

HEALTHCARE

POLICY

Politiques de Santé

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

Volume 18 + Number 4

Value-Based Healthcare: Is It Just Another Buzzword?

FIONA CLEMENT

**Bilateral Federalism, Value-Based Healthcare and the Future of
Canadian Intergovernmental Diplomacy on Health**

TOM MCINTOSH

**Innovating for Value-Based Surgical Care in Canada:
A Post-Pandemic Necessity**

ALANA M. FLEXMAN, JANNY KE AND JULIE HALLET

**Value in Primary Care: Evidence from the Canadian Primary Care
Sentinel Surveillance Network**

SABRINA T. WONG, RACHAEL MORKEM, AYAT SALMAN, DAVID BARBER AND
JEROME A. LEIS

Data Matters + Discussion and Debate + Research Papers

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

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

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

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.


FROM THE EDITOR-IN-CHIEF



- 8 A Problem of Money and Health: The Need for Value in Healthcare
JASON M. SUTHERLAND

PERSPECTIVES ON VALUE IN HEALTHCARE


- 18 Value-Based Healthcare: Is It Just Another Buzzword?
FIONA CLEMENT
- 26  Bilateral Federalism, Value-Based Healthcare and the Future of Canadian
Intergovernmental Diplomacy on Health
TOM McINTOSH
- 43  Innovating for Value-Based Surgical Care in Canada: A Post-Pandemic Necessity
ALANA M. FLEXMAN, JANNY KE AND JULIE HALLET

RESEARCH PAPERS

- 57  Value in Primary Care: Evidence from the Canadian Primary Care Sentinel
Surveillance Network
SABRINA T. WONG, RACHAEL MORKEM, AYAT SALMAN, DAVID BARBER AND
JEROME A. LEIS
- 72  Use of Electronic Medical Record Data to Create a Dashboard on Access to Primary Care
MYLAINE BRETON, ISABELLE GABOURY, FRANÇOIS BORDELEAU, CATHERINE
LAMOUREUX-LAMARCHE, ÉLISABETH MARTIN, VÉRONIQUE DESLAURIERS AND
JEAN-BENOÎT DEVILLE-STOETZEL
- 89  Patients Living with Social Vulnerabilities Experience Reduced Access at Team-Based
Primary Healthcare Clinics
NADIA DEVILLE-STOETZEL, ISABELLE GABOURY, JEANNIE HAGGERTY AND
MYLAINE BRETON

- 106  "A Band-Aid Solution": Policy Maker and Primary Care Provider Perspectives on the Value of Attachment Incentives
EMILY GARD MARSHALL, MACKENZIE COOK, LAUREN MORITZ, RICHARD BUOTE,
MARIA MATHEWS AND MYLAINE BRETON
- 120  A North Star Vision: Results from a Deliberative Dialogue to Identify Policy Strategies to Improve Value in Healthcare
AMITY E. QUINN, RACHELLE DRUMMOND, FIONA CLEMENT, MELANIE COLUMBUS,
STEPHANA J. MOSS, EMILY FITZGERALD, RUKHSAAR DAYA, KARLA KREWULAK,
LIZA MASTIKHINA, JEANNA PARSONS LEIGH AND HENRY T. STELFOX

DISCUSSION AND DEBATE



- 134  Psychedelics to Relieve Psychological Suffering Associated with a Life-Threatening Diagnosis: Time for a Canadian Policy Discussion
SARAH KRATINA, CHRISTOPHER LO, CAROL STRIKE, ROBERT SCHWARTZ AND
BRIAN RUSH
- 143 Commentary: Access to Psychedelics for Psychological Suffering at the End of Life – Prioritizing Our Priorities
DANIEL ROSENBAUM, SARAH HALES AND DANIEL Z. BUCHMAN

 Peer Reviewed




DU RÉDACTEUR EN CHEF



- 13 Un problème d'argent et de santé : le besoin de valeur dans les soins de santé
JASON M. SUTHERLAND

PERSPECTIVES SUR LA VALEUR DES SOINS DE SANTÉ


- 18 Soins de santé axés sur la valeur : est-ce juste un nouveau mot à la mode?
FIONA CLEMENT
- 26  Le fédéralisme bilatéral, les soins de santé axés sur la valeur et l'avenir de la diplomatie
intergouvernementale canadienne en matière de santé
TOM McINTOSH
- 43  Innover pour des soins chirurgicaux axés sur la valeur au Canada : une nécessité
post-pandémique
ALANA M. FLEXMAN, JANNY KE ET JULIE HALLET

RAPPORTS DE RECHERCHE

- 57  Valeur des soins primaires : les données probantes du Réseau canadien de surveillance
sentinelle en soins primaires
SABRINA T. WONG, RACHAEL MORKEM, AYAT SALMAN, DAVID BARBER ET
JEROME A. LEIS
- 72  Utilisation des données du dossier médical électronique pour créer un tableau de bord
sur l'accès aux soins primaires
MYLAINE BRETON, ISABELLE GABOURY, FRANÇOIS BORDELEAU, CATHERINE
LAMOUREUX-LAMARCHE, ÉLISABETH MARTIN, VÉRONIQUE DESLAURIERS ET
JEAN-BENOÎT DEVILLE-STOETZEL
- 89  Expérience d'accès réduit aux équipes cliniques de première ligne chez les personnes
aux prises avec des vulnérabilités sociales
NADIA DEVILLE-STOETZEL, ISABELLE GABOURY, JEANNIE HAGGERTY ET
MYLAINE BRETON

- 106  « Une solution de fortune » : points de vue des décideurs et des fournisseurs de soins primaires sur la valeur des incitations à l'adhésion
EMILY GARD MARSHALL, MACKENZIE COOK, LAUREN MORITZ, RICHARD BUOTE, MARIA MATHEWS ET MYLAINE BRETON
- 120  Vision à long terme : résultats d'un dialogue délibératif visant à identifier des stratégies politiques pour améliorer la valeur des soins de santé
AMITY E. QUINN, RACHELLE DRUMMOND, FIONA CLEMENT, MELANIE COLUMBUS, STEPHANA J. MOSS, EMILY FITZGERALD, RUKHSAAR DAYA, KARLA KREWULAK, LIZA MASTIKHINA, JEANNA PARSONS LEIGH ET HENRY T. STELFOX

DISCUSSION ET DÉBAT

- 134  Thérapie psychédélique pour soulager la souffrance psychologique associée à un diagnostic menaçant la vie : discussion en cours sur les politiques canadiennes
SARAH KRATINA, CHRISTOPHER LO, CAROL STRIKE, ROBERT SCHWARTZ ET BRIAN RUSH
- 143 **Commentaire : Accès aux thérapies psychédéliques pour soulager la souffrance psychologique en fin de vie – mettre de l'ordre dans nos priorités**
DANIEL ROSENBAUM, SARAH HALES ET DANIEL Z. BUCHMAN



Examen par les pairs

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A Problem of Money and Health: The Need for Value in Healthcare

ALMOST TEN YEARS AGO, ON JUNE 5, 2013, JEFFREY SIMPSON OF *THE GLOBE AND MAIL* wrote that more money was not the answer to reducing wait times for elective surgery (Simpson 2013). The editorial's text described the billions that had been spent by provinces through the federal Wait Times Reduction Fund to supply more surgeries and that meaningful progress on surgical wait times was still lacking.

Simpson (2013) opined that the answer to wait times was not more money but to create wait-time guarantees for patients and to hold governments and healthcare organizations more accountable for patients' wait times. The editorial might as well have been written today – wait-time guarantees were not adopted by provinces and progress on surgical wait times continues to elude governments.

In my opinion, provinces and regional health authorities have “moved on” from seemingly intractable problems such as waitlists or crowded emergency rooms and shifted the discussion elsewhere. Now, the discourse from provincial governments and their health systems is on improving “value” from spending on healthcare services, therapies and products.

But, what does it mean to improve the value of a province's spending?

The federal government and the provinces' ministries of health have not established a common definition of value. Simple interpretations define value as patients' gain or maintenance of health relative to the amount spent to achieve the outcome. More thoughtful interpretations of value incorporate multiple dimensions of patients' lives known to be associated with health and well-being, such as patients' and families' preferences, their wealth and their race (Sutherland 2019; Wodchis 2019).

Improving value is made more complex by significant gaps in the data. It is well known that provinces have neither begun the systemic collection of costs across all sectors of care, nor do they collect patients' health or well-being outcomes in order to reasonably and transparently measure value.

Canadian scholars have stepped up and have been tackling the issue of how to improve value from a province's spending on healthcare. They have proposed a number of options, including implementing incentives and regulations for cross-sector care (Wodchis 2019; Hellsten and Dhalla 2019), adopting measures of quality-of-life years into decision making (Melberg 2019) and reforming physician payment models (Strumpf 2020).

Several months ago, *Healthcare Policy* held an open call for manuscripts centred on improving value from healthcare. This issue is the result – the articles describe current efforts, successes and failures to improve value from healthcare.

But this is not the end of the story, and there is much work to be done.

In This Issue

This issue's lead commentary provides a strategic road map for provinces in their pursuit of improving value. The author, Fiona Clement, first highlights the discordance between the spending priorities of ministries of health and their stated goal of maximizing the health of their populations (Clement 2023). The commentary argues that new streams of cost and outcome data are needed to create a body of evidence for decision makers. The text then posits that health system leaders and governments need to be accountable for their spending, programs and patients' health outcomes – an element that is lacking in the current structures of healthcare delivery (Clement 2023).

A second commentary authored by Tom McIntosh tackles the complex interplay between the federal government and the provincial governments regarding funding for healthcare (McIntosh 2023). The commentary leads by describing how past federal funding accords failed to achieve the substantial delivery system reforms that they were intended to spur. More recent provincially tailored federal healthcare spending initiatives – referred to as bilateral federalism – are described in the commentary as possibly being more successful than the national health accords since they reflect differences in provinces' priorities and infrastructures. McIntosh (2023) then opines that federal–provincial bilateral agreements might be an approach to measuring value that transcends single provinces and leads to the expansion of health services beyond the *Canada Health Act* (1985). McIntosh (2023) follows the commentary up with an epilogue that offers insights into the new bilateral agreements between the federal government and the provinces. The epilogue explains that the new bilateral agreements will “split” federal funds between services guaranteed in the *Canada Health Act* (1985) and specific health reform priorities, accompanied by clearer parameters for transparency and accountability than the previous health accords.

A third commentary is focused on improving value through surgical services. Flexman et al. (2023) note that the COVID-19 pandemic has laid bare important limitations of surgical services. At the same time, the commentary describes a number of innovations introduced during the pandemic that have improved value from hospitals' surgical services, such as

virtual consultations and shorter lengths of stays. Flexman et al. (2023) conclude with several specific recommendations for surgical health policy, including approaches to improving equity and patient segmentation.

This issue's first research paper by Wong et al. (2023) describes trends in antibiotic prescribing for respiratory tract infections, making use of unique clinical data accessed through the Canadian Primary Care Sentinel Surveillance Network. The results suggest variability in prescribing rates attributable to rurality and material/social deprivation. The study highlights the value of networked clinical information to decrease potentially avoidable prescriptions.

A multi-method study is used by Breton et al. (2023) to study the feasibility and acceptability of creating and using a dashboard of primary healthcare-focused performance indicators. Using a systematic review, the authors identified eight indicators for their dashboard. Data extraction was then piloted from electronic medical record data to populate the dashboard for primary healthcare providers. The study concludes that dashboards are a viable approach to supporting quality improvement efforts in primary healthcare, though there are significant barriers to province-wide efforts to doing so.

The next research study is focused on measuring experiences of perceived access to team-based primary healthcare clinics. Deville-Stoetzel et al. (2023) use patient surveys linked with social vulnerability profile information to measure associations between perceived access to team-based primary healthcare clinics and social vulnerability. The study concluded that patients with high vulnerability experienced more difficulties related to receiving the health services that they needed at their clinic, healthcare continuity needs and interprofessional collaborations at their team-based clinics.

The value and effectiveness of financial incentives for attachment between primary care providers and patients were studied using a descriptive qualitative approach involving family physicians, nurse practitioners and policy makers in Nova Scotia. Marshall et al. (2023) report that financial incentives may provide short-term benefits but do not overcome system-wide barriers to accessing primary care providers. The authors provide a number of policy options for decision makers to support the furtherance of primary care practice models that support attachment with primary care.

The final research paper explores barriers and facilitators of evidence-informed health policy options to improve health system sustainability. Using a deliberative dialogue format that included citizens, policy researchers, government decision makers and health system leaders, Quinn et al. (2023) found support for community-based models of care, transparency in healthcare delivery and accountability in outcomes measurement and for community mobilization.

This issue presents a Discussion and Debate article focused on psychedelic therapies for the relief of psychological suffering among patients with life-threatening diagnoses. Kratina et al. (2023) report on system-level barriers to accessing psychedelics, including uncertain

processes of approval, inconsistencies in the scheduling system and precedents for psychedelic use. The authors conclude with a number of barriers that need to be addressed by federal and provincial policy makers in order for psychedelic therapies to become more accessible.

A rejoinder written by Rosenbaum et al. (2023) concurs that suffering at the end of life needs additional attention from health systems and policy makers and that psychedelic therapies are promising. However, the authors offer competing priorities: an evolving evidence base for psychedelics and inequitable access to early, high-quality palliative care. Rosenbaum et al. (2023) conclude that a more tempered approach to access to psychedelic therapies is warranted.

JASON M. SUTHERLAND, PHD

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A photograph of several lit green candles with orange flames, arranged in a row on a reflective surface. The candles are lit, and their flames are bright orange. The background is dark, and the surface they are on is highly reflective, showing clear reflections of the candles and their flames.

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Un problème d'argent et de santé : le besoin de valeur dans les soins de santé

IL Y A PRÈS DE DIX ANS, LE 5 JUIN 2013, JEFFREY SIMPSON DU *GLOBE AND MAIL* écrivait qu'injecter plus d'argent n'était pas la solution pour réduire les temps d'attente pour les chirurgies non urgentes (Simpson 2013). L'éditorial évoquait les milliards dépensés par les provinces, grâce au Fonds fédéral pour la réduction des temps d'attente, et signalait le manque d'amélioration sur les temps d'attente en chirurgie, lesquels faisaient toujours défaut.

