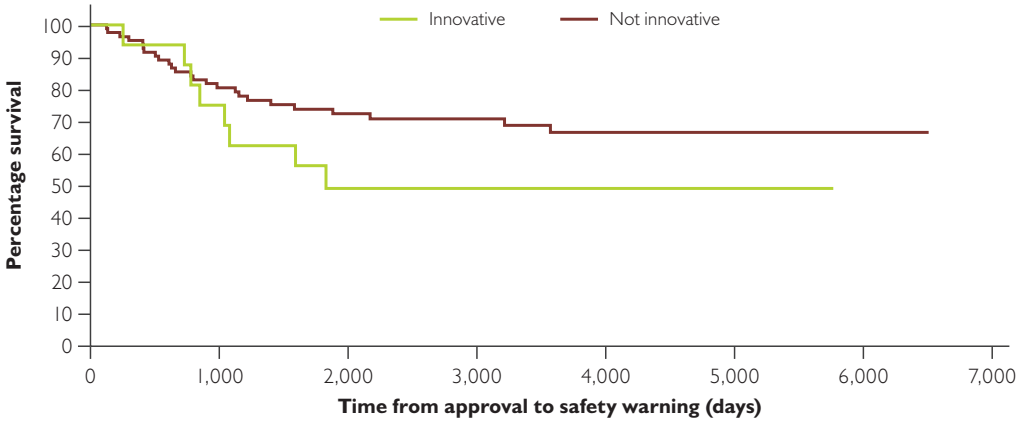


No significant difference between curves, $p = 0.0799$, Log rank (Mantel–Cox) test.

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

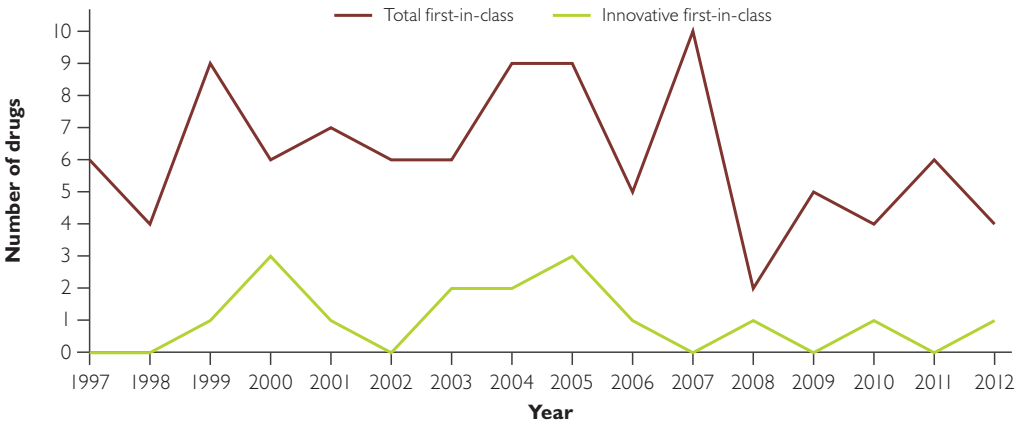
Drug	First-in-class status	Innovation status
Cerivastatin	No	No
Drotrecogin alfa	Yes	Yes
Efalizumab	Yes	No
Gatifloxacin	No	No
Grepafloxacin	No	No
Rofecoxib	No	No
Sibutramine	Yes	No
Tegaserod	Yes	No
Tolcapone	Yes	No
Trovafloxacin	No	No
Valdecoxib	No	No

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.

FIGURE 3. Number of (total and innovative) first-in-class drugs, 1997–2012



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.

Correspondence may be directed to: Joel Lexchin, MD, School of Health Policy and Management, York University, 4700 Keele St., Toronto, ON M3J 1P3; tel.: 416-736-2100 ext. 22119; e-mail: jlexchin@yorku.ca.

References

Health Canada: Health Products and Food Branch. 2009. *Guidance for Industry: Priority Review of Drug Submissions*. Ottawa, ON: Minister of Public Works and Government Services Canada.

Lanthier, M., K. Miller, C. Nardinelli and J. Woodcock. 2013. "An Improved Approach to Measuring Drug Innovation Finds Steady Rates of First-in-Class Pharmaceuticals." *Health Affairs* 32(8): 1433–39.

Lexchin, J. 2014a. "How Safe Are New Drugs? Market Withdrawal of Drugs Approved in Canada between 1990 and 2009." *Open Medicine* 8(1): e14–e19.

Lexchin, J. 2014b. "Post-Market Safety Warnings for Drugs Approved in Canada under the Notice of Compliance with Conditions Policy." *British Journal of Clinical Pharmacology* 79(5): 847–59.

Lexchin, J. 2015. "Health Canada's Use of Its Priority Review Process for New Drugs: A Cohort Study." *BMJ Open* 5: e006816.

Marketed Health Products Directorate. 2004. *How Adverse Reaction Information on Health Products Is Used*. Ottawa, ON: Health Canada.

Patented Medicine Prices Review Board (PMPRB). 2014. *Compendium of Policies, Guidelines and Procedures – Reissued June 2013*. Retrieved July 20, 2014. <www.pmprb-cepmb.gc.ca/view.asp?ccid=492>.

Pharmaceutical Research and Manufacturers of America. 2015a. *2015 Biopharmaceutical Research Industry Profile*. Washington, DC: Author.

Pharmaceutical Research and Manufacturers of America. 2015b. *Innovative Oncology Medicines Have Led to Impressive Gains in Patient Survivorship*. Retrieved August 26, 2015. <www.phrma.org/innovative-oncology-medicines-have-led-to-impressive-gains-in-survivorship>.

Prescrire Editorial Staff. 2002. "Prescrire's Rating System." *Prescrire International* 11: 43.

Prescrire Editorial Staff. 2011. "Prescrire's Ratings System: Gauge the Usefulness of New Products at a Glance." Retrieved August 26, 2015. <http://english.prescrire.org/en/81/168/46800/0/NewsDetails.aspx>.

Rawson, N. and K. Kaitin. 2003. "Canadian and US Drug Approval Times and Safety Considerations." *Annals of Pharmacotherapy* 37(10): 1403–08.

WHO Collaborating Centre for Drug Statistics Methodology & Norwegian Institute of Public Health. 2011. "Structure and Principles." Retrieved December 15, 2015. <www.whocc.no/atc/structure_and_principles/>.