Simpson (2013) était d'avis que la solution pour les temps d'attente ne venait pas avec plus d'argent, mais plutôt avec la mise en place de garanties pour les patients et avec la responsabilisation des gouvernements et des organisations de santé quant aux temps d'attente. Cet éditorial aurait pu être rédigé aujourd'hui – les provinces n'ont pas mis en place de garanties et les améliorations en matière de temps d'attente pour les chirurgies se font toujours attendre.

À mon avis, les provinces et les régies régionales de la santé sont « passées à autre chose », déplaçant la discussion ailleurs que sur des problèmes apparemment insolubles tels que les listes d'attente ou les salles d'urgence bondées. Maintenant, le discours des gouvernements provinciaux et des systèmes de santé porte sur l'amélioration de la « valeur » des dépenses pour les services, les thérapies et les produits de santé.

Mais, que veut-on dire par améliorer la valeur des dépenses d'une province?

Le gouvernement fédéral et les ministères provinciaux de la Santé n'ont pas établi de définition commune de la valeur. Elle peut se définir simplement comme un gain ou le maintien de la santé des patients par rapport au montant dépensé pour atteindre ce résultat. Mais une définition plus approfondie tient compte de plusieurs dimensions associées à la santé et au bien-être, telles que les préférences des patients et des familles, leur richesse ou leur race (Sutherland 2019; Wodchis 2019).

L'amélioration de la valeur se complexifie en raison de lacunes importantes en matière de données. Il est connu que les provinces n'ont pas amorcé la collecte systématique des coûts

dans tous les secteurs de soins, pas plus qu'elles ne recueillent les résultats en matière de santé ou de bien-être des patients afin de mesurer la valeur de manière raisonnable et transparente.

Les chercheurs canadiens cherchent de plus en plus à comprendre comment améliorer la valeur des dépenses de santé d'une province. Ils ont proposé un certain nombre de pistes, notamment la mise en œuvre de mesures incitatives et de réglementations pour les soins intersectoriels (Wodchis 2019; Hellsten et Dhalla 2019), l'adoption de mesures des années de qualité de vie dans la prise de décision (Melberg 2019) et la réforme des modèles de rémunération des médecins (Strumpf 2020).

Il y a plusieurs mois, *Politiques de Santé* lançait un appel à manuscrits axé sur l'amélioration de la valeur dans les soins de santé. Le présent numéro en est le fruit – les textes décrivent les efforts, les réussites et les échecs actuels en matière d'amélioration de la valeur dans les soins de santé.

Mais ce n'est pas la fin de l'histoire, il reste beaucoup de travail à faire.

Dans ce numéro

Le commentaire principal de ce numéro propose une feuille de route stratégique pour les provinces dans leur quête d'amélioration de la valeur. Son auteure, Fiona Clement, souligne d'abord la discordance entre les priorités de dépenses des ministères de la Santé et l'objectif de maximiser la santé des populations (Clement 2023). Le commentaire soutient que de nouveaux flux de données sur les coûts et les résultats seront nécessaires pour créer un ensemble de données probantes à l'intention des décideurs. Le texte postule ensuite que les dirigeants du système de santé et les gouvernements doivent être responsables des dépenses, des programmes et des résultats pour les patients – un élément qui fait défaut dans les structures actuelles de prestation des soins de santé (Clement 2023).

Un deuxième commentaire, rédigé par Tom McIntosh, aborde l'interaction complexe entre le gouvernement fédéral et les gouvernements provinciaux concernant le financement des soins de santé (McIntosh 2023). Le commentaire commence en décrivant comment les accords de financement fédéraux n'ont pas abouti aux réformes substantielles qu'ils étaient censés stimuler. Des initiatives fédérales plus récentes en matière de dépenses de santé adaptées aux provinces – désignées comme fédéralisme bilatéral – sont décrites dans le commentaire comme étant peut-être plus efficaces que les accords nationaux sur la santé, car elles reflètent les différences dans les priorités et les infrastructures des provinces. McIntosh (2023) est d'avis que les ententes bilatérales fédérales-provinciales pourraient être une façon de mesurer la valeur qui transcende les provinces et pourraient mener à l'expansion des services de santé au-delà de la *Loi canadienne sur la santé* (1985). McIntosh (2023) termine avec un épilogue qui donne un aperçu des nouveaux accords bilatéraux entre le gouvernement fédéral et les provinces. L'épilogue explique que ces accords « sépareront » les fonds fédéraux entre, d'une part, les services garantis par la *Loi canadienne sur la santé* (1985) et, d'autre part, les priorités des réformes de la santé, accompagnées de paramètres de transparence et de responsabilité plus clairs que dans les accords précédents.

Un troisième commentaire porte sur l'amélioration de la valeur grâce aux services chirurgicaux. Flexman et al. (2023) notent que la pandémie de COVID-19 a fait voir d'importantes limites dans les services chirurgicaux. En parallèle, le commentaire décrit un certain nombre d'innovations introduites pendant la pandémie qui ont amélioré la valeur des services chirurgicaux des hôpitaux, telles que les consultations virtuelles et les durées de séjour plus courtes. Flexman et al. (2023) concluent avec plusieurs recommandations pour les politiques chirurgicales, notamment des façons d'améliorer l'équité et la catégorisation des patients.

Le premier article de recherche du présent numéro, par Wong et al. (2023), décrit les tendances en matière de prescription d'antibiotiques pour les infections des voies respiratoires, en utilisant des données cliniques accessibles par le biais du Réseau canadien de surveillance sentinelle en soins primaires. Les résultats font voir une variabilité des taux de prescription attribuable à la ruralité et à la défavorisation matérielle ou sociale. L'étude met en évidence la valeur des informations cliniques en réseau pour réduire les prescriptions potentiellement évitables.

Breton et al. (2023) ont recours à une étude multi-méthodes pour examiner la faisabilité et l'acceptabilité de la création d'un tableau de bord d'indicateurs de performance axés sur les soins de santé primaires. À l'aide d'une revue systématique, les auteurs ont identifié huit indicateurs pour leur tableau de bord. L'extraction de données a ensuite été pilotée à partir des données des dossiers médicaux électroniques pour remplir le tableau de bord des prestataires de soins primaires. L'étude conclut que les tableaux de bord constituent une approche viable pour soutenir les efforts d'amélioration de la qualité dans les soins de santé primaires, bien qu'il existe des obstacles importants à l'échelle provinciale.

L'étude de recherche suivante se concentre sur la perception de l'accès aux équipes cliniques de première ligne. Deville-Stoetzel et al. (2023) ont recours à des sondages qu'ils lient aux profils de vulnérabilité sociale afin de mesurer l'association entre la perception de l'accès aux équipes cliniques et la vulnérabilité sociale. L'étude conclut que les patients ayant une vulnérabilité élevée éprouvent plus de difficultés liées à l'obtention des services de santé nécessaires, à la continuité des soins et aux collaborations interprofessionnelles dans leur équipe clinique.

La valeur et l'efficacité des incitatifs financiers à l'adhésion entre les fournisseurs de soins primaires et les patients ont été étudiées à l'aide d'une approche qualitative descriptive réunissant des médecins de famille, des infirmières praticiennes et des décideurs de la Nouvelle-Écosse. Marshall et al. (2023) signalent que les incitatifs financiers peuvent offrir des avantages à court terme, mais ne permettent pas de surmonter les obstacles systémiques à l'accès aux fournisseurs de soins primaires. Les auteurs proposent aux décideurs un certain nombre d'options politiques pour l'avancement de modèles de pratique des soins primaires qui favorisent l'adhésion.

Le dernier document de recherche du présent numéro explore les obstacles et les facilitateurs pour des choix de politiques fondées sur les données probantes dans le but d'améliorer la durabilité du système de santé. À l'aide d'un dialogue délibératif qui regroupait des

citoyens, des chercheurs, des décideurs gouvernementaux et des dirigeants du système de santé, Quinn et al. (2023) ont dégagé des éléments pour appuyer les modèles de soins communautaires, la transparence dans la prestation des soins de santé et la responsabilité dans la mesure des résultats et la mobilisation communautaire.

La section « Discussion et débat » présente un article axé sur les thérapies psychédéliques pour le soulagement de la souffrance psychologique chez les patients présentant un diagnostic menaçant leur vie. Kratina et al. (2023) font état des obstacles à l'accès aux psychédéliques, notamment des processus d'approbation incertains, des incohérences dans le système de classification et les précédents en matière d'utilisation des psychédéliques. Les auteurs concluent en énumérant un certain nombre d'obstacles que devront surmonter les décideurs fédéraux et provinciaux pour rendre plus accessibles les thérapies psychédéliques.

Dans une réplique à cet article, Rosenbaum et al. (2023) conviennent que la souffrance en fin de vie nécessite une attention supplémentaire de la part des systèmes de santé et des responsables de politiques et sont d'avis que les thérapies psychédéliques sont prometteuses. Cependant, les auteurs proposent des priorités concurrentes : une base de données dynamique pour les psychédéliques et un accès inéquitable à des soins palliatifs précoces de haute qualité. Rosenbaum et al. (2023) concluent qu'une approche plus tempérée de l'accès aux thérapies psychédéliques est justifiée.

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Rédacteur en chef

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Value-Based Healthcare: Is It Just Another Buzzword?

Soins de santé axés sur la valeur : est-ce juste un nouveau mot à la mode?

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Abstract

The concept of value-based healthcare has been gaining traction, with several issues of *Healthcare Policy* discussing the agenda and highlighting pockets of excellence. However, we currently have no shared common goal that would define value-based healthcare. Furthermore, we have major limitations in measuring both the cost and benefit components of the concept of value, irrespective of the definition. It is time to make progress, which will include a recognition of the need to engage the public in a discussion around the values of the Canadian healthcare system and the federal government taking a hands-on role for the accountability of value as an outcome.

Résumé

Le concept de soins de santé axés sur la valeur gagne du terrain. En effet, plusieurs numéros de *Politiques de Santé* abordent la question et en soulignent les regroupements d'excellence. Cependant, il n'y a actuellement aucun objectif commun pour définir en quoi consistent des soins de santé axés sur la valeur. De plus, il y a d'importantes limites quant à la mesure des coûts et bénéfices associés au concept de valeur, et ce, indépendamment de la définition retenue. Il est temps de faire des progrès, et cela comprendra la reconnaissance du besoin d'engager le public dans une discussion sur les valeurs du système de santé canadien et sur le rôle du gouvernement fédéral pour tenir compte de la valeur en tant que résultat.

Introduction

Healthcare costs in Canada continue to rise. Healthcare spending reached \$265.5 billion in 2019 (CIHI 2020). As a share of gross domestic product (GDP), healthcare spending has increased from 5.2% in 1981 (IFSD 2019) to 11.5% in 2019 (CIHI 2020). In addition, healthcare now, on average, represents 37% of each provincial budget (CIHI 2020). The COVID-19 pandemic has accelerated spending growth; the long-term impact of this spending increase on healthcare costs' growth trajectory is unknown but is anticipated to be substantive (The Conference Board of Canada 2020).

Increased healthcare spending comes at the expense of other social spending and may not improve health. Calls to *bend the cost curve* are often motivated by concerns that healthcare spending will overtake governments' abilities to spend money on other social services (Marchildon and Di Matteo 2014). Other social services, such as education, are vital to our productivity and are also highly correlated with health outcomes (Conti et al. 2010; Dutton et al. 2018). In addition, a 2019 survey found that Canadians are worried about healthcare more than any other national issue (CMA 2019). In addition to being costly, the Canadian healthcare system is not producing leading outcomes when compared with other international systems. For example, the Canadian healthcare system ranks second to last overall among Organisation for Economic Co-operation and Development countries (OECD 2021). Notably, Canada also ranks second to last in equity, health outcomes and performance versus spending when compared with 12 selected peer countries, including the UK, France, Australia and the US (Schneider et al. 2021). This underscores the need to focus on value: What are we getting for the resources we invest in healthcare?

Value-based healthcare is gaining traction. There have been several issues published by *Healthcare Policy* that reflect on the agenda and highlight pockets of excellence. In this commentary, I reflect on the macro policy questions that I believe are hindering the widespread adoption of value-based healthcare. While the issues herein require substantial investment and time, I believe that a renewed focus on these issues is crucial at this moment in time to capitalize on the significant push for change amplified by the COVID-19 pandemic.

What Is the Goal?

To think strategically about achieving a goal within a specific budget, the goal needs to be clear. What are we trying to achieve with the resources being allocated? At times, the goal may be stated as to achieve the most health for a population. However, current care and policy conversations make it plain that this is not the goal. If we were simply pursuing the most health, we would not be paying for multiple procedures and treatments; instead, we would be investing heavily in the social determinants of health or, at the minimum, effective mental healthcare. The way we are currently allocating our budget demonstrates that we prioritize acute illness care over care that may maintain health.

The Triple Aim has also been put forward as aims that a healthcare system should pursue: improving the health of populations, reducing the per capita cost of healthcare and improving the patient experience of care (Berwick et al. 2008). It was initially developed as required aims that the US healthcare system should pursue to improve the system. The Triple Aim has been expanded to include the Quadruple Aim, which encompasses the provider experience, and, recently, the Quintuple Aim, which incorporates equity (Nundy et al. 2022; Sikka et al. 2015). There is no claim that this framework covers *every* goal of the US healthcare system or that this be the set of aims that *every* healthcare system should pursue, recognizing the different structures (and goals). Yet, the Triple Aim has gathered significant momentum (Ashton 2015; CMA 2010; Saskatchewan Ministry of Health 2012; Health Quality and Safety Commission New Zealand 2013; Tholl and Grimes 2012). It is worth noting, however, that there is substantial variation to and adaption of the concepts within the framework, presumably to respond to the local context and political needs (Mery et al. 2017). For example, in many places, *reducing the cost per capita* has been replaced with the language of *better value* (Mery et al. 2017). Even here, within a widely adopted framework, one only needs to ask the question, “What does this mean?” to realize that we have no shared understanding of the concepts underneath the (buzz) words. The concepts are poorly defined and despite this being set out as the goal of multiple healthcare systems, including several provincial healthcare systems here in Canada (CMA 2010; Saskatchewan Ministry of Health 2012; Tholl and Grimes 2012), the Triple Aim does not yet provide a clear goal against which resource-allocation decisions could be made.