Wiktorowicz, M., J. Lexchin, K. Moscou, A. Silversides and L. Eggertson. 2010. *Keeping an Eye on Prescription Drugs … Keeping Canadians Safe: Active Monitoring Systems for Drug Safety and Effectiveness in Canada and Internationally*. Toronto, ON: Health Council of Canada.

RESEARCH PAPER

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

ANDREA GRUNEIR, PHD
Assistant Professor
Department of Family Medicine
University of Alberta
Edmonton, AB

SUSAN E. BRONSKILL, PHD
Scientist
Institute for Clinical Evaluative Sciences
Toronto, ON

ALICE NEWMAN, MSC
Analyst
Institute for Clinical Evaluative Sciences
Toronto, ON

CHAIM M. BELL, MD, PHD
Professor
Department of Medicine
Mount Sinai Hospital/University of Toronto
Toronto, ON

PETER GOZDYRA, MA
Medical Geographer
Institute for Clinical Evaluative Sciences
Toronto, ON

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

GEOFFREY M. ANDERSON, MD, PhD
Professor
Institute of Health Policy, Management and Evaluation
University of Toronto
Toronto, ON

PAULA A. ROCHON, MD, MPH
Senior Scientist
Women's College Research Institute
Women's College Hospital
Toronto, ON

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.
Méthode : Étude de cohorte rétrospective utilisant des données administratives de l'Ontario.
Participants : 71 780 patients suivis pendant une année, en 2010, provenant de 604 FSI.

Mesures : Des diagrammes en entonnoir ont été utilisés pour déterminer les transferts élevés des FSI et des analyses de régression logistique ont été utilisées pour établir des liens avec l'emplacement et l'importance du FSI, les propriétaires de l'établissement et l'historique des taux de transfert vers les SU.
Résultats : Le taux de transfert vers les SU, par an, se situe entre 4,3 % et 58,6 % (une moyenne de 28,4 %) ; le taux de transfert de 115 (19 %) des FSI était considéré comme élevé. Pour les FSI à moins de cinq minutes d'un SU, de grande importance et avec un taux de transfert historique élevé, ces FSI sont associés à un taux de transfert élevé.
Conclusion : Il y a des variations majeures parmi les FSI. Considérer des caractéristiques telles que la proximité d'un SU peut être important afin de cibler et de développer les diverses interventions nécessaires pour les 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_{NH}) that was plotted against the total number of residents in the NH. The STR_{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_{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_{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).

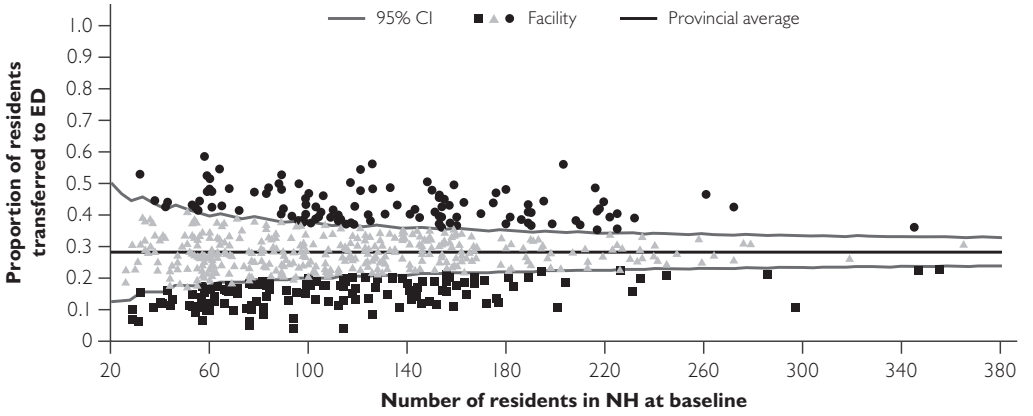
TABLE 1. Facility-level distribution of resident baseline characteristics for full cohort of NHs and stratified by relative ED transfer rate (71,780 residents at baseline)

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

	All NHs in cohort *N* = 604	"High" transfer NHs *n* = 115	"Intermediate" transfer NHs *n* = 359	"Low" transfer NHs *n* = 130
CHESS scale score, mean proportion (SD)				
0	46.9% (14.7%)	50.9% (14.0%)	46.9% (14.4%)	43.3% (15.2%)
1	31.7% (7.8%)	31.0% (7.6%)	31.6% (7.8%)	32.5% (7.9%)
2	14.8% (7.4%)	12.9% (6.1%)	14.9% (7.4%)	16.1% (8.2%)
3	4.5% (3.7%)	3.6% (2.8%)	4.5% (3.5%)	5.5% (4.5%)
4	1.7% (1.8%)	1.4% (1.5%)	1.6% (1.6%)	2.1% (2.3%)
5	0.4% (0.9%)	0.2% (0.5%)	0.4% (0.9%)	0.5% (1.1%)
Facility average CHESS score, mean (SD)	0.8 (0.3)	0.7 (0.3)	0.8 (0.3)	0.9 (0.4)
Major diagnoses – mean proportion (SD)				
Diabetes mellitus	24.7% (6.2%)	26.4% (6.8%)	24.9% (6.1%)	22.7% (5.5%)
Arteriosclerotic heart disease	12.9% (10.5%)	11.9% (10.4%)	12.9% (10.8%)	13.6% (10.0%)
Cardiac dysrhythmia	7.0% (5.7%)	6.0% (4.8%)	7.2% (6.0%)	7.4% (5.6%)
Congestive heart failure	12.5% (5.2%)	11.8% (4.7%)	12.5% (5.1%)	13.2% (5.8%)
Peripheral vascular disease	5.3% (3.9%)	5.5% (3.8%)	5.2% (3.7%)	5.4% (4.7%)
Arthritis	39.3% (12.8%)	35.7% (12.3%)	39.2% (12.1%)	42.9% (14.1%)
Osteoporosis	25.7% (10.3%)	24.4% (8.1%)	25.3% (9.8%)	28.1% (12.6%)
Alzheimer's disease	18.6% (9.1%)	17.0% (8.6%)	18.8% (9.2%)	19.7% (8.9%)
Dementia (other than Alzheimer's)	44.1% (11.2%)	44.3% (11.8%)	44.2% (11.2%)	43.6% (11.0%)
Stroke (cerebrovascular accident)	21.5% (6.5%)	21.8% (6.7%)	21.5% (6.5%)	21.2% (6.7%)
Parkinson disease	6.9% (3.0%)	6.5% (3.0%)	7.0% (3.1%)	7.1% (3.0%)
Anxiety disorder	7.8% (5.3%)	7.1% (5.3%)	7.7% (5.5%)	8.6% (4.7%)
Depression	28.5% (11.1%)	25.7% (9.6%)	28.2% (10.9%)	31.6% (12.3%)
Emphysema/Chronic obstructive pulmonary disease	14.8% (6.5%)	14.4% (6.3%)	14.8% (6.6%)	15.1% (6.4%)
Cancer	8.5% (4.9%)	8.3% (4.7%)	8.6% (5.0%)	8.5% (5.1%)
Renal failure	8.1% (6.2%)	8.1% (6.4%)	8.1% (6.2%)	7.9% (5.9%)
Accidents, mean proportion (SD)				
Fell in past 30 days	13.2% (4.9%)	12.6% (5.1%)	13.4% (4.8%)	13.3% (4.9%)
Fell in past 180 days	25.3% (8.9%)	24.0% (9.0%)	25.3% (8.8%)	26.3% (9.0%)
Fracture in past 180 days (hip or other)	2.8% (2.0%)	2.5% (1.9%)	2.9% (2.1%)	2.6% (2.0%)

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.

FIGURE 1. Proportion of nursing home residents in facility with at least 1 ED visit over one year, plotted with funnels approximated using exact binomial limit



CI = confidence interval; ED = emergency department; NH = nursing home.

TABLE 2. Distribution of NH characteristics by ED transfer rate

	NH-specific rates of ED transfer				Association between NH characteristics and high transfer rate NH
	High rate	Intermediate rate	Low rate	Total	
	n = 115	*n* = 359	*n* = 130	*N* = 604	Adjusted OR[§] (95% CI)
ED transfer rate range*	35.5–58.6%	17.7–41.2%	4.3–23.1%	4.3–58.6%	–
Location, *n* (%)					
Rural	20 (17.4%)	111 (30.9%)	35 (26.9%)	166 (27.5%)	Reference
Urban	95 (82.6%)	248 (69.1%)	95 (73.1%)	438 (72.5%)	1.41 (0.76, 2.61)
≥5 minutes to closest ED	37 (31.6%)	171 (47.3%)	60 (46.2%)	268 (44.1%)	Reference
<5 minutes to closest ED	78 (68.4%)	188 (52.7%)	70 (53.8%)	336 (55.9%)	1.77 (1.09, 2.86)
Size, *n* (%)					
<100 beds	28 (24.4%)	161 (44.8%)	56 (43.1%)	245 (40.6%)	Reference
≥100 beds	87 (75.6%)	198 (55.2%)	74 (56.9%)	359 (59.4%)	1.91 (1.13, 3.23)
Ownership,[¶] *n* (%)					
Municipal	14 (12.3%)	61 (17.2%)	27 (20.9%)	102 (17.1%)	Reference
Non-profit	27 (23.7%)	80 (22.5%)	36 (27.9%)	143 (23.9%)	1.64 (0.76, 3.56)
For-profit	73 (64.0%)	214 (60.3%)	66 (51.2%)	353 (59.0%)	1.57 (0.79, 3.12)
Historical transfer rate, *n* (%)					
<13%	96 (84.2%)	183 (51.0%)	12 (9.2%)	291 (48.3%)	Reference
≥13%	19 (15.8%)	176 (49%)	118 (90.8%)	313 (51.7%)	7.03 (4.04, 12.24)

CI = confidence intervals; ED = emergency department; NH = nursing homes; OR = odds ratio.

*Transfer rates overlap owing to funnel shape of control bounds. [§]All NH factors modelled simultaneously and adjusted for NH case-mix variables (proportion of residents with each behavioural problems, cognitive impairment and high levels of instability). [¶]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

The authors would like to thank Dilzayn Panjwani, MSc at the Women's College Research Institute for her assistance in preparing the manuscript. This work was supported by the Canadian Institutes of Health Research (CIHR); Institute of Health Services and Policy Research [grant number MOP 89943]; CIHR Institute of Nutrition, Metabolism, and Diabetes [grant number OTG-88591] to [AG]; and the CIHR New Investigator Award to [AG]. There are no conflicts of interest to declare.

Correspondence may be directed to: Andrea Gruneir; e-mail: gruneir@ualberta.ca.

References

Bronskill, S.E., G.M. Anderson, K. Sykora, W.P. Wodchis, S. Gill, K.I. Shulman and P.A. Rochon. 2004. "Neuroleptic Drug Therapy in Older Adults Newly Admitted to Nursing Homes: Incidence, Dose, and Specialist Contact." *Journal of the American Geriatrics Society* 52: 749–55.

Canadian Institute for Health Information (CIHI). 2007. *NACRS Background and General Data Limitations Documentation 2006–2007.* Ottawa, ON: CIHI.

Chan, B.T.B., M.J. Schull and S.E. Schultz. 2001. *Emergency Department Services in Ontario 1993–2000.* Toronto, ON: Institute of Clinical Evaluative Sciences.

Gessert, C.E., B.A. Elliott and C. Peden-McAlpine. 2006. "Family Decision-Making for Nursing Home Residents with Dementia: Rural–Urban Differences." *Journal of Rural Health* 22(1): 1–8.

Goodman, D.C., E. Fisher, T.A. Stukel and C. Chang. 1997. "The Distance to Community Medical Care and the Likelihood of Hospitalization: Is Closer Always Better?" *American Journal of Public Health* 87(7): 1144–50.

Gruneir, A., C.M. Bell, S.E. Bronskill, M. Schull, G.M. Anderson and P.A. Rochon. 2010. "Frequency and Pattern of Emergency Department Visits by Long-Term Care Residents – A Population-Based Study." *Journal of the American Geriatrics Society* 58(3): 510–17.

Hawes, C., J.N. Morris, C.D. Phillips, V. Mor, B.E. Fries and S. Nonemaker. 1995. "Reliability Estimates for the Minimum Data Set for Nursing Home Resident Assessment and Care Screening (MDS)." *Gerontologist* 35(2): 172–78.

Hillmer, M.P., W.P. Wodchis, S.S Gill, G.M. Anderson and P.A. Rochon. 2005. "Nursing Home Profit Status and Quality of Care: Is There Any Evidence of an Association?" *Medical Care Research and Review* 62(2): 139–66.

Hirdes, J.P., D.H. Frijters and G.F. Teare. 2003. "The MDS-CHESS Scale: A New Measure to Predict Mortality in Institutionalized Older People." *Journal of the American Geriatrics Society* 51(1): 96–100.