Data

To achieve any marked improvement in value-based healthcare, data are required. As the old adage goes, “What gets measured gets done.” There is little hope for improving or integrating value-based approaches without data that can measure and report on value regularly. There are two aspects to value a measure of benefit and costs (Drummond et al. 2015); we need more accurate and consistent data for both. There have been substantial, and important, strides made in the data landscape in Canada. For example, the SPOR [Strategy for Patient-Oriented Research] Canadian Data Platform is an infrastructure that aims to support improved access to data, automation of data analysis and ongoing engagement with diverse citizens (Dahl et al. 2020). This has led to the Data Access Support Hub, which is a “one-stop” data access service portal for researchers (<https://www.hdrn.ca/en/dash>). While formal evaluation is still required, anecdotally, these initiatives have greatly improved access to data holdings across the country. However, improved access is only one piece of the requirement. To measure value, an investment in data gathering and infrastructure is required.

Microcosting, a methodological approach that uses direct enumeration and costing of every input consumed in the treatment of a particular patient, is regarded as the reference standard for costing (Gold et al. 1996). Yet, only two Canadian provinces (Alberta and

Ontario) routinely generate these data within a limited, mostly urban, geographical area (CADTH 2017). Everywhere else in Canada, gross costing approaches are used. Gross costing is a methodological approach that allocates a total budget to specific services, such as hospital stays, by grouping encounters with similar utilization profiles (Raftery 2000). At an individual level, this approach does not allow for variation. For example, one of the 522 gross cost groupers used in Canada (case-mix grouper code 193) captures myocardial infarction/shock/arrest with a coronary angiogram (CIHI n.d.). Thus, all encounters coded to this grouper code are assigned the same cost. One can imagine that some patient encounters may result in short hospital stays, whereas others may be long, complex encounters with significantly more intense resource use. The gross-costing methodology used by the majority of Canada, indeed globally, is unable to capture these individual patient differences. Without precise costing data, measuring and subsequently managing value is challenging.

Thinking about the benefit aspect, the issues are similar. The data regarding major clinical outcomes, such as death, strokes and heart attacks, are robust. However, if the benefit considered in the value equation includes patient-reported outcomes and patient experience, we need to measure consistently across the system using validated instruments. There are centres and specific hospitals across Canada that are routinely measuring patient-reported outcomes and doing it very well, but data are required at an expanded level across the healthcare system (Alberta PROMs and EQ-5D Research and Support Unit n.d.).

Thinking about Different Perspectives on Value

As we embark on a larger pursuit of value-based healthcare, we must remember that value is subjective. What represents value to one group of people may not match the perspective of another. For example, the Triple Aim as laid out above does not include the concept of equity (Berwick et al. 2008). Equity as one of the central goals of a healthcare system is a reflection of societal values. Furthermore, a quality-adjusted life-year commonly used in drug reimbursement recommendations is often measured using the EQ-5D scale, which includes the dimensions of self-care, mobility, usual activities, pain/discomfort and anxiety/depression (Bansback et al. 2012). It is easy to imagine people and communities who would not adopt this lens to measure the value of their healthcare. This underscores the importance of diverse public involvement and deliberate reflection about how we identify the “value” in value-based healthcare. There are multiple approaches and frameworks that have been developed to understand the different perspectives on values (Leneghan 1999; Mooney and Blackwell 2004); all of them start with listening to communities whom the system is intended to serve.

It has been several decades since the public has been engaged, in a meaningful way, in public discussion and deliberation about what the healthcare system should do. Within the Romanow Commission, citizens were brought together to participate in deliberative dialogue, a method where participants have the opportunity to work through conflicting values and difficult choices in order to reach judgments on an important issue (Maxwell et al.

2003). Participants were asked to consider four scenarios: (1) more public investment in doctors, nurses and equipment, either through tax increases or by reallocating funds from other government programs; (2) a form of private payment for healthcare that proposes a system of small copayments by users; (3) restructuring of healthcare to create a parallel private system; and (4) internal restructuring to reorganize service delivery whereby Canadians would sign up with a healthcare provider network. The results of these deliberations signified that the participants hoped – albeit said in different words – that the system could become a value-based healthcare system. Importantly, this work demonstrated that the public can meaningfully participate in these tough conversations, a point of contention at the time and, arguably, still today. A primary recommendation from the commission is that these dialogues be re-run regularly (Maxwell et al. 2003). Unfortunately, this has not occurred. Such a dialogue now is likely to provide important insight into what the goal of healthcare should be at this time of change. With this, resource decisions could be made to prioritize those goals that would help kick-start the system out of its state of stasis.

Accountability

Finally, for the pursuit of value-based healthcare to become a reality, the outcome of value in the healthcare system needs to be someone's accountability. At the moment, no one is responsible for achieving value, no matter how it is measured within the healthcare budget. There are healthcare executives who may be responsible for value within their organizations but not broadly across the system of care. Of course, there are also ministers of health – provincial, territorial and federal – who control budgets but have no clear responsibility for value. If no one is responsible, little will get done. Until the accountability loop is closed, we are unlikely to see major strides toward value-based healthcare systems.

The question of who *should* be accountable is one of much debate. The federal government holds the purse and sets the terms, while the provinces squarely own the operational responsibility for healthcare. The provinces have made it clear that they do not want the federal government “interfering” (University of Ottawa Law RPS Submitter et al. 2017). However, given how big a piece of the federal budget healthcare is and how important healthcare is to Canadians, it seems unreasonable to expect that the federal government would have no desire to shape healthcare by attaching strings to their funding. Demonstrated in the Health Accord of 2017, where a specified component of the funding within the Canada Health Transfer was earmarked for priorities that the federal government and provinces both wanted to advance (home care and mental healthcare) (Government of Canada 2017), the federal government and provinces can find common ground in the interest of Canadians. The federal government holds the provinces accountable to the principles within the *Canada Health Act* (1985), and at the end of the day, the federal government controls the most powerful tool available – money. If we are serious about value-based healthcare, the federal government must take a hands-on role for the accountability of it as an outcome.

Conclusion

The COVID-19 pandemic has proven to us that many of the barriers to change are artificial, and when the desire for change is aligned across the system, the Canadian healthcare policy environment and healthcare system can change rapidly. For example, the COVID-19 pandemic has facilitated the implementation of stalled or slow-moving policy agendas; the provision of virtual care was implemented rapidly (Webster 2020), data were embedded to support rapid decision making (Neil-Sztramko et al. 2021) and specialist advice services were rapidly implemented to support care (Wake et al. 2020). Each of these changes was implemented within weeks despite multiple pre-pandemic implementation attempts that were bogged down by complex policy landscapes, structures and politics. This implies that the state of stasis of Canadian healthcare is self-imposed. Let us get on with it.

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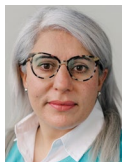


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Bilateral Federalism, Value-Based Healthcare and the Future of Canadian Intergovernmental Diplomacy on Health

Le fédéralisme bilatéral, les soins de santé axés sur la
valeur et l'avenir de la diplomatie intergouvernementale
canadienne en matière de santé



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Abstract

The COVID-19 pandemic has laid bare some profound challenges facing the preservation of Canada's single-payer, publicly administered healthcare system. At the same time, it may have presented an opportunity to take bold action on system reform. Part of that opportunity may lie in linking recent developments in intergovernmental diplomacy (termed bilateral federalism) with the growing emphasis on value-based healthcare initiatives coming out of some of the provinces. Bilateralism may be a means to steer reform efforts toward a value-based healthcare system that can articulate pan-Canadian values while accommodating provincial asymmetry in a highly decentralized federation like Canada.

Résumé

La pandémie de COVID-19 a mis au jour de sérieux défis pour la préservation du système de santé public à payeur unique du Canada. En parallèle, cela présente peut-être l'occasion de prendre des mesures audacieuses de réforme. Une partie de cette opportunité réside peut-être dans le lien entre, d'une part, les développements récents de la diplomatie

intergouvernementale (appelée fédéralisme bilatéral) et, d'autre part, l'accent mis sur les initiatives de services de santé axés sur la valeur qui émanent de certaines provinces. Le bilatéralisme peut être un moyen d'orienter les efforts de réforme vers un système de santé fondé sur des valeurs qui sait articuler les valeurs pancanadiennes tout en tenant compte de l'asymétrie provinciale dans une fédération hautement décentralisée comme le Canada.

Introduction

By many popular accounts, the Canadian healthcare system is in crisis. Despite well over a decade of increased spending (and regular significant increases in federal transfers) (McIntosh 2021a), the two-plus years of fighting the COVID-19 pandemic has stretched the system to what some feel is its breaking point (Picard 2022).

From one angle, this may be a recipe for despair and resignation that Canada's most cherished social program may not survive to see its 60th anniversary. However, from a different angle, the current state of affairs is also an opportunity to rethink, refinance, restructure and recommit to both the values that created Canada's medicare system and the value that medicare provides to Canada and Canadians. There are processes at work in the political arena (the emergence of a new kind of *bilateral federalism* [McIntosh and DeCorby 2022]), as well as in the health policy world (the increasingly influential debates around "value-based healthcare" [cf. EXPH 2019: 1]) that could, if brought together, provide a means for instituting the reforms that have been called for repeatedly in the past two decades.

The Rise of Bilateral Federalism

Since 2017, the Canadian government has taken what appears to be a new approach to social and health policy renewal that can be described as bilateral federalism. The approach looks manifestly different from the co-operative federalism that built the post-war welfare state (Banting 1987; Hueglin 2021) but also bears some similarity to the bilateralism that Marchildon (2016) noted was used by the federal government to prepare the ground for the larger pan-Canadian cornerstones of medicare – namely, the *Hospital Insurance and Diagnostic Services Act (HIDSA)* (1957) and the *Medical Care Act (MCA)* (1966) (Government of Canada 2019a). It was through bilateral health transfer agreements (HTAs) throughout the late 1940s and the 1950s that the federal government had funded:

... hospital construction, public health, mental health, cancer control, public health services and research, professional training and sexual disease control In 1949, grants for provincial health surveys were added in order to: (1) ensure the effective use of other health grants; (2) plan the extension of hospital utilization; and (3), most significantly, "*plan the proper organization of hospital and medical care insurance*" (Marchildon 2016: 5, quoting Taylor 1978: 163–64).

This can, perhaps, be characterized as bilateralism in service of pan-Canadianism. The bilateral agreements were necessary to get each province to the place where they had the infrastructure and capacity to fully participate in pan-Canadian projects such as the *HIDSA* and the *MCA*. Befitting a prime minister like William Lyon Mackenzie King, bilateral agreements were a policy instrument needed to achieve a goal rather than a reflection of a particular stance toward or approach to both federalism and intergovernmental relations.

In the early 2000s, bilateral agreements again became a feature of the healthcare landscape when they were used to allocate the funding provided in a series of earmarked federal transfers and contribution agreements relating to health reform, wait times, health human resources and internationally educated health professionals (Marchildon 2016: 7–8). Writing about the Primary Health Care Transition Fund of 2000, Marchildon (2016) noted that the bilateral agreements relating to the fund were “tailored to fit the primary care reform priorities, timelines and goals, as well as administrative capacities of the individual jurisdiction” (p. 7). This characterization is interesting because it may well mark the beginning of seeing bilateral HTAs less instrumentally and more as a way of conducting intergovernmental diplomacy.¹

What is true of the pan-Canadian health accords of the early 2000s, and especially true of the 2004 Health Accord (Health Canada 2004) that was touted as “a fix for a generation” (Andreatta 2013), is that they fundamentally failed to buy much in the way of substantive reform despite their price tag. Nor had they ended debates about the size of the transfer (Beland and Tombe 2021; McIntosh 2021a; McIntosh and DeCorby 2022; Ogilvie and Eggleton 2012). It is also the case that the assessments made of the 2004 Health Accord were based on the commitments made in the accord itself, not any bilateral agreement that stemmed from them.

In the years that followed, the Harper government had little interest in intergovernmental diplomacy around health or healthcare reform. It was content to abide by the 6.5% per year increase in the transfer set out in the 2004 Health Accord and indeed extended it until 2017. With that extension came an announcement that after 2017, the transfer would increase by a three-year rolling average of the increase in the GDP or by 3%, whichever was greater. Upon taking office in 2015, the Liberal government of Justin Trudeau initially announced it would stick with the Harper funding arrangement (McIntosh 2021b).

At the same time, there were new and emerging challenges for the system (Advisory Panel on Healthcare Innovation 2015; Forest and Martin 2018). This led to a substantive change of tack by the federal government when the 2004 Health Accord came up for renewal in 2017. The federal government proposed a solution to the impasse over provincial demands for unconditional increases to the transfer and the federal desire to push particular reforms. The Canada Health Transfer (CHT) would increase by 3.5% per year but there would be an additional \$11.5 billion under an umbrella Common Statement of Principles on Shared Health Priorities that targeted improved mental health and community-based care in the provinces (Marchildon 2016). In order to access their share of the \$11.5 billion, each province

would be asked to sign a bilateral agreement specifying where and how the money would be spent.²

What differentiated the process stemming from the 2017 agreements was that it was the bilateral agreements that were the story, not the pan-Canadian umbrella statement. For almost two decades, the story had been “pan-Canadian accords” to fund healthcare, even longer if one wants to include the negotiation with the provinces over the tax point transfer as part of the federal government’s *Federal-Provincial Fiscal Arrangements and Established Programs Financing Regulations*, 1977 commonly referred to as the EPF. Indeed, we tend to tell the story of medicare in terms of legislation and agreements meant to create a sense of a single national system – from *HIDSA* to the *MCA* to the *Canada Health Act (CHA)* (1985); from cost-sharing agreements to the EPF and the Canada Assistance Plan to the Canada Health and Social Transfer (CHST) to the CHT and the Canada Social Transfer (CST). We do this despite knowing that the reality is 14 moderately coordinated systems covering mostly the same services but organizing and delivering those services quite differently from province to province.

And this might have been simply a tactical move on the part of the federal government, a case of divide and conquer. Despite the attempts of the provinces to present a united front to Ottawa (especially since the creation of the Council of the Federation [COF]), it is readily apparent that provinces have different interests, different fiscal capacities and challenges and different approaches to health policy. In 2021–22, federal transfers amounted to \$1,500 per capita in Newfoundland, Ontario, Saskatchewan, Alberta and British Columbia but over \$4,400 per capita in New Brunswick and Prince Edward Island (Government of Canada 2022). Negotiating one on one with each province may have been designed to break provincial solidarity. Each time a province signed an agreement, the remaining provinces would be faced with the inevitable question from both the public and the media: “Why are you not getting our province’s share of federal funding?”