Hux, J.E., F. Ivis, V. Flintoft and A. Bica. 2002. "Diabetes in Ontario: Determination of Prevalence and Incidence Using a Validated Administrative Data Algorithm." *Diabetes Care* 25 (3): 512–16.

Intrator, O., N.G. Castle and V. Mor. 1999. "Facility Characteristics Associated with Hospitalization of Nursing Home Residents: Results of a National Study." *Medical Care* 37(3): 228–37.

Intrator, O., J. Zinn and V. Mor. 2004. "Nursing Home Characteristics and Potentially Preventable Hospitalizations of Long-Stay Residents." *Journal of the American Geriatrics Society* 52(10): 1730–36.

Kang, Y., H. Meng and N.A. Miller. 2011. "Rurality and Nursing Home Quality: Evidence from the 2004 National Nursing Home Survey." *Gerontologist* 51(6): 761–73.

Lamb, G., R. Tappen, S. Diaz, L. Herndon and J.G. Ouslander. 2011. "Avoidability of Hospital Transfers of Nursing Home Residents: Perspectives of Frontline Staff." *Journal of the American Geriatrics Society* 59: 1665–72.

Loeb, M., S.C. Carusone, R. Goeree, S.D. Walter, K. Brazil, P. Krueger et al. 2006. "Effect of a Clinical Pathway to Reduce Hospitalizations in Nursing Home Residents with Pneumonia: A Randomized Controlled Trial." *Journal of the American Medical Association* 295(21): 2503–10.

Ludwick, A., R. Fu, C. Warden and R.A. Lowe. 2009. "Distances to Emergency Department and to Primary Care provider's Office Affect Emergency Department Use in Children." *Academic Emergency Medicine* 16: 411–17.

McAiney, C.A., D. Haughton, J. Jennings, D. Farr, L. Hillier and P. Morden. 2008. "A Unique Practice Model for Nurse Practitioners in Long-Term Care Homes." *Journal of Advanced Nursing* 62(5): 562–71.

McGrail, K.M., M.J. McGregor, M. Cohen, R.B. Tate and L.A. Ronald. 2007. "For-Profit Versus Not-For-Profit Delivery of Long-Term Care." *Canadian Medical Association Journal* 176(1): 57–58.

McGregor, M.J., M. Cohen, K. McGrail, A.M. Broemeling, R.N. Adler, M. Schulzer et al. 2005. "Staffing Levels in Not-For-Profit and For-Profit Long-Term Care Facilities: Does Type of Ownership Matter?" *Canadian Medical Association Journal* 172(5): 645–49.

McGregor, M.J., R.B. Tate, K.M. McGrail, L.A. Ronald, A.M. Broemeling and M. Cohen. 2006. "Care Outcomes in Long-Term Care Facilities in British Columbia, Canada. Does Ownership Matter?" *Medical Care* 44(10): 929–35.

Mor, V., A. Gruneir, Z. Feng, D.C. Grabowski, O. Intrator and J. Zinn. 2011. "The Effect of State Policies on Nursing Home Resident outcomes." *Journal of the American Geriatrics Society* 59(1): 3–9.

Morris, J.N., B.E. Fries, D.R. Mehr, C. Hawes, C.D. Phillips, V. Mor et al. 1994. "MDS Cognitive Performance Scale." *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 49(4): M174–M82.

Morris, J.C., B.E. Fries and S.A. Morris. 1999. "Scaling ADLs Within the MDS." *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 54A: M546–M53.

Phillips, C.D., S. Holan, M. Sherman, M.L. Williams and C. Hawes. 2004. "Rurality and Nursing Home Quality: Results from a National Sample of Nursing Home Admissions." *American Journal of Public Health* 94: 1717–22.

Rochon, P.A., T.A. Stukel, S.E. Bronskill, T. Gomes, K. Sykora, W.P. Wodchis et al. 2007. "Variation in Nursing Home Antipsychotic Prescribing Rates." *Archives of Internal Medicine* 167: 676–83.

Schull, M.J., A. Kiss and J.P. Szalai. 2007. "The Effect of Low-Complexity Patients on Emergency Department Waiting Times." *Annals of Emergency Medicine* 49: 257–64, 64 e1.

Spiegelhalter, D.J. 2005. "Funnel Plots for Comparing Institutional Performance." *Statistics in Medicine* 24: 1185–202.

Temkin-Greener, H., N.T. Zheng and D.B. Mukamel. 2012. "Rural–Urban Differences in End-of-Life Nursing Home Care: Facility and Environmental Factors." *Gerontologist* 52(3): 335–44.

Zinn, J.S., V. Mor, Z. Feng and O. Intrator. 2007. "Doing Better to do Good: The Impact of Strategic Adaptation on Nursing Home Performance." *Health Services Research Journal* 42: 1200–18.

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.

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; 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.

To view the full article, please visit http://www.longwoods.com/content/24853.

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

ANNA DE GROOD, KENNETH BLADES AND SACHIN R. PENDHARKAR

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.

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

ONLINE EXCLUSIVE

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, PhD
McMaster Health Forum, McMaster University
Centre for Health Economics and Policy Analysis, McMaster University
Department of Clinical Epidemiology and Biostatistics, McMaster University
Hamilton, ON

JOHN N. LAVIS, MD, PhD
McMaster Health Forum, McMaster University
Centre for Health Economics and Policy Analysis, McMaster University
Department of Clinical Epidemiology and Biostatistics, McMaster University
Department of Political Science, McMaster University
Hamilton, ON
Department of Global Health and Population
Harvard School of Public Health
Cambridge, MA

FRANCOIS-PIERRE GAUVIN, PhD
McMaster Health Forum, McMaster University
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

Project	Objective	Key methodological features
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

*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 to 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.

Correspondence may be directed to: Michael G. Wilson; e-mail: wilsom2@mcmaster.ca.

References

Boult, C., L. Reider, B. Leff, K.D. Frick, C.M. Boyd, J.L. Wolff et al. 2011. "The Effect of Guided Care Teams on the Use of Health Services: Results from a Cluster-Randomized Controlled Trial." *Archives of Internal Medicine* 171(5): 460–66.

Boyd, C.M., C. Boult, E. Shadmi, B. Leff, R Brager, L. Dunbar et al. 2007. "Guided Care for Multimorbid Older Adults." *Gerontologist* 47: 697–704.

Boyd, C.M., J. Darer, C. Boult, L.P. Fried, L. Boult and A.W. Wu. 2005. "Clinical Practice Guidelines and Quality of Care for Older Patients with Multiple Comorbid Diseases: Implications for Pay for Performance." *Journal of the American Medical Association* 294(6): 716–24.

Boyd, C.M. and M. Fortin. 2010. "Future of Multimorbidity Research: How Should Understanding of Multimorbidity Inform Health System Design?" *Public Health Reviews* 32(2): 451–74.

Boyd, C.M., M.K. McNabney, N. Brandt, R. Correa-de-Araujo, K.M. Daniel and American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity. 2012a. "Patient-Centered Care for Older Adults with Multiple Chronic Conditions: A Stepwise Approach from the American Geriatrics Society." *Journal of the American Geriatrics Society* 60(10): 1957–68.

Boyd, C.M., M.K. McNabney, N. Brandt, R. Correa-de-Araujo, K.M. Daniel and American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity. 2012b. "Guiding Principles for the Care of Older Adults with Multimorbidity: An Approach for Clinicians." *Journal of the American Geriatrics Society* 60: E1–E25.

Canadian Institute for Health Information (CIHI). 2011. *Seniors and the Health Care System: What Is the Impact of Multiple Chronic Conditions*. Ottawa, ON: Author.

Chatham House. 2014. "Chatham House Rule." Retrieved October 19, 2016. <www.chathamhouse.org>.

Cox, L., M. Kloseck, R. Crilly and L. Diachun. 2011. "Underrepresentation of Individuals 80 Years of Age and Older in Chronic Disease Clinical Practice Guidelines." *Canadian Family Physician* 57(7): e263–e269.

de Bruin, S.R., N. Versnel, L.C. Lemmens, C.C. Molema, F.G. Schellevis, G. Nijpels et al. 2012. "Comprehensive Care Programs for Patients with Multiple Chronic Conditions: A Systematic Literature Review." *Health Policy* 107(2/3): 108–45.

Eddy, D.M., J. Adler, B. Patterson, D. Lucas, K.A. Smith and M. Morris. 2011. "Individualized Guidelines: The Potential for Increasing Quality and Reducing Costs." *Annals of Internal Medicine* 154(9): 627–34.

Fabbri, L.M., C. Boyd, P. Boschetto, K.F. Rabe, A.S. Buist, B. Yawn et al. 2012. "How to Integrate Multiple Comorbidities in Guideline Development." *Proceedings of the American Thoracic Society* 9(5): 1–8.

Fortin, M., G. Bravo, C. Hudon, L. Lapointe, J. Almirall, M.F. Dubois et al. 2006. "Relationship Between Multimorbidity and Health-Related Quality of Life of Patients in Primary Care." *Quality of Life Research* 15(1): 83–91.

Fortin, M., E. Contant, C. Savard, C. Hudon, M.E. Poitras and J. Almirall. 2011. "Canadian Guidelines for Clinical Practice: An Analysis of their Quality and Relevance to the Care of Adults with Comorbidity." *BMC Family Practice* 12: 74.

France, E.F., S. Wyke, J.M. Gunn, F.S. Mair, G. McLean and S.W. Mercer. 2012. "Multimorbidity in Primary Care: A Systematic Review of Prospective Cohort Studies." *British Journal of General Practice* 62(597): e297–e307.

Gauvin, F.-P., J. Abelson, J.N. Lavis and M. Hirji. 2014a. *Panel Summary: Improving Care and Support for People with Multiple Chronic Health Conditions in Ontario*. Hamilton, ON: McMaster Health Forum. Retrieved October 31, 2016. <https://www.mcmasterhealthforum.org/docs/default-source/Product-Documents/citizen-panel-summaries/care-for-people-with-multiple-chronic-health-conditions-cps.pdf?sfvrsn=2>.

Gauvin, F.-P., M.G. Wilson, J. Abelson and J.N. Lavis. 2014b. *Citizen Brief: Improving Care and Support for People with Multiple Chronic Health Conditions in Ontario*. Hamilton, ON: McMaster Health Forum.

Gauvin, F.-P., M.G. Wilson and E. Alvarez. 2013. *Identifying Optimal Treatment Approaches for People with Multimorbidity in Ontario*. Hamilton, ON: McMaster Health Forum.

Gill, A., K. Kuluski, L. Jaakkimainen, G. Naganathan, R. Upshur and W. Wodchis. 2014. "Where Do We Go from Here?" Health System Frustrations Expressed by Patients with Multimorbidity, Their Caregivers and Family Physicians." *Healthcare Policy* 9(4): 73–89.

Government of Ontario. 2015. *Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario*. Toronto, ON: Queen's Printer for Ontario.

Guthrie, B., K. Payne, P. Alderson, M.E. McMurdo and S.W. Mercer. 2012. "Adapting Clinical Guidelines to Take Account of Multimorbidity." *BMJ* 345: e6341.

Health Council of Canada. 2007. *Population Patterns of Chronic Health Conditions in Canada – A Data Supplement to Why Healthcare Renewal Matters: Learning from Canadians with Chronic Health Conditions*. Toronto, ON: Health Council of Canada.

Health Council of Canada. 2011. *How Do Sicker Canadians with Chronic Disease Rate the Health Care System? Results from the 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults*. Toronto, ON: Health Council of Canada.

Hughes, L.D., M.E.T. McMurdo and B. Guthrie. 2012. "Guidelines for People Not for Diseases: The Challenges of Applying UK Clinical Guidelines to People with Multimorbidity." *Age and Ageing* 0: 1–8.

Institute for Healthcare Improvement. 2014. *The IHI Triple Aim. Institute for Healthcare Improvement*. Retrieved October 19, 2016. <www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx>.

International Initiative for Impact Evaluation. 2014. *Evidence Gap Maps. International Initiative for Impact Evaluation*. Retrieved October 19, 2016. <http://www.3ieimpact.org/en/about/what-3ie-does/systematic-reviews-programme/evidence-gap-maps/>.

Ishani, A., N. Greer, B.C. Taylor, L. Kubes, P. Cole, M. Atwood et al. 2011. "Effect of Nurse Case Management Compared with Usual Care on Controlling Cardiovascular Risk Factors in Patients with Diabetes: A Randomized Controlled Trial." *Diabetes Care* 34(8): 1689–94.