However, even if this was simply a tactical move – the best means to get agreements – its impact and its import can be seen to be qualitatively different from the bilateral agreements that came before. By making the bilateral agreements the centrepiece of the process rather than a by-product of the process, it necessarily heightens the import of the specifics of those accords.

Furthermore, an approach that puts the bilateral agreements at the centre of intergovernmental diplomacy can change the very dynamics of that diplomacy and may serve to lessen the tension between those who want a key social program such as healthcare to be seen in pan-Canadian terms, and those who seek to protect and preserve jurisdictional autonomy. It can be a federalism premised on both the symmetry of underlying pan-Canadian values (e.g., the desire for an accessible, universal public healthcare system across the country) and the asymmetry of provincial policy design and program implementation at the coalface of service delivery.

It is this tension between the symmetry of broad policy goals and asymmetry of policy design and implementation that bilateral federalism can seek to accommodate and work within. By creating a process that recognizes both shared high-level goals and individual paths toward those goals, it may actually strengthen the pan-Canadian elements of our social citizenship. And it is fair to say that both the 2017 healthcare agreements and the more recent agreements on child care may be nascent examples of a new kind of intergovernmental diplomacy that is rooted in bilateralism.

The 2017 bilateral agreements vary considerably in terms of their specificity as to the allocation of the funding, and, perhaps most tellingly, they contain no commitment to report on the progress of realizing the commitments to their respective provincial publics (a feature they share with previous bilateral HTAs). While not wanting to downplay those problems, the bilateral agreements should still be seen as a significant improvement over the agreements of the early 2000s that placed a pan-Canadian grand bargain-style accord as the centrepiece. They speak to shared pan-Canadian priorities but recognize a province's right to tackle those priorities with its own policy and programmatic responses.

By noting the areas and programs the provinces committed to adopt, expand or improve, the provinces were, in effect, putting their own conditions on this new money. And they were accepting the need to change the system, not just sustain it.

If bilateralism is to take hold as a viable form of intergovernmental diplomacy, a means to both recognize the realities of asymmetries in the federation while affirming pan-Canadian values, it will need to yield future agreements with greater levels of specificity over where the money is being spent, clearer goals over what will be achieved, better metrics to measure outcomes and, finally, fulsome and accessible reporting to provincial publics. No one should delude themselves into thinking that this is not a tall order.

There is, of course, a legitimate question to be asked as to whether policy and programmatic asymmetries may themselves challenge pan-Canadian goals of equity in access to healthcare. However, if outcomes are rigorously tracked and measured, then they need not. There is no single way to design a high-quality, accessible long-term care system or pharmacare program. If two different (or 10 different) models produce comparable improvements in health, at comparable cost and with comparable levels of public/patient satisfaction, then what would be the rationale to insist on one model over another? And if there are significant variations in quality, cost or outcomes, then those too would become apparent and create the political pressure to adopt best (or at least better) practices from other jurisdictions.³

Indeed, it seems more likely that rather than 10 increasingly divergent systems, Canada would see a coalescing around a small number of models based on political preferences for particular local trade-offs. Quebec's drug plan is designed around the presence of a significant pharmaceutical industry in the province that is economically important to the province even if the program itself may be more costly than other options. That is not a trade-off Saskatchewan needs to make when designing drug policy, and so, it may choose a different

route. Assuming that both provinces can meet the pharmaceutical needs of their residents with programs – the cost of which they are willing to bear – pan-Canadianism is not threatened.

Value-Based Healthcare in Canada

However, if bilateral federalism is going to drive intergovernmental diplomacy in the coming years, then it will need a stronger motivating framework than just simply acknowledging and accommodating asymmetries in the design of public policy in the provinces. It will need a framework that can encompass those asymmetries within a set of clearly articulated and measurable pan-Canadian values.

It may be possible to bring the debates over “value-based healthcare” (cf. EXPH 2019: 2; Smith et al. 2020) to bear on Canada’s emerging model of bilateral federalism to move the political conversation on healthcare reform into a more productive form. At first blush, and perhaps especially to the non-health economist, the phrase *value in healthcare* may conjure up economic discussions of cost-benefit analyses aimed at reducing costs, enhancing competition and limiting consumption of care – a neo-liberal skill meant to disguise nefarious intentions to dismantle public healthcare systems. However, value-based healthcare encompasses both *value* as a financial consideration and *values* as non-monetary expressions of the kind of society in which we want to live.

Thus, the European Commission’s framework of a value-based healthcare system encompasses four kinds of value: “personal value” (it meets patient’s needs), “technical value” (it achieves the best outcomes with available resources), “allocative value” (resources are distributed equitably across the population) and “societal value” (it contributes to social solidarity and cohesion) (EXPH 2019: 5).

This kind of talk should not be unfamiliar to Canadians. Roy Romanow’s Commission on the Future of Health Care in Canada’s final report was titled *Building on Values* precisely because this was how Canadians saw their system; it is the embodiment of a range of different values (Romanow 2002). Making those links explicit and unpacking what those values mean and how they interact could move us (indeed might force us) to make the necessary changes to a system that is costing forever more and lagging in its ability to deliver (Sutherland 2019).

Four successive issues of *Healthcare Papers* published in 2019 and 2020 provide important lessons, cautions and prescriptions on how we might think about value-based healthcare in Canada. This sustained discussion begins with the admission that this is a difficult task to operationalize – it is “complex, multilayered and multidimensional” (Wodchis 2019: 12) and “has a high hype-to-system transformation ratio” (Duckett 2019: 15). Knowing how to conceptualize value-based healthcare means little if you can neither measure the value to patients and caregivers of different types (Gilmore et al. 2019; Kuluski and Guilcher 2019; Raveendran et al. 2019), nor the value of different medical technologies (Horne and Manion 2019), nor understand where the gaps in data exist (Wong et al. 2019).

Even seemingly successful local case studies aimed at improving the integration of care and value all speak to the complexity of the challenge (cf. Downey et al. 2020; Lewanczuk et al. 2020; Zwicker 2020), both in making the necessary changes to service delivery and organization and to scaling these changes. As Sutherland (2020a) stated, “there is a dearth of concurrent cost and outcome data that inhibit comparisons of provinces’ strategies for improving value” (p. 5). The lessons that emerge when moving back from the local to the national level are that the challenges remain immense in terms of the kind of collaboration and coordination needed at all levels inside the system (Strumpf 2020), the need to think about how overall determinants of health link to getting value in healthcare (Wodchis and Reid 2020) and, tellingly, the disconnect between the logics that motivate health policy researchers outside government and policy makers inside government (Forest 2020).

Bilateral Federalism and a Framework for Value-Based Healthcare

So far, value-based healthcare is not part of either the political conversation or the inter-governmental dynamics around healthcare reform in Canada; it is not about how either Canadians or Canadian leaders speak about healthcare. And for that reason, it is worth thinking about how one might use the ideas behind value-based healthcare to articulate a vision of the system’s future that can be linked to and perhaps drive forward the ongoing initiatives underway in different parts of the country. What follows then is an outline of how these ideas could be used to further the processes of bilateral federalism and, in turn, provide a framework for accelerating value-based health system change.

Let us start with some basic parameters around the nature of intergovernmental diplomacy in healthcare. First, we can say that, *de facto*, there may now be two health transfers. There is the CHT, which is essentially unconditional and is used for the overall operation of the healthcare system. Then, there is the transfer of money that is earmarked in some way for priorities agreed to by the parties (e.g., the \$11.5 billion given in 2017). The existence of two transfers may be important to providing a focal point to a value-based reform initiative precisely because they can be differentiated and put to different purposes.

Second, the once crucial distinction that the CHT was meant for the financing of physician and hospital services under the *CHA* and not for other health programming offered by the provinces no longer holds water. Both the provinces and the federal government, perhaps for different reasons, have an interest in focusing on the whole of the system in the diplomatic negotiations over health financing.⁴ Furthermore, if value-based healthcare is a goal, then the distinction between *CHA* services and non-*CHA* services only hinders the kind of integration that value-based healthcare works toward.

Third, provincial governments have to accomplish two if not contradictory then at least friction-laden things at once. They have to sustain and operate the system as it is while also working to transform the system into something better and more efficient with better outcomes and better managed costs. This is difficult, messy and complicated and likely means

that we are talking about various incremental changes over time that, if well managed and thought out, can accumulate into substantive change.

Finally, any commitment to value-based healthcare must respect the relative jurisdiction of each order of government and recognize the asymmetry within the federation. That recognition makes bilateral federalism a workable process for Canada, and it will need to be accommodated in a Canadian understanding of value-based healthcare. And to return to an earlier point, a value-based healthcare framework would be the very set of instruments that would keep bilateral federalism from spinning out 10 highly divergent, highly unequal healthcare systems in the provinces.

To date, the landscape of value-based healthcare is one of relatively localized change. What is needed is the ability to both scale those achievements across provincial systems and replicate/adapt them interprovincially. Neither of these things is something Canadians are particularly good at. We remain “a country of perpetual pilot projects” (Bégin et al. 2009: 1185). Again, this is where an intergovernmental commitment to value-based healthcare and the resources and capacities of the federal government could help.

Bringing a value-based healthcare approach to intergovernmental health diplomacy will require an agreed-upon framework of what it means in a pan-Canadian sense. Canadian governments could do worse than to start with some variation of the four pillars enunciated above from the European Commission along with a fifth around data, measurement and metrics. This would be a vision of a system:

- that meets the needs of patients, providers and payers;
- that achieves the best outcomes at the individual and population levels with the available resources;
- that allocates resources equitably across the country and within provinces;
- that contributes to social solidarity, social cohesion, reconciliation and population health; and
- that is built upon robust and comparable data collection, shared measurement and interoperable information technology.⁵

Like the principles in the European Commission report, or indeed like the five principles of the *CHA*, these cannot or should not be read as separate or distinct goals. They are integrated, overlapping and mutually reinforcing. And they all involve trade-offs both internally and with other policy objectives of governments. Put together into a common statement of principles from Federal-Provincial-Territorial (FPT) governments, akin to the Common Statement of Principles on Shared Health Priorities in 2017, it might begin to frame a conversation about how intergovernmental diplomacy can move a healthcare reform agenda forward.

However, to be effective, such a framework will have to move beyond a mere intergovernmental agreement. The experiences with the Agreement on Internal Trade (*Agreement on Internal Trade Implementation Act* 1996) and the Social Union Framework Agreement (CICS 1999) show us quite clearly that such agreements can be easily abandoned or forgotten about when political priorities shift. Even in the realm of healthcare itself, governments have a long history of embracing reform ideas one day and forgetting about them the next. Outside of restoring federal funding and splitting the CHST into its component parts, the recommendations of the Romanow Commission (Romanow 2002) got little buy-in from either order of government. More recently, neither the Naylor report (Advisory Panel on Healthcare Innovation 2015) nor the Forest and Martin (2018) report has prompted much government action on their respective recommendations.

What might make a value-based healthcare agreement different, though, is the particularity of the moment we are in when it comes to healthcare. The system, battered by the COVID-19 pandemic and years of unmet reform proposals, is floundering. And citizens have noticed and so, too, have the hucksters selling magical “all you have to do is ...” solutions to complex, multifaceted problems. The calls for governments to take action are growing.

In the best instance, a *New Canada Health Act* that enshrines these principles, bolstered by provincial legislation articulating what and how those principles will be operationalized in each province, would give the necessary heft to the ideas of value-based healthcare and make them hard(er) for governments to ignore. Such a legislative web could also bridge the *CHA*/non-*CHA* service divide and further the necessity of seeing provincially funded services such as community-based care, home care, pharmaceuticals and long-term care as part of a continuum with *CHA*-governed hospital and physician care. Value-based healthcare cannot, if it is to mean much of anything, be limited only to *CHA* services. Any restructuring or expansion of provincial services outside the *CHA* needs to reflect those values.

There is, also, a political dynamic to all of this that goes beyond the specifics of the healthcare system and its financing. As was already noted, different provinces have different degrees of reliance on federal transfers, and this may create a built-in advantage for the federal government in a system focused on bilateral arrangements. The simple fact is that some provinces need the federal resources more than others and may, therefore, be more likely to acquiesce to federal priorities. But it has always been thus. That is the realpolitik of Canadian federalism and the uneven regional political economies that have been a feature of Canadian federalism since at least 1867.

The counter to this federal government advantage may lie in a more active and collaborative COF, one that is more engaged in collaborative efforts by provincial governments in areas of shared concern. There was some of this in the Harper years when provinces looked for ways to lower drug prices through better and more bulk purchasing (McIntosh 2021b), but it has never amounted to much. At present, the benefits of a united front against Ottawa are quite unevenly distributed. If it had to, Alberta could, at present, finance healthcare in

the province without federal assistance, but there would be no pay-off for New Brunswick, Nova Scotia or Manitoba to act in solidarity with Alberta and similarly forego federal health transfers.

The other overarching political dynamic is the issue of partisan politics as it plays itself out in the arena of intergovernmental diplomacy. Can governments of such different ideological and political convictions ever come to an agreement? But to return to Simeon's (2006) metaphor of intergovernmental relations as a form of diplomatic negotiation, the clear answer is yes. Internationally, the Liberal government of Prime Minister Justin Trudeau, the Republican administration of US President Donald Trump and the left-progressive coalition headed by Mexican President López Obrador negotiated and signed a new free trade agreement in 2020 (Chapell 2018). So too, domestically, Canadian intergovernmental processes have demonstrated a capacity to ignore the day-to-day partisan differences between Liberal, New Democratic Party (NDP) and Conservative (of whatever stripe or label) governments to reach agreements on shared issues.

If pan-Canadian policy making relied on a confluence of ideological outlooks across jurisdictions, then there would never have been a post-war welfare state or a constitutional agreement in 1981. In the latter case, only two Progressive Conservative (PC) provincial governments supported the Liberal federal government's constitutional package. A coalition of five PC, one Social Credit, one NDP and one separatist Parti Québécois premiers opposed the federal plan. Yet in November of 1981, thanks in part to compromises proposed by a federal Liberal minister, a PC and an NDP Attorney General, a deal acceptable to nine of the 10 provinces and the federal government was reached (Romanow et al. 1984). The deal was not perfect. It has had both foreseen and unforeseen consequences. But on the whole, there can be little doubt that Canadians would balk at a return to the status quo ante. Yes, partisan and personal differences between actors may complicate, delay or even derail such processes (as they sometimes do on the international front as well), but they do not have to be an insurmountable hurdle.