Katon, W., J. Russo, E.H. Lin, J. Schmittdiel, P. Ciechanowski, E. Ludman et al. 2012. "Cost-Effectiveness of a Multicondition Collaborative Care Intervention: A Randomized Controlled Trial." *Archives of General Psychiatry* 69(5): 506–14.

Lin, E.H., K.M. Von, P. Ciechanowski, D. Peterson, E.J. Ludman, C.M. Rutter et al. 2012. "Treatment Adjustment and Medication Adherence for Complex Patients with Diabetes, Heart Disease, and Depression: A Randomized Controlled Trial." *Annals of Family Medicine* 10(1): 6–14.

Lugtenberg, M., J.S. Burgers, C. Clancy, G.P. Westert and E. Schneider. 2011. "Current Guidelines Have Limited Applicability to Patients with Comorbid Conditions: A Systematic Analysis of Evidence-Based Guidelines." *PLoS ONE* 6: e25987.

Marengoni, A., S. Angleman, R. Melis, F. Mangialasche, A. Karp, A. Garmen et al. 2011. "Aging with Multimorbidity: A Systematic Review of the Literature." *Ageing Research Reviews* 10: 430–39.

McGregor, M., E.H. Lin and W.J. Katon. 2011. "TEAMcare: An Integrated Multicondition Collaborative Care Program for Chronic Illnesses and Depression." *Journal of Ambulatory Care Management* 34: 152–62.

Mutasingwa, D.R., H. Ge and R.E.G. Upshur. 2011. "How Applicable Are Clinical Practice Guidelines to Elderly Patients with Comorbidities?" *Canadian Family Physician* 57(7): e253–62.

National Institute for Health and Clinical Excellence (NICE). 2009. *Depression in Adults with a Chronic Physical Health Problem: Treatment and Management*. London, UK: Author.

National Institute for Health and Clinical Excellence (NICE). 2012. *NICE Should Consider Multimorbidity in Guidelines. National Institute for Health and Clinical Excellence*. Retrieved October 19, 2016. <http://www.nice.org.uk/newsroom/news/NICEShouldConsiderMultimorbidityInGuidelines.jsp>.

Organisation for Economic Co-operation and Development (OECD). 2011. *Health Reform: Meeting the Challenge of Ageing and Multiple Morbidities*. Paris, FR: Author.

Patterson, S.M., C. Hughes, N. Kerse, C.R. Cardwell and M.C. Bradley. 2012. "Interventions to Improve the Appropriate Use of Polypharmacy for Older People." *Cochrane Database of Systematic Reviews* 5(12): CD008165.

Pefoyo, A.J., S.E. Bronskill, A. Gruneir, A. Calzavara, K. Thavorn, Y. Petrosyan et al. 2015. "The Increasing Burden and Complexity of Multimorbidity." *BMC Public Health* 15(1): 1–11.

Roberts, K.C., D.P. Rao, T.L. Bennett, L. Loukine and G.C. Jayaraman. 2015. "Prevalence and Patterns of Chronic Disease Multimorbidity and Associated Determinants in Canada." *Health Promotion and Chronic Disease Prevention in Canada* 25: 87–94.

Shea, B., J. Grimshaw, G. Wells, M. Boers, N. Andersson, C. Hamel et al. 2007. "Development of AMSTAR: A Measurement Tool to Assess the Methodological Quality of Systematic Reviews." *BMC Medical Research Methodology* 7: 10–16.

Smith, S.M., H. Soubhi, M. Fortin, C. Hudon and T. O'Dowd. 2012. "Interventions for Improving Outcomes in Patients with Multimorbidity in Primary Care and Community Settings." *Cochrane Database of Systematic Reviews* (4): CD006560. doi:10.1002/14651858.CD006560.pub2.

Stewart, M., M. Fortin, H.C. Britt, C.M. Harrison and H.L. Maddocks. 2013. "Comparisons of Multi-Morbidity in Family Practice – Issues and Biases." *Family Practice* 30(4): 473–80.

Taveira, T.H., A.G. Dooley, L.B. Cohen, S.A. Khatana and W.C. Wu. 2011. "Pharmacist-Led Group Medical Appointments for the Management of Type 2 Diabetes with Comorbid Depression in Older Adults." *Annals of Pharmacotherapy* 45(11): 1346–55.

Tinetti, M.E., T.R. Fried and C.M. Boyd. 2012. "Designing Health Care for the Most Common Chronic Condition – Multimorbidity." *Journal of the American Medical Association* 307(23): 2493–94.

Tinetti, M.E., S.T. Bogardus and J.V. Agostini. 2004. "Potential Pitfalls of Disease-Specific Guidelines for Patients with Multiple Conditions." *New England Journal of Medicine* 351(27): 2870–74.

US Department of Health and Human Services. 2010. *Multiple Chronic Conditions – A Strategic Framework: Optimum Health and Quality of Life for Individuals with Multiple Chronic Conditions*. Washington, DC: Author.

van den Brink, A.M., D.L. Gerritsen, R.C. Voshaar and R.T. Koopmans. 2012. "Residents with Mental-Physical Multimorbidity Living in Long-Term Care Facilities: Prevalence and Characteristics: A Systematic Review." *International Psychogeriatrics* 25(4): 1–18.

van Weel, C. and F.G. Schellevis. 2006. "Comorbidity and Guidelines: Conflicting Interests." *Lancet* 367(9510): 550–51.

Vitry, A.I. and Y. Zhang. 2008. "Quality of Australian Clinical Guidelines and Relevance to the Care of Older People with Multiple Comorbid Conditions." *Medical Journal of Australia* 189(7): 360–65.

Von, K.M., W.J. Katon, E.H. Lin, P. Ciechanowski, D. Peterson, E.J. Ludman et al. 2011. "Functional Outcomes of Multi-Condition Collaborative Care and Successful Ageing: Results of Randomised Trial." *BMJ* 343: d6612.

Wagner, E.H., B.T. Austin and K.M. Von. 1996. "Organizing Care for Patients with Chronic Illness." *Milbank Quarterly* 74(4): 511–44.

Williams, A., E. Manias, R. Walker and A. Gorelik. 2012. "A Multifactorial Intervention to Improve Blood Pressure Control in Co-Existing Diabetes and Kidney Disease: A Feasibility Randomized Controlled Trial." *Journal of Advanced Nursing* 68: 2515–25.

Wilson, M.G. and J.N. Lavis. 2013. *Dialogue Summary: Designing Integrated Approaches to Support People with Multimorbidity in Ontario*. Hamilton, ON: McMaster Health Forum.

Wilson, M.G. and J.N. Lavis. 2014. *Rapid Synthesis: Engaging in Priority Setting About Primary and Integrated Healthcare Innovations in Canada*. Hamilton, ON: McMaster Health Forum.

Wilson, M.G., J.N. Lavis and Gauvin, F.-P. 2013. *Issue Brief: Designing Integrated Approaches to Support People with Multimorbidity in Ontario*. Hamilton, ON: McMaster Health Forum.

Wodchis, W.P., P. Austin, A. Newman, A. Corallo and D. Henry. 2012. *The Concentration of Healthcare Spending: Little Ado (yet) About Much (Money)*. Presented at the Canadian Association for Health Services and Policy Research Conference, Montreal, ON.

ONLINE EXCLUSIVE

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

ANNA DE GROOD, BSc
Research Assistant, Ward of the 21st Century
University of Calgary
Calgary, AB

KENNETH BLADES, MA
Research Associate, Ward of the 21st Century
University of Calgary
Calgary, AB

SACHIN R. PENDHARKAR, MD, MSc
Associate Professor, Departments of Medicine and Community Health Sciences
University of Calgary
Calgary, AB

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

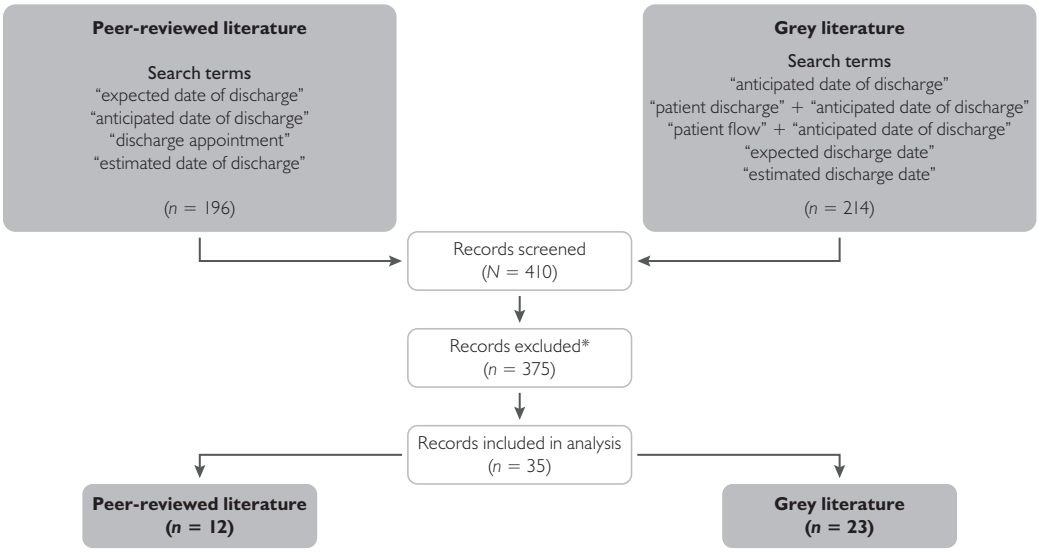
We realized early in the study that a traditional systematic review was unlikely to yield a meaningful synthesis of study results. Initial exploratory searches of several databases (PubMed, Scopus, Cumulative Index to Nursing and Allied Health Literature [CINAHL], Cochrane), which we conducted to refine 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



*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

	Country	Setting*	Hospital type§	Hospital size¶	Who assigns predicted date	Prediction method	Location of DP date	Outcomes reported
1	Canada	Urban	Community	Medium	Physician	Clinical judgment	Patient chart	Staff compliance
2	US	Urban	Academic	Large	Physician	–	Patient chart, whiteboard	Staff compliance
3	US	Urban	Academic	Large	Physician	–	Patient chart	ALOS
4	US	Urban	Community	Large	Clinical resource manager	Algorithm	Patient chart	ALOS
5	UK	Urban	Academic	Large	Physician	–	Patient chart	ALOS
6	England	Urban	Community	Large	Physician	Clinical judgment	Patient chart	Staff compliance
7	Wales	Urban	Academic	Large	Nurses	Algorithm	Patient chart	ALOS, staff communication
8	England	Urban	Community	Large	Team	–	Patient chart, whiteboard	Staff satisfaction, compliance
9	England	Urban	Community	Large	Team	Algorithm	Patient chart	Staff knowledge
10	US	Urban	Academic	Large	–	–	Patient chart	Staff compliance
11	US	Urban	Academic	Large	–	–	Patient chart, whiteboard	Patient satisfaction
12	Australia	Urban	Academic	Medium	–	–	Patient chart	Staff communication

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

	Country	Setting*	Hospital type§	Hospital size¶	Who assigns predicted date	Prediction method	Location of DP date	Outcomes reported
1†	Canada	Urban	Both	Large	Physician	Clinical judgment	Patient chart	–
2	Canada	Urban	Community	Medium	Team	–	–	–
3†	Canada	Urban	Both	All	Team	Judgment, checklist	Patient chart	–
4	Canada	Urban	Academic	Large	Physician	–	Patient chart, whiteboard	–
5†	Australia	Both	Both	All	Team	Judgment, checklist	Patient chart	–
6†	Australia	Both	Both	All	Senior medical officer	Algorithm	Patient chart	–
7†	Australia	Both	Both	All	–	–	–	–
8	Scotland	Urban	Academic	Large	Senior medical staff	–	–	Patient satisfaction
9†	UK	Both	Both	All	Team	Clinical judgment	Patient chart	–
10	Scotland	Urban	Community	Large	Consultant	–	Patient chart	–
11†	UK	Both	Both	All	Physician	Unit benchmarks	Patient chart	–
12	Scotland	Urban	Community	Large	Team	–	–	–
13	England	Urban	Academic	Large	–	Clinical judgment	–	–
14†	Scotland	Both	Community	All	–	–	Patient chart	–
15	US	Urban	Academic	Medium	Nurse	–	Patient chart	Patient satisfaction
16	US	Rural	Community	Medium	Team	Clinical judgment	Patient chart	–
17	US	Urban	Community	Medium	–	–	–	Patient satisfaction, reduced costs
18	US	Urban	Academic	Large	Physician	Clinical judgment	Patient chart	Staff compliance, patient satisfaction
19	Australia	Urban	Academic	Large	–	–	–	Staff compliance, patient satisfaction
20	Canada	Urban	Academic	Large	Team	Clinical judgment	Patient chart	–
21	US	Urban	Academic	Large	Physician	Clinical judgment	Electronic	–
22	Australia	Urban	Academic	Large	Team	–	Patient chart	–
23†	Australia	Both	Both	All	Team	–	Patient chart	–

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

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).