The saving grace in the current political dynamic may prove to be the very crisis the healthcare system currently faces. No jurisdiction, regardless of the political stripe of the government, appears untouched by the various dimensions of the health human resource challenges, the infrastructure challenges, the access challenges or the wait-time challenges that have come to the forefront since the height of the COVID-19 pandemic. A pan-Canadian values-based framework that can be adapted to the specific organizational and delivery mechanisms of each jurisdiction and which speaks directly to the increasingly urgent concerns expressed by citizens about the future of the healthcare system has the potential to drive governments to an agreement.

The goal should be a health reform framework that both appeals to the public desire for real and substantive action on healthcare and meets potential objections from provinces concerned about jurisdictional autonomy. While Canadians have long put "healthcare" at or near

the top of their list of most important political issues, the pandemic has not only heightened public concern but also illuminated how little reform has been accomplished over the past two decades despite the billions spent. But that has not (yet, perhaps) diminished their commitment to the basic principles of universal publicly administered and financed healthcare. Furthermore, the public has clearly concluded that both orders of government need to take action; the federal government has to contribute more, and provincial governments have to actually implement the reforms they have long promised but failed to deliver (Hahn 2022).

Thus, it may well be the governments (at either level) that take these messages to heart and seek out a new way of conducting intergovernmental diplomacy around healthcare that win the day politically. Indeed, in an interview with CTV News, Nova Scotia Premier Tim Houston recently said he would offer “no pushback” to the idea that the province “guarantee[s] outcomes and performances” in a new healthcare financing arrangement with Ottawa (Wentzell 2022).

As the 2017 agreements come up for renewal, there is an opportunity to put these principles (or some variation of them) into practice. Setting out value-based healthcare principles in an intergovernmental agreement could then guide the allocation, in the first instance, of the “second” health transfer on specific FPT priorities. These would be the subject of more detailed commitments in subsequent bilateral agreements that, as in 2017, specify where and how the monies will be spent to operationalize the principles. Within those agreements, unlike in 2017, there would need to be clear requirements for provinces to report to their residents on progress toward the specified goals. The public needs to see the value in the reform,⁶ especially given the current state of the system post the COVID-19 pandemic.

Going forward, a process would be needed to move funding for successful innovations under the “second transfer” into the general CHT, perhaps tied to federal commitments to assist in funding, scaling and adapting what works to other jurisdictions. This would free up governments to move to other priorities as the focus of the “second transfer” without abandoning successful pilots. Such a process could be outlined as a *New Canada Health Act* and in companion legislation in the provinces.

Again, this is potentially a massive undertaking and one that will take significant intergovernmental goodwill to achieve. Only the federal government has the fiscal capacity to fund the scaling of successful innovations, and only the provinces have the knowledge of how to best deliver services in their specific contexts. Scaling innovations will take working both bilaterally (scaling a local innovation within a province) and multilaterally (scaling innovations across provinces). Taking a page from collective impact theory (Cabaj and Weaver 2016), what one may need to accomplish this is a *backbone organization* that can, in service of the collective, provide the resources, data and evaluation components necessary to effectively scale and adapt innovations across jurisdictions with different policy design and implementation capacities. Such a backbone organization would have to be both embedded in FPT

governments and independent from them – embedded in order to understand the local context in which an innovation succeeded and to have access to the data needed, but independent enough to thoroughly evaluate effectiveness and compliance with the value-based framework that would guide it.

Concluding Thoughts and Caveats

What has been attempted here is, at best, a sketch of where and how we might consider taking an emerging (and I believe positive) development on the intergovernmental front and use it to help operationalize and extend positive developments down on the ground in terms of reform efforts around value-based healthcare. And admittedly, there is much more that would need to be thought through to make it a reality.

But the future of bilateralism is far from assured. Statements by provincial premiers at the recent COF meeting in British Columbia made no mention of subsequent rounds of bilateral agreements (COF 2022). And, too, the federal government has said little about its own agenda when it comes to any adjustments to the CHT (Owen 2022).

Undoubtedly it is true that bilateralism has, to date, been driven by the federal government. Given the current efforts being put into maintaining provincial solidarity over the current demand for a \$28 billion unconditional increase in the CHT, it may be fair to say that some provinces felt, perhaps, bullied into the 2017 arrangement, especially after it was unilaterally extended in 2014. The federal government's current task is to make the case that bilateralism is not federal interference in provincial jurisdiction but is, in fact, a means to the kind of partnership that the premiers have called for.

And this puts the onus on the federal government to be the kind of reliable, knowledgeable and engaged partner that it has not often been in the past, perhaps first by working with provinces to create the kind of backbone organization needed to successfully move a value-based framework forward. What we know about operationalizing value-based healthcare in Canada comes from the provinces' own initiatives and experiments. The federal response should be to understand that its best role in replicating and scaling achievements is to follow the provincial lead. The provincial response should be to understand that if they are driving the reform process, then there is an obligation to both the other funder and their own residents to be more transparent and accountable about the direction the system is going and the destination. An intergovernmental framework for value-based healthcare that is focused on agreed reform priorities could be a starting point for this.

Sutherland (2020b) characterized the search for value-based healthcare as perhaps a choice between seeking a "Holy Grail" (p. 3) and "incremental progress" (p. 4). But perhaps it is both. Grail quests are long, arduous and filled with detours, but even if the Grail is never completely in our grasp, we can get progressively closer to it over time. The emergence of bilateral federalism could be one means by which we bring value-based healthcare into a national conversation about the future of Canadian healthcare.

Epilogue: The 2023 Healthcare “Deal”

On February 7, 2023, the federal government presented to the premiers its proposal for a new national health accord (Health Canada 2023a). It included an immediate \$2 billion top-up to the CHT and a guaranteed 5% annual growth in the CHT for the next five years to be paid as annual top-ups. Access to those top-up funds would be conditional on provinces committing to increased and more transparent data collection.

An additional \$25 billion would be allocated to four priority areas (Health Canada 2023a):

- expanding access to family health services (including in rural and remote areas);
- supporting health workers and reducing backlogs;
- improving access to quality mental health and substance use services; and
- modernizing the healthcare system with standardized health data and digital tools.

This money would be accessed via tailored bilateral agreements that include “action plans,” “the addition of targeted results with indicators” on which “provinces and territories would publicly report on results to their own residents” (Health Canada 2023a). The initial provincial reaction was to refer to the federal offer as a “starting point” and a “down payment” (Aiello 2023). But by March 20, 2023, all jurisdictions but Quebec and the territories had signed agreements with Ottawa.

It seems clear that the federal government very much wants to continue to move down the bilateralism road with an essentially bifurcated health transfer – the CHT proper is to remain more or less unconditional, while a second pot of money offered for more specific health reform priorities (including both *CHA* and non-*CHA* services) will be dependent on greater levels of transparency and accountability written into bilateral agreements. Whether those transparency and accountability mechanisms are sufficient to meet public demands that health transfers are indeed spent on healthcare remains to be seen.

Furthermore, the federal offer amounts to about \$50 billion in “new” spending over a decade, which is far short of the provincial demand for an immediate annual increase of \$28 billion per year. The difference between what provinces wanted and what the federal government offered likely means that the “who-is-paying-how-much-and-for-what” debate will continue. This does not bode well for the prospects of real reform or for furthering any discussion of value in health as it might pertain to the Canadian system.

Interestingly, on March 10, 2023, the federal government announced that it was making the first deductions to provincial transfers under the Diagnostic Services Policy (DSP), which articulated a commitment to curb the private payment for magnetic resonance imaging and computed tomography scans by individuals by deducting their cost from provincial transfers (Government of Canada 2019b; Health Canada 2023b). A total of \$82.5 million is to be clawed back, mostly from British Columbia (\$23.1 million), Alberta (\$13.8 million) and Quebec (\$41.9 million). The government of Saskatchewan publicly stated that it will

not change its private MRI policy (Mantyka 2023), becoming perhaps the first province to explicitly commit to the ongoing violation of the terms of the *CHA*. For nearly 50 years, provincial governments of all stripes swore fealty to the five *CHA* principles, and to have the province known as the “birthplace of medicare” be the first to unapologetically shrug off federal enforcement may constitute a new front in the intergovernmental struggle over Canada’s ailing system and the values that underpin it.

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Notes

1. I use the term “intergovernmental diplomacy” as a contemporary variation on “federal-provincial diplomacy” used by Simeon (2006) to refer to the processes of “executive federalism” that, akin to international diplomatic negotiations, work to achieve pan-Canadian policy consensuses on specific issues. The “cost-sharing” arrangements that created Canadian medicare in the 1960s, the tax-point transfer that underpinned the EPF changes in 1977 and the Health Accords of 2002, 2003 and 2004 are all products of these kinds of negotiations. I chose intergovernmental rather than federal–provincial as the descriptor only to acknowledge the presence of the territorial governments at the table.
2. A summary of each of the 13 bilateral agreements, showing the nature and degree of specificity of each province’s commitments, can be found in the Appendix to McIntosh and DeCorby (2022).
3. This, in fact, could be an important role for the federal government – encouraging provinces with financial and other incentives to adopt best practices and to facilitate the transfer of “what works” across provincial boundaries.
4. The provinces prefer to talk about “healthcare spending” as a whole because it strengthens their case for increases in the transfer from the federal government. The federal government has expressed a desire to see (and invest in) expanded public pharmacare and dental care programs that are clearly beyond the confines of the *CHA*. The blurring of the lines between *CHA* and non-*CHA* services serves both sets of political interests.
5. It is worth noting that in many of the reviews of what was accomplished with the 2004 Health Accord, the one area that was consistently seen as a high point was the steady improvement of the system’s ability to produce high-quality, comparable data across jurisdictions (McIntosh and DeCorby 2022).
6. One might also consider principles like “transparency,” “accountability” and “public reporting” as additional principles to the five listed above, which would form part of the overall framework for value-based healthcare in a highly decentralized federation like Canada.

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Innovating for Value-Based Surgical Care in Canada: A Post-Pandemic Necessity

Innover pour des soins chirurgicaux axés sur la valeur au Canada : une nécessité post-pandémique



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Abstract

Providing high-quality, efficient and cost-effective surgical care to Canadians has become increasingly challenging since the pandemic, resulting in long waitlists due to limited staff and resources. The pandemic has facilitated some areas of innovation in surgical care, notably in virtual care and expedited discharge, although many challenges remain. Key policy recommendations for reform include investing in infrastructure to collect and report on value-based metrics beyond volume, devising strategies to improve health equity, enhancing out-of-hospital support for surgical patients by using remote monitoring and digital technology, increasing patient segmentation into low- and high-complexity pathways, centralizing surgical triage and initiating careful financial incentivization of integrated groups of clinicians.

Résumé

Il est de plus en plus difficile, depuis la pandémie, de fournir aux Canadiens des soins chirurgicaux de haute qualité, efficaces et rentables, comme en témoignent les longues listes d'attente, en raison du manque de personnel et des ressources limitées. La pandémie a facilité certains domaines d'innovation dans les soins chirurgicaux, notamment les soins virtuels et la sortie accélérée, bien que de nombreux défis subsistent. Les principales recommandations politiques pour la réforme comprennent l'investissement dans l'infrastructure pour collecter et rapporter des mesures fondées sur la valeur au-delà du volume, la conception de stratégies pour améliorer l'équité en matière de santé, l'amélioration du soutien en soins externes pour les patients opérés au moyen d'une surveillance à distance et des technologies numériques, l'augmentation de la segmentation des patients en voies de complexité faible ou élevée, la centralisation du triage chirurgical et la mise en place d'incitations financières prudentes pour les groupes intégrés de cliniciens.

Introduction

Providing high-quality, efficient and cost-effective surgical care to Canadians has become increasingly challenging. All aspects of the surgical trajectory are strained, from referral to recovery, and have created an urgent need for reform toward value-based care. Even before the pandemic, we saw increased emphasis being placed on longer-term, patient-centred outcomes (Wijeysundera and Johnson 2016). Surgery represents a substantial component of healthcare costs, with over two million surgeries performed every year in Canada at a cost of nearly \$60 million in 2021 (CIHI 2021). Value must incorporate both the measurable change in patient outcome and the cost required for this care (Porter 2010), although the measurement of value is complex and currently rarely done for surgical care in Canada.

The 2021 Commonwealth Fund Report ranked the Canadian healthcare system second to last among high-income countries, sitting only above the US (Schneider et al. 2021). Canada performed particularly poorly on access to care, equity and healthcare outcomes, and many Canadians have previously reported difficulty accessing surgical care specifically

(Sommer et al. 2020). Despite long delays to accessing surgical care, the British Columbia Court of Appeal recently upheld a decision concluding that provisions of the *Medicare Protection Act* (1996) are not unconstitutional by disallowing private medical care (*Cambie Surgeries Corporation v. British Columbia* 2022). As a result, publicly funded healthcare will remain the primary provider of surgical care in Canada for the foreseeable future and must respond to these challenges.

The strain on surgical care worsened during the COVID-19 pandemic for several reasons but largely through exacerbation of pre-existing issues. Elective (scheduled) surgery was repeatedly delayed to increase critical care capacity, which, in turn, worsened pre-existing waitlists, including those for cancer and cardiac surgery. In addition, an “acute on chronic” shortage of healthcare workers further reduced surgical capacity. As a result, many emergency departments and operating rooms in Canada are currently unable to operate at full capacity. After several up and down cycles of ramping elective surgeries, we have not yet caught up to baseline pre-pandemic levels (Fu et al. 2022), let alone address backlogs. The consequences of these reductions are significant, with a nearly two-fold increase in mortality reported for patients awaiting cardiac procedures (Tam et al. 2021) and a projected reduction in long-term survival for those requiring cancer surgery during the pandemic (Parmar et al. 2022).

As surgical services experienced unprecedented pressures, the pandemic also served to facilitate innovation in surgical care. In this article, we explore examples of accelerated innovation during the pandemic, identify ongoing threats to high-value surgical care and provide policy recommendations going forward.

Surgical Care Innovation during the Pandemic

One of the most striking innovations to patient care was the implementation of virtual care at the onset of the pandemic. During earlier tentative attempts at virtual care, regulatory and technological hurdles were perceived as difficult to overcome; the attempts were further disincentivized by the limitations and conditions of the virtual fee codes available for physician compensation. Due to the pandemic, surgery and anaesthesiology clinics quickly adopted *good enough* technologies by using either phone or video consultation to avoid in-person visits. Simultaneously, provincial governments implemented new fee codes and regulatory amendments to allow virtual care (Health Services Branch, Ministry of Health 2020). After an initial learning curve, virtual care proved effective and convenient – associated with reduced travel time – particularly for those in remote areas, and demonstrated high patient satisfaction in both surgical and anaesthesiology clinics (McMaster et al. 2023; Wienhold et al. 2021). Limitations were also noted, such as lack of infrastructure (e.g., software, audiovisual equipment), lack of technical support, electronic security issues, poor usability, inability to perform physical examinations and lack of access to preoperative materials (Davenport et al. 2022; McMaster et al. 2023). In addition, the value of telehealth was not universally realized

as illustrated by the barriers faced by patients experiencing language, hearing or visual impairment and those without robust Internet access. Given high patient acceptability, perioperative virtual consultations should continue going forward, albeit with careful patient selection for in-person visits by clinic staff using pre-specified criteria and patient preference. Finally, surgical programs should continuously monitor safety endpoints, such as cancellations on the same day of surgery because of inadequate assessment or miscommunication. Overall, further research into the relative merits and appropriate application of virtual care in the perioperative period is required.

The other process innovation was expedited discharge after surgery, including conversion of in-patient to outpatient surgery. This shift was already under way and accelerated during the pandemic given the pressure on hospital capacity and patients' desire to avoid hospital stays. For example, same-day discharge after joint replacement or transfemoral aortic valve replacement was successfully implemented at some sites without causing an increase in readmission (Barker et al. 2022; Cherry et al. 2021). In patients undergoing breast cancer surgery, a combination of team-based care, centralized triage and conversion to regional anaesthesia allowed a significant increase in same-day discharge (Cadili et al. 2021). These examples of process innovation had several commonalities: multidisciplinary input, careful patient selection, increased efficiency and standardization and greater willingness to change due to pandemic disruptions and resource scarcity. Across the examples above, value increased because of maintained or improved patient outcomes, reduced cost from shorter stays or both (Barker et al. 2022; Cadili et al. 2021; Cherry et al. 2021).

Remaining Gaps in Surgical Care in Canada

Many issues remain, including the fact that the concept of value of surgical care in Canada is not fully defined and largely unmeasured. Value is typically defined by providers and focuses on metrics such as mortality because these outcomes are more easily captured and perceived as priority. However, provider priorities may differ and often do not incorporate patients' priorities for their health, such as symptom burden and quality of life (Guan et al. 2020). In addition, most health systems lack infrastructure to routinely capture patient-reported outcomes, vastly limiting our ability to implement strategies to improve value.

Other issues include lack of coordination across healthcare sectors and regions, geographical challenges and health inequities. Access to surgical care requires referral from a primary care physician, yet an increasing number of Canadians do not have access to a family doctor (Esler 2022). The escalating primary care crisis contributes to chaotic and fragmented care before and after surgery, with sometimes inefficient and confusing referral pathways. For example, an unattached patient may miss routine screening visits and present for surgery with more advanced cancer or poorly controlled comorbid conditions, both of which increase perioperative risks. In addition, expedited discharge can shift acute recovery into the home, such as wound care and pain and symptom management, yet patient-centred infrastructure

to support patients during recovery is lagging. Surgical care reform will not be effective without cross-sector coordination with community resources both before and after the acute hospital episode. The unique challenges of providing specialized surgical care across a large, geographically diverse country such as Canada means many patients must travel far from home to access these services and face barriers to follow-up. Finally, and most critically, inequity in access and surgical outcome disparities for Indigenous Peoples (McVicar et al. 2021), women (Wallis et al. 2022), Black patients (Azin et al. 2020) and other groups experiencing marginalization have been preliminarily identified, but metrics on equity in surgical access and outcomes for these groups remain largely uncaptured and the issues, unaddressed.

Going Forward: Recommendations for Surgical Care Policy

Provinces and territories face considerable challenges in the face of long waitlists and limited resources. Our recommendations for surgical health policy going forward are as follows, in the order of importance.

Invest in infrastructure to measure value in surgical care transparently and consistently

This recommendation is neither new nor unique but remains unheeded by many provinces and the federal government, resulting in a lack of accountability. The most widely used metric by the provincial health systems is surgical volume, which provides some measure of system efficiency and aligns well with the fee-for-service reimbursement model used by most physicians. However, volume alone does not provide a complete picture of value and does not incorporate patient perspective or health equity. To better measure value, Wodchis (2019) proposed the following simplified principles: (1) direct patient input – for example, patient-reported outcomes and experience measures; (2) process measures that incorporate the values of healthcare providers, organizational quality and operational efficiency; and (3) population measures of equity and distributive efficiency. In practical terms, provinces can mandate reporting of value-based metrics by hospitals, which will require regional or provincial health authorities to invest in infrastructure (staff, survey platforms, analysts) to provide timely perioperative patient-reported measures in addition to traditional metrics such as length of stay. These data should incorporate equity metrics, identify areas for improvement and evaluate interventions. Provinces should hold health authorities accountable for gaps in equity to drive change.

Process measures should seek to evaluate not just traditional outcomes (case volume, adherence to standards and resource consumption) but also the level of stress in accessing treatment (Wallace and Teisberg 2016). The Canadian health system has largely de-prioritized the patient experience in surgical care, with long wait times, frequent last-minute case cancellations, fragmented communication and unsupported transitions from hospital to home. Although cost is an important part of the value equation – efficiency, rather than care

rationing, should be the focus (Teisberg et al. 2020). Taken together, these metrics can also be used to facilitate the administration of rewards for high performance (or penalties for low performance).

In selected populations, provinces can also sample outcome data for patients seeking non-operative management options to determine the overall efficacy of surgical intervention in the context of shared decision making. For example, a recent study of frail, institutionalized patients with hip fracture showed that non-operative management resulted in non-inferior quality of life as assessed by proxies and caregivers and shorter length of hospital stay (Loggers et al. 2022). Although the 30-day mortality rate was high (greater than 80%), proxies in the non-operative group reported greater satisfaction with the quality of dying and death compared with those in the operative group. Because healthcare providers have identified time and resource constraints as barriers to shared decision making (Spronk et al. 2022), hospitals can provide tools, implement pathways and support patients in exploring non-operative interventions at a local level.

Address equity gaps in surgical care

Disparities in access and outcomes following surgery have become more visible during the pandemic (Urbach and Martin 2020), and health disparities represent an urgent and complex problem. Although these issues are complex, identifying the underlying reasons and corrective strategies must be urgently prioritized. The stress inflicted by the pandemic highlighted the need to build a resilient healthcare system that can respond to uncertainty and change in an equitable way. Change should be data-driven and informed by appropriate metrics routinely collected by the provinces and territories. The Canadian Institute for Health Information (CIHI) recently released guidance on the collection and reporting of race-based and Indigenous identity data in order to harmonize collection and ensure that high-quality data are comparable across jurisdictions (CIHI 2022). An intentional and culturally safe strategy for collection of equity-related metrics is important to avoid survey non-response bias in already marginalized groups. These data will create accountability and help avoid policy creation based on assumptions. Surgical waitlists, case cancellations and access to data by patient race, ethnicity, gender and geography should be tracked, in addition to post-operative outcomes, and these can be used to develop and evaluate policy changes. An example of this concept is illustrated by the policy changes to the US Kidney Allocation System in 2014 to address identified racial disparities in kidney transplantation (Melanson et al. 2017). The primary reform was to revise the priority criteria from wait time on the transplant list to also include time spent on dialysis, resulting in a reduction in transplant disparities for Black and Hispanic patients given the presence of disparities in time to referral (Melanson et al. 2017). In contrast, Canada does not collect key demographics such as race in its large CIHI databases, making similar analyses and interventions very challenging.

Research in surgical health equity should be prioritized by universities and funding agencies to identify ongoing disparities and solutions. Critically, value-based incentives should be carefully applied to avoid penalizing institutions that disproportionately care for marginalized individuals who require more complex care, and instead consider rewarding relative improvements and stratifying benchmarks and incentive pools (Navathe and Liao 2022). Mandatory education in the principles of health equity is increasingly being adopted at medical schools across Canada, and additional education and diverse healthcare leadership are essential to ensure policy decisions are made with an equity lens.

Enhance patient support before and after surgery using virtual care and digital health

Patients generally receive high-quality care in Canadian hospitals but often lack support, including pain and symptom management and mental health support, during long waits before surgery and after discharge from hospital. Patients travelling long distances for surgical care in Canada can also benefit from remote monitoring and virtual care follow-up. Despite the best efforts of healthcare professionals, overcoming systemic barriers is challenging. Digital health approaches representing innovative and cost-effective solutions to bridge these gaps in care are now more accessible and acceptable to patients than ever before (McMaster et al. 2023). Patient engagement technology after colorectal surgery has been shown to facilitate discharge, prevent readmission and reduce costs (Gleason et al. 2022). A digital pain management application demonstrated high engagement with patients from both urban and rural settings in Ontario, and may improve patient-reported outcomes (Bhatia et al. 2021). Digital health infrastructure can also support the collection of patient-reported outcomes needed for value measurement. Health authorities should be responsible for providing access to technology that can be customized by individual programs and groups, likely through partnerships with digital health companies.

Increase patient segmentation and resource centralization

Today's operating rooms typically encompass a spectrum of case acuity, complexity and hospital volume. Some institutions focus more on low-acuity, rapid discharge procedures, while others offer expertise in caring for complex patients and procedures. Although many hospitals attempt to segregate these groups of patients, the process is incomplete and these two streams commonly co-exist within one institution, mixing low- and high-risk patients and procedures. Using Christensen's model of innovation, hospitals or surgical centres can be separated into *solution shops* and *value-adding processes* (VAPs) (Christensen et al. 2017). Solution shops are structured to diagnose and treat unstructured medical issues and provide personalized care plans to complex patients with high variability in outcome and resource consumption. These surgical systems create value in their expertise, adaptability and scalable resources rather than efficiency. Examples include tertiary hospitals providing a high volume of lengthy, complex

cancer surgeries or designated transplant centres. In contrast, VAP models focus on patients with definitive diagnoses and predictably low variation in outcome. These centres create value in their process innovation for efficiency, consistency and cost-reduction. For example, a low-risk, rapid-turnover eye surgery often takes place at specialized centres that exclusively focus on a narrow range of procedures and benefit from an efficient, refined pathway from patient entry to discharge. Christensen et al. (2017) argue that these models are difficult to effectively innovate together under the same roof, yet these models are conflated throughout operating rooms in Canada. Large operating rooms focusing on high volumes of complex patients and procedures can rarely achieve the efficiency of smaller, lower acuity centres, but may produce better outcomes for patients with the most complex issues (McIsaac et al. 2017).

Segmentation gains several advantages by promoting greater standardization of high-quality care and lower variability between providers for straightforward cases as seen by the shift toward expedited discharge during the pandemic for selected patients. Regionalization of complex patients or high-acuity procedures to designated centres also increases hospital volume, which is associated with improved outcomes for complex surgery and for frail patients (Hallet et al. 2021; McIsaac et al. 2017). Even within a complex population, segmentation can allow process innovation. For example, stratification of cardiac surgery patients into high- and low-risk pathways led to reduced length of stay, resource consumption and cost (Cook et al. 2014), and these “pathways” are now commonly used in many cardiac surgical centres. Many hospitals, including those in remote areas, must provide a spectrum of surgical care in a single centre; however, innovation can occur by segregation of specialized lists and can serve as a local prototype. This concept is illustrated by one centre’s use of a standardized regional anaesthesia pathway in a parallel orthopaedic surgery “swing” operating room to increase surgical case volume by over 50% (Head et al. 2011). However, smaller centres should avoid taking on infrequent, highly complex elective procedures when possible, given the evidence of better outcomes at high-volume centres (Hallet et al. 2021). Hospitals should develop triage mechanisms and designated pathways for both types of patients collaboratively and iteratively by involving all stakeholders, including patients, families/caregivers, surgeons, anesthesiologists, nurses and other allied professionals. On a higher level, regional and provincial health systems should continue to refine efficient referral pathways to regional surgical centres for complex surgery.

Re-evaluate surgical triage strategy

Medical urgency is often used to determine surgical priority when triaging both elective and emergent cases during instances of resource scarcity. With increasing scarcity, triage considerations have become more acute and difficult. Long waits have a substantial impact on patients, causing deterioration of function and mental health (Guo et al. 2022) and reducing outcome gains for patients. While acutely life-threatening emergencies should still take precedence, we must now re-evaluate surgical prioritization and waitlist management along

the full spectrum of both urgent and non-urgent surgery. As advocated by others (Urbach and Martin 2020; Wiebe et al. 2022), central referral pathways to groups of surgeons with similar expertise can increase efficiency and equity, and facilitate tracking of metrics. The creation of such pathways is optimally done in full collaboration with surgeons, given the nuances of specialization and expertise. For example, common and uncomplicated surgical procedures can be optimally shared among groups of surgeons who possess broad expertise, while other less common procedures requiring additional expertise (e.g., complex cancer surgery) may benefit from directed referral. Financial incentives, infrastructure support and easier access to surgical resources can facilitate creation of necessary physician networks.

These waitlist strategies can build upon previous research on waitlist management that identified value-based tools such as priority scores developed through the Western Canada Waiting List Project (De Coster et al. 2007). However, prioritization strategies must also avoid introducing unnecessary complexity, which can waste resources (Kreindler 2008). In addition, provinces should provide parallel capacity for both non-urgent surgery and urgent surgery to avoid repeated cancellation of some “elective” surgeries for conditions with substantial impact on function and which can result in alternative healthcare resource consumption (e.g., the emergency department) and diminishing value. Joint replacement, rectal prolapse repair and deep brain stimulator insertion are examples of elective procedures that can have a major impact on quality of life, promote function and mitigate chronic resource consumption (Mäkelä-Kaikkonen et al. 2019; Perestelo-Pérez et al. 2014; Quintana et al. 2006). Although controversial, publicly funded private surgical centres continue to provide dedicated capacity for non-urgent, lower complexity, short-stay surgery and have already been a key part of addressing backlogs in Canada – health authorities contracted \$27.2 million to private clinics in British Columbia in 2021 alone (Longhurst 2022). Until the provincial health ministries are willing to establish similar, publicly run, dedicated surgical centres distinct from full-service hospitals, private surgical centres will likely continue to offer a viable avenue for low-complexity and outpatient surgery.