Correspondence may be directed to: Dr. Sachin R. Pendharkar, TRW Building, Rm 3E23, University of Calgary, 3280 Hospital Drive NW, Calgary, AB T2N 4Z6; tel.: 403-943-8470; e-mail: sachin.pendharkar@ucalgary.ca.

References

Campbell, N.C., E. Murray, J. Darbyshire, J. Emery, A. Farmer, F. Griffiths et al. 2007. "Designing and Evaluating Complex Interventions to Improve Health Care." *BMJ* 334(7591): 455–59.

Canadian Institutes for Health Information (CIHI). n.d. *Acute Care Hospitals*. Retrieved November 30, 2016. <https://secure.cihi.ca/estore/coreplan.htm?locale=en>.

Carratalà, J., C. Garcia-Vidal, L. Ortega, N. Fernández-Sabé, M. Clemente, G. Albero et al. 2012. "Effect of a 3-Step Critical Pathway to Reduce Duration of Intravenous Antibiotic Therapy and Length of Stay in Community-Acquired Pneumonia: A Randomized Controlled Trial." *Archives of Internal Medicine* 172(12): 922–28.

Clancy, C.M. 2009. "Reengineering Hospital Discharge: A Protocol to Improve Patient Safety, Reduce Costs, and Boost Patient Satisfaction." *American Journal of Medical Quality* 24(4): 344–46.

Clarke, A., P. Rowe and N. Black. 1996. "Does a Shorter Length of Hospital Stay Affect the Outcome and Costs of Hysterectomy in Southern England?" *Journal of Epidemiology and Community Health* 50(5): 545–50.

Clements, A., K. Halton, N. Graves, A. Pettitt, A. Morton, D. Looke et al. 2008. "Overcrowding and Understaffing in Modern Health-Care Systems: Key Determinants in Methicillin-Resistant *Staphylococcus aureus* Transmission." *Lancet Infectious Diseases* 8(7): 427–34.

Crawford, M.J., D. Rutter, C. Manley, T. Weaver, K. Bhui, N. Fulop et al. 2002. "Systematic Review of Involving Patients in the Planning and Development of Health Care." *BMJ* 325(7375): 1263–68.

Davidoff, F. and P. Batalden. 2005. "Toward Stronger Evidence on Quality Improvement. Draft Publication Guidelines: The Beginning of a Consensus Project." *BMJ Quality & Safety in Health Care* 14(5): 319–325.

Davidoff, F., P. Batalden, D. Stevens, G. Ogrinc and S. Mooney. 2008. "Publication Guidelines for Quality Improvement in Health Care: Evolution of the SQUIRE Project." *BMJ Quality & Safety in Health Care* 17: i3–i9.

Dickersin, K. 1990. "The Existence of Publication Bias and Risk Factors for Its Occurrence." *Journal of the American Medical Association* 263(10): 1385–89.

Donabedian, A. 1988. "The Quality of Care: How Can It Be Assessed?" *Journal of the American Medical Association* 260(12): 1743–48.

Fatovich, D.M., Y. Nagree and P. Sprivulis. 2005. "Access Block Causes Emergency Department Overcrowding and Ambulance Diversion in Perth, Western Australia." *Emergency Medicine Journal* 22(5): 351–54.

Greenwald, J.L., C.R. Denham and B.W. Jack. 2007. "The Hospital Discharge: A Review of a High Risk Care Transition with Highlights of a Reengineered Discharge Process." *Journal of Patient Safety* 3(2): 97–106.

Groene, O. 2011. "Does Quality Improvement Face a Legitimacy Crisis? Poor Quality Studies, Small Effects." *Journal of Health Services Research & Policy* 16(3): 131–32.

Li, C., L.E. Ferri, D.S. Mulder, A. Ncuti, A. Neville, L. Lee et al. 2012. "An Enhanced Recovery Pathway Decreases Duration of Stay after Esophagectomy." *Surgery* 152(4): 606–14.

Ospina, M.B., K. Bond, M. Schull, G. Innes, S. Blitz and B.H. Rowe. 2007. "Key Indicators of Overcrowding in Canadian Emergency Departments: A Delphi Study." *Canadian Journal of Emergency Medicine* 9(5): 339–46.

Rodi, S.W., M.V. Grau and C.M. Orsini. 2006. "Evaluation of a Fast Track Unit: Alignment of Resources and Demand Results in Improved Satisfaction and Decreased Length of Stay for Emergency Department Patients." *Quality Management in Health Care* 15(3): 163–70.

Ross, J.S., S. Sheth and H.M. Krumholz. 2010. "State-Sponsored Public Reporting of Hospital Quality: Results Are Hard to Find and Lack Uniformity." *Health Affairs* 29(12): 2317–22.

Shojania, K.G. and J.M. Grimshaw. 2005. "Evidence-Based Quality Improvement: The State of the Science." *Health Affairs* 24(1): 138–50.

Virtanen, M., K. Terho, T. Oksanen, T. Kurvinen, J. Pentti, M. Routamaa et al. 2011. "Patients with Infectious Diseases, Overcrowding, and Health in Hospital Staff." *Archives of Internal Medicine* 171(14): 1296–98.

Walters, M., C. Blanton, D. Wilson and J. Young. 2007. "Criteria Led Discharge (CLD): A Pilot Study Initiative to Reduce Average Length of Stay (ALOS) for Elective Cardiac Procedure Patients." *Heart, Lung, and Circulation* 16: S181–S182.

Welch, S.J. 2010. "Twenty Years of Patient Satisfaction Research Applied to the Emergency Department: A Qualitative Review." *American Journal of Medical Quality* 25(1): 64–72.

Yergens, D.W., W.A. Ghali, P.D. Faris, H. Quan, R.J. Jolley and C.J. Doig. 2015. "Assessing the association between occupancy and outcome in critically Ill hospitalized patients with sepsis." *BMC Emergency Medicine* 15: 31.

Policy is always in the making. This journal is designed to serve readers from diverse backgrounds including health system managers, practitioners, politicians and their administrators, educators and academics. Our authors come from a broad range of disciplines including social sciences, humanities, ethics, law, management sciences and knowledge translation. They want good policy – a foundation for best practices.

www.healthcarepolicy.net