System-level incentivization of value-based care

Rewarding value in the Canadian healthcare system is challenging, given the difficulty in accurately measuring value with little accountability from providers or hospitals. Other contributors include a mix of payment models for different sectors and health professionals and lack of competition in a single-payer system. Financial incentives should be carefully considered as the current strategy of primarily rewarding volume in the fee-for-service payment model to physicians does little to encourage value-based care and is not aligned with a hospital’s fixed budget for comprehensive services. As value “should encompass all services or activities that jointly determine success in meeting a set of patient needs” (Porter 2010: 2478), incentives should ideally be applied to integrated units of surgical providers that include the anesthesiologists, surgeons and the hospital; yet physician services, hospital costs

and out-of-hospital care are funded separately. Even the physicians involved are incentivized differently as surgeons are paid by case and anesthesiologists, by time. In the authors' experience, applying incentives to individual physicians based on sparsely collected, surrogate-quality metrics does little to incentivize behaviour. However, pure bundled payment models in the Canadian single-payer system are challenging due to disparate compensation models, lack of information sharing across groups and lack of appropriately adjusted value-based metrics (Golden and Hannam 2021). A better approach would be for provinces, together with provincial medical associations, to develop separate reward payments to linked groups of surgeons, anesthesiologists and hospitals for selected patient groups with established benchmarked outcomes (e.g., joint replacement or Caesarean section), and shift the focus away from individual physicians.

Pitt and Dossett (2022) recently advocated for the de-implementation of low-value care in surgery, including careful financial incentivization that includes eliminating unnecessary and costly investigations and interventions. For example, routine blood type and screening can safely be omitted for non-anemic patients undergoing joint arthroplasty (Nuñez et al. 2022), but is not universally adopted. The Choosing Wisely Canada campaign was a relatively successful intervention to educate and eliminate low-value care, including routine preoperative testing; however, implementation has been uneven (Bouck et al. 2019). Potential strategies to reduce low-value care further include clinical decision support tools embedded in electronic health records and publication of guidelines and best practices from societies and journals (Pitt and Dossett 2022). Hospitals and provincial medical associations are increasingly supporting physician time and training to lead multidisciplinary quality improvement projects and change management for best practices – activities that are not typically compensated. Provinces should establish stable funding to support these activities, which are otherwise disincentivized.

Role of the Federal Government

In Canada, the provinces and territories are largely responsible for administering healthcare after receiving transfers from the federal government. Given the discussion to date, is there a role for the federal government in surgical care reform? Our view is yes, the federal government could support the implementation of value-based surgical care in several ways. Building upon the Health Council of Canada's (2014) recommendations to develop comparable health indicators and increase public reporting of health information, the federal government can hold the provinces accountable to value-based metrics, incentivize reform financially and facilitate collaboration between the provinces and territories. At a federal level, mandated reporting of a more comprehensive set of equity-based metrics by the provinces is essential to monitor disparities and support equity initiatives. Finally, the federal government should support policy development on value-based surgical care.

Conclusion

Surgical care in Canada is under significant strain due to chronic issues exacerbated by the COVID-19 pandemic, creating an ideal opportunity to harness emergent innovation and drive further reform at all levels. We propose several recommendations to address these challenges, which must include reporting value-based metrics beyond volume, investing in strategies to improve health equity, enhancing out-of-hospital support for surgical patients using remote monitoring and digital technology, increasing patient segmentation into low- and high-complexity pathways, centralizing surgical triage and careful financial incentivization of integrated groups of clinicians.

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Innovating for Value-Based Surgical Care in Canada: A Post-Pandemic Necessity

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Value in Primary Care: Evidence from the Canadian Primary Care Sentinel Surveillance Network

Valeur des soins primaires : les données probantes du Réseau canadien de surveillance sentinelle en soins primaires



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Abstract

Primary care antimicrobial stewardship programs are virtually non-existent. Using electronic medical record (EMR) data for an interrupted time series study, the authors examined the relationship between antibiotic prescriptions for acute respiratory tract infections (RTIs) and the COVID-19 pandemic. The main outcome of the study was to gauge the proportion of

RTI encounters with an antibiotic prescription. The pre-pandemic RTI antibiotic prescribing rate was 27.8%. During the COVID-19 pandemic, prescribing dropped significantly by 9.4% ($p < 0.001$). Almost 750,000 fewer patients could potentially avoid receiving an antibiotic prescription for RTI. The authors also discuss the value of EMR data; their use can help develop insights for health system improvement.

Résumé

Les programmes de gestion des antimicrobiens en soins primaires sont pratiquement inexistant. À l'aide des données du dossier médical électronique (DME) pour une étude de série chronologique interrompue, les auteurs ont examiné la relation entre les prescriptions d'antibiotiques pour une infection aiguë des voies respiratoires (IAVR) et la pandémie de COVID-19. Le principal objectif de l'étude était d'évaluer la proportion de rencontres d'IAVR avec une prescription d'antibiotiques. Le taux de prescription d'antibiotiques pour une IAVR avant la pandémie était de 27,8 %. Pendant la pandémie de COVID-19, la prescription a chuté de manière significative de 9,4 % ($p < 0,001$). Près de 750 000 patients de moins pourraient potentiellement éviter de recevoir une prescription d'antibiotiques pour une IAVR. Les auteurs discutent également de la valeur des données du DME, dont l'utilisation pourrait aider à développer des idées pour l'amélioration du système de santé.

Introduction

Value for healthcare in North America has typically been based on the concept of value from different actors' viewpoints, including regulators, insurers, physician organizations and health authorities. Another approach comes from the European Commission's Expert Panel on Effective Ways of Investing in Health (EXPH 2019) that proposes a more holistic approach based on four pillars of value created by the health system that focus on equity, person-centredness and social participation: (1) achievement of best possible outcomes with available resources (technical value), (2) equitable distribution of resources across all patient groups (allocative value), (3) appropriate care to achieve each patient's personal goals (personal value) and (4) contribution of healthcare to social participation and connectedness (societal value) in addition to health itself. Indeed, investments in health have positive returns for both the society and the economy (Bell et al. 2023). Past work demonstrates that investments in health contribute to advances in research and innovation, economic growth and a better society (Boyce and Brown 2019).

The ubiquitous use of antibiotics leads to antimicrobial resistance (AMR) that is now recognized as a major contributor to disease burden and one of the greatest threats to the future of human health. One area ripe for generating value in healthcare is preserving the efficacy of antibiotics through stewardship programs (Feazel et al. 2014; MacDougall and Polk 2008). Antibiotic stewardship (AS) programs combine education, public health

surveillance, policies and practice audits to optimize antimicrobial prescribing. Lowering inappropriate antibiotic use can contribute to better outcomes for patients (technical, allocative and personal value) and societal value.

The majority of AS programs are aimed at tertiary care centres (Barlam et al. 2016). That is, there are few programmatic efforts to lower inappropriate antibiotic use in primary care (Keller et al. 2022). Yet, decreasing potentially avoidable antibiotic prescribing (and use) in primary care is essential since this part of the healthcare system could greatly contribute to an overall reduction of antimicrobial-related adverse events and AMR (Hersh et al. 2011; Shapiro et al. 2014). In any given month, an average of 113 people in every 1,000 visit a primary care practice, whereas only eight people in 1,000 are hospitalized (Green et al. 2001). Previous work suggests that between 25% and 46% of antibiotic prescriptions for non-bacterial respiratory infections could be potentially avoidable (Kitano et al. 2021; Silverman et al. 2017). The majority of antibiotic use in healthcare (90% by volume) occurs in the primary care setting where many prescriptions are not indicated (Hersh et al. 2021; Leis et al. 2020). Respiratory tract infections (RTIs) are the leading cause of avoidable antimicrobial use in primary care (PHAC 2020; Silverman et al. 2017).

The COVID-19 pandemic has had a major impact on primary care as there was a more than 89% reduction in preventive care visits and a general decline in primary care visits. With regard to antibiotic prescribing, the long-term repercussions of the COVID-19 pandemic on AMR have been raised as a global concern due to an initial elevated antibiotic use in patients infected with SARS-CoV-2 (Nieuwlaat et al. 2021; van Duin et al. 2020). Antibiotics were frequently being prescribed to patients diagnosed with COVID-19, mainly due to suspected bacterial co-infections (Langford et al. 2020; Lansbury et al. 2020). The overall goal of this work is to provide a use case examining the utility of primary care electronic medical record (EMR) data for identifying potentially avoidable antibiotic use for RTI. The specific objectives of this work are two-fold: (1) to examine pre- and post-pandemic RTI antibiotic prescribing rates; and (2) to examine whether the RTI antibiotic prescribing rates vary by rural/urban, deprivation and mode of visit (in-person versus virtual).

Methods

Study design

Antibiotic prescription rates were analyzed based on an interrupted time series (ITS) quasi-experimental study design before and after the COVID-19 pandemic. We also examined whether prescription rates differed based on mode of visit (in-person versus virtual). The ITS analyses span five years: from before the COVID-19 pandemic (1 January 2017 to 31 March 2020) to after the start of the pandemic (1 April 2020 to 31 December 2021). We used regression modelling to examine whether rates of antibiotic prescribing varied by the service delivery mode after the COVID-19 pandemic.

Data source

We used EMR data from the Canadian Primary Care Sentinel Surveillance Network (CPCSSN). The CPCSSN is a network of networks across Canada that includes 1,500 clinicians and almost two million patients. Contributing clinicians are located in all provinces except Saskatchewan and Prince Edward Island. For the purposes of this work, we used all CPCSSN data except those from Manitoba due to technical challenges in the data extraction process from this provincial network. Across CPCSSN, de-identified data are extracted from various EMR systems ($n = 11$) semi-annually and transformed to a standard CPCSSN schema to form a regional and pan-Canadian data repository. Each EMR system has a different architecture, and even within one EMR system there may be province-specific differences in the EMR structure where information is stored. As such, the transformation of EMR data to meet a standard CPCSSN schema includes advanced data cleaning and coding techniques. These data include information on patients' socio-demographic characteristics, providers, encounters/visits, health conditions, risk factors, biometrics, laboratory results, procedures, medications and referrals (Vijh et al. 2021).

Antibiotic prescribing for patients having a primary care visit (in-person or virtual) for RTI was based on a previously validated case definition (Wong et al. 2022). Potentially avoidable antibiotic use for RTI was based on Choosing Wisely Canada's recommendations (Choosing Wisely Canada 2020). For example, the Choosing Wisely Canada guidelines state that no antibiotics are indicated for an upper RTI (common cold) or bronchitis/asthma. With a diagnosis of sinusitis, a course of antibiotics over five days is recommended if a patient has at least two of the below-mentioned PODS symptoms, one of those being O or D AND symptoms lasting greater than 7–10 days OR the symptoms are severe OR there is no response after a 72-hour trial with nasal corticosteroids. PODS symptoms include the following: P = facial pain/pressure/fullness, O = nasal obstruction, D = purulent nasal or postnasal discharge and S = hyposmia/anosmia (smell) (Choosing Wisely Canada 2020).

Variables of interest

OUTCOME MEASURE

The main outcome is the proportion of RTI visits that resulted in an antibiotic prescription. This value is determined by measuring the number of RTI visits that received a prescription for an oral antibiotic (the antibiotics are listed in Appendix 1: Table A1, available online at longwoods.com/content/27093).

NEGATIVE CONTROL OUTCOME MEASURE

To understand the impact of potential time-varying confounding (Jandoc et al. 2015; Penfold and Zhang 2013; Wagner et al. 2002), we analyzed, as a control outcome, the proportion of visits for urinary tract infections (UTIs) that were treated with an antibiotic. This control

outcome was chosen because it has been previously validated (Ouldali et al. 2017; Simonsen et al. 2014) and because UTI is a condition that is often treated with antibiotics but has no overlap with COVID-19 symptoms. Antibiotics used to treat UTI are listed in Appendix 1: Table A2, available online at longwoods.com/content/27093.

For the main outcome measure, we used the previously validated sensitive and specific RTI algorithm (Wong et al. 2022). A diagnosis of RTI includes five syndromes: common cold, pharyngitis, sinusitis, otitis media and acute asthma/bronchitis. We report here on the aggregated RTIs. The negative control, UTI, is determined using a predefined algorithm. In order to minimize misclassification (antibiotics potentially prescribed for infections other than RTI or UTI), we excluded patients who had concomitant infections on the same day.

INDEPENDENT VARIABLE OF INTEREST: COVID-19 PANDEMIC

For the purposes of this study, the start of the COVID-19 pandemic is defined as April 1, 2020.

Statistical analysis

We conducted an ITS analysis using segmented linear regression, with the inclusion of an autoregressive parameter for secular trends and seasonality where appropriate (Jandoc et al. 2015). A time unit of 30 days (one month) was chosen based on the data to provide optimal precision to the model (see Appendix 2, available online at longwoods.com/content/27093). ITS modelling included adjusting for seasonality since the rate of RTI can be higher based on the season (e.g., winter).

SUB-ANALYSIS

To understand the effect of moving to virtual care, we used linear regression to examine antibiotic prescribing in the post-interruption period by service delivery mode (in-person versus virtual). This sub-analysis only includes data from sites with less than 30% missing rate for visit type after the COVID-19 pandemic. Within the sub-analysis dataset, any missing visit types are accounted for by single imputation.

All the work was approved by Queen's University's Research Ethics Board (FMED-6813-21).

Results

There were 1,523,592 patients with a valid birth year and sex; of these, 1,147,699 patients had at least one primary care visit between January 2017 and December 2021. During the time period, there were 316,958 unique patients that had at least one visit for an RTI. Among these patients, 266,598 had at least one visit for an RTI in the pre-pandemic period, 99,683 had at least one visit for an RTI in the post-pandemic period. Table 1 shows that there were more female patients, the median age was 41 years and most lived in an urban

TABLE 1. Sociodemographic characteristics pre- and post-pandemic for patients who visited primary care for an RTI

Characteristic	Pre-COVID-19 pandemic period (January 2017–February 2020)	Post-COVID-19 pandemic period (March 2020–December 2021)
Patients	<i>n</i> = 266,598	<i>n</i> = 99,683
Sex		
Female	156,929 (58.89%)	59,484 (59.73%)
Age group, years		
0–18	72,497 (27.19%)	24,474 (24.55%)
19–39	61,651 (23.13%)	24,677 (24.67%)
40–64	82,288 (30.87%)	32,111 (32.21%)
65+	50,162 (18.82%)	18,421 (18.48%)
Rurality		
Urban	216,055 (83.16%)	82,227 (84.65%)
Province		
British Columbia	18,597 (6.98%)	9,309 (9.34%)
Alberta	71,299 (26.74%)	27,999 (28.09%)
Ontario	163,567 (61.35%)	57,183 (57.36%)
Nova Scotia	12,141 (4.55%)	4,997 (5.01%)
Newfoundland	877 (0.33%)	188 (0.19%)
Quebec	117 (0.04%)	7 (0.01%)
Deprivation level		
Material		
1 (most deprived)	35,806 (28.41%)	13,617 (27.84%)
2	28,541 (22.64%)	11,191 (22.88%)
3	23,934 (18.99%)	9,440 (19.30%)
4	21,176 (16.80%)	8,123 (16.61%)
5 (least deprived)	16,587 (13.16%)	6,538 (13.37%)
Missing	140,554	50,774
Social		
1 (most deprived)	24,746 (19.63%)	9,161 (18.73%)
2	28,014 (22.23%)	10,609 (21.69%)
3	27,483 (21.80%)	10,840 (22.16%)
4	22,721 (18.03%)	8,942 (18.28%)
5 (least deprived)	23,080 (18.31%)	9,357 (19.13%)
Missing	140,554	50,774

RTI = respiratory tract infection.

area. Where a deprivation score could be created, there was an even distribution of patients in each social deprivation category in both time periods. In contrast, over one in four patients fell into the least materially deprived categories in both time periods.

Our analyses revealed that the prevalence of an acute RTI visit, as a proportion out of all visits to a primary care provider, dropped by 47.3% in the post-COVID-19 pandemic period (from 3.59% to 1.89%). Table 2 shows that the distribution of visits by RTI syndrome remains similar between the pre-COVID-19 pandemic and post-COVID-19 pandemic period for otitis media and sinusitis, with a slight drop for those diagnosed with pharyngitis (1.3%). There was a more substantial drop in visits for patients diagnosed with a common cold (8.4%) and an increase in visits for those diagnosed with bronchitis/asthma (9.5%) in the post-COVID-19 pandemic period. Compared with the pre-COVID-19 pandemic period, in-person visits decreased by 37% and virtual visits correspondingly increased.

TABLE 2. Pre- and post-pandemic visits for those diagnosed with an RTI

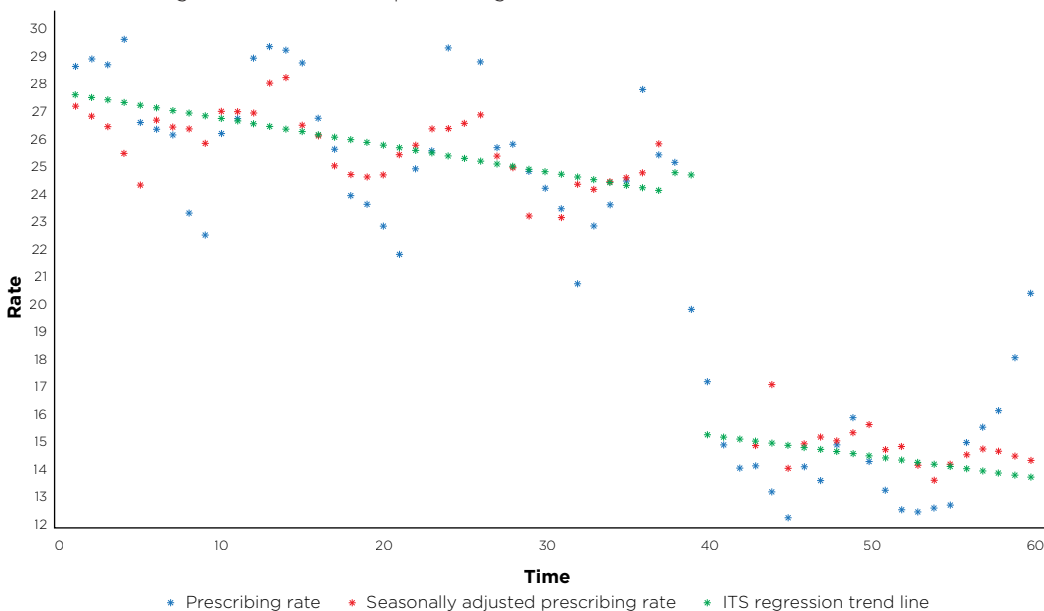
Characteristic	Pre-pandemic period (January 2017–February 2020)	Post-pandemic period (March 2020–December 2021)
Visits	<i>n</i> = 518,779	<i>n</i> = 162,541
RTI syndrome		
Otitis media	61,416 (11.84%)	19,894 (12.24%)
Common cold	207,978 (40.09%)	51,469 (31.67%)
Sinusitis	55,019 (10.61%)	16,916 (10.41%)
Pharyngitis	57,872 (11.16%)	16,036 (9.87%)
Acute bronchitis/asthma	136,494 (26.31%)	58,226 (35.82%)
Visit type		
Face-to-face	428,848 (73.87%)	67,911 (37.75%)
Virtual	3,287 (0.57%)	67,326 (37.42%)
Missing	148,432 (25.57%)	44,679 (24.83%)

RTI = respiratory tract infection.

Our results show that the pre-pandemic RTI antibiotic prescribing rate was 27.8% in 2017, falling by 0.1% each month. The onset of the COVID-19 pandemic led to a 9.4% statistically significant ($p < 0.001$) drop in prescribing in April of 2020 (see Figure 1). For this same time period, the antibiotic prescribing rates for UTI dropped slightly but was not statistically significant (see Figure A1, available online at [longwoods.com/content/27093](https://www.longwoods.com/content/27093)).

While this observed trend was consistent in both rural and urban settings, the baseline prescribing rate was significantly higher in patients living in a rural setting (see Figure 2).

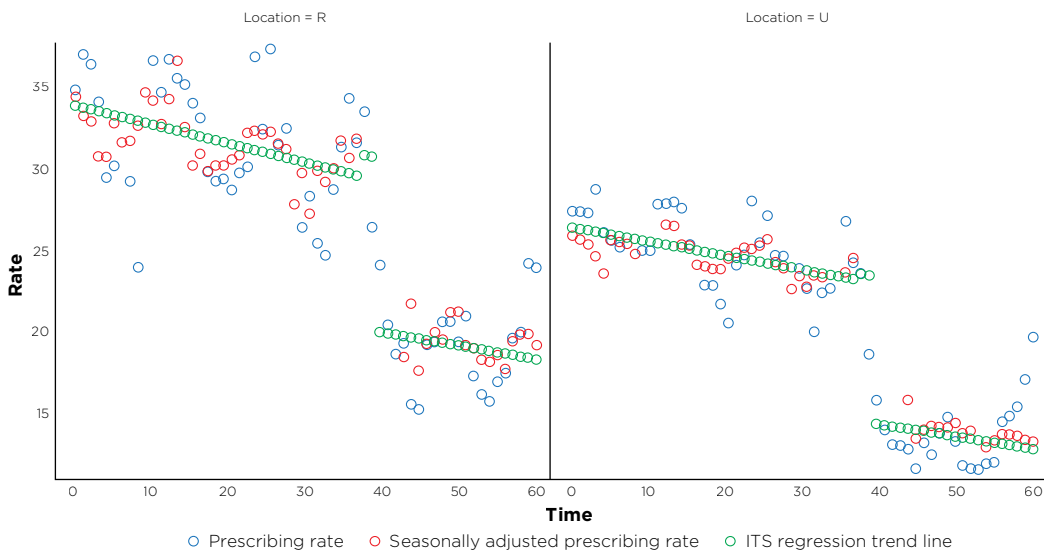
FIGURE 1. ITS regression of antibiotic prescribing rates for RTI



ITS = interrupted time series; RTI = respiratory tract infection.

Blue asterisks signify the observed monthly prescribing rates over time; red asterisks signify observed monthly prescribing rates with variance adjusted for seasonality; green asterisks signify the regression line.

FIGURE 2. ITS results for antibiotic prescribing rates in rural versus urban settings



ITS = interrupted time series; R = rural; U = urban.

Blue circles signify the observed monthly prescribing rates over time; red circles signify the observed monthly prescribing rates with variance adjusted for seasonality; green circles signify the regression line.

Analyses of antibiotic prescribing rates by provincial CPCSSN site suggests variability in baseline prescribing rates and the subsequent effect of the COVID-19 pandemic on prescribing levels (see Figure A2, available online at longwoods.com/content/27093). British Columbia, Alberta and Ontario had significant ($p < 0.001$) decreases in antibiotic prescribing rates. The same trend was not seen for Nova Scotia or Newfoundland.

Our analyses revealed that patients at all social and material deprivation levels experienced a significant drop in receiving an antibiotic prescription for their RTI (see Table 3). Interestingly, the baseline (pre-COVID-19 pandemic) trend reveals that patients with less social and material deprivation (more privilege) were being prescribed an antibiotic less often over time, with the rate of reduction three times higher than in patients with higher deprivation. This suggests treatment for RTI differed by deprivation level.

TABLE 3. ITS regression of antibiotic prescribing rates for RTI, by social and material deprivation level

Parameter	Estimate	Standard error	t value	p value
More socially deprived (3-5)[†]				
Intercept β_0	23.6306	0.5804	40.71	<0.0001
Baseline trend β_1	-0.0273	0.0271	-1.01	0.3190
Step change immediately after the start of the pandemic β_2	-9.4301	1.9172	-4.92	<0.0001
Trend change immediately after the start of the pandemic β_3	0.005327	0.0405	0.13	0.8957
Less socially deprived (1-2)[†]				
Intercept β_0	27.4206	0.6568	41.75	<0.0001
Baseline trend β_1	-0.0901	0.0308	-2.93	0.0050
Step change immediately after the start of the pandemic β_2	-10.9715	2.1734	-5.05	<0.0001
Trend change immediately after the start of the pandemic β_3	0.0364	0.0458	0.80	0.4298
More materially deprived (3-5)[†]				
Intercept β_0	25.1660	0.6573	38.28	<0.0001
Baseline trend β_1	-0.0137	0.0307	-0.45	0.6571
Step change immediately after the start of the pandemic β_2	-8.8168	2.1130	-4.17	0.0001
Trend change immediately after the start of the pandemic β_3	-0.0104	0.0447	-0.23	0.8176
Less materially deprived (1-2)[†]				
Intercept β_0	25.3687	0.5932	42.77	<0.0001
Baseline trend β_1	-0.0928	0.0278	-3.34	0.0015
Step change immediately after the start of the pandemic β_2	-11.0257	1.9688	-5.60	<0.0001
Trend change immediately after the start of the pandemic β_3	0.0412	0.0416	0.99	0.3263

ITS = interrupted time series; RTI = respiratory tract infection.

[†] Significant autocorrelation (seasonality) in the data series; an autoregressive term was included in the model.

Regression modelling shows that RTI prescribing rates did not significantly change based on whether the visit was in-person or virtual (see Table A3, available online at longwoods.com/content/27093).

Discussion

A silver lining of the COVID-19 pandemic was a significant drop in potentially avoidable

antibiotic prescribing in primary care. Certainly, the COVID-19 pandemic with its associated public health measures influenced a change in the epidemiology of circulating viruses (Kitano et al. 2021). It is also likely that patients with RTI were seen less often (Knight et al. 2022), because of other factors including: patient choice, more serious healthcare needs taking precedence and any benefits of implementing public health measures that reduced the rates of all communicable diseases (Brueggemann et al. 2021). Nonetheless, extrapolating our findings to the population, there could be almost 750,000 fewer patients prescribed a potentially avoidable antibiotic for RTI in primary care. Put another way, there could be 1.4 million fewer visits where an antibiotic was prescribed. Our analyses suggest evidence that technical value was added in that fewer potentially avoidable antibiotic prescriptions were generated.

The reason for the disparity in which rural areas saw higher antibiotic prescribing for RTI versus urban areas during the first year of the COVID-19 pandemic is not known. One possibility may be related to the differential impact of the COVID-19 pandemic, which saw a lower prevalence of COVID-19 in rural areas but potentially more marked changes in clinician–patient interactions where people were concerned regarding antibiotic supply. It is not surprising that those who had higher material or social deprivation received slightly higher antibiotic prescriptions for RTI compared with those who had lower deprivation. Past work suggests those with low socio-economic status (and, therefore, higher deprivation) have higher use when healthcare services are accessed (Langton et al. 2020). While we did not see any difference in antibiotic prescribing for RTIs by modality of visit, more work is needed to understand if this trend would continue.

Contributions of primary care in decreasing potentially avoidable prescribing could result in increased societal value. The use, including avoidable use, of antimicrobials continues to increase (OECD 2018). Today, the number and breadth of resistant organisms are mounting to unprecedented levels (CCA 2019). The global increase in AMR resulted in over 4.9 million deaths globally in 2019 and \$1.4–\$4.7 billion in costs to healthcare across North America and Europe (CCA 2019). While the emergence of AMR is a natural process, selection for these traits is facilitated by the overuse of antimicrobials (Olesen et al. 2018).

Consortiums such as the CPCSSN and primary care clinicians in collaboration with federal, provincial and territorial ministries of health could lead efforts in building a pan-Canadian EMR repository as an invaluable resource. These data can be used for practice improvement, health system planning, public health surveillance and policy making, especially when linked to other administrative data. EMR data are an important resource because of clinical data that are held within these electronic charts. Collecting these data once to be used by many actors, ranging from clinicians and practice staff to policy makers, for the purposes of public good and improved quality of healthcare is possible to inform practice improvement and healthcare resource allocation. Indeed, appropriate permissions to use de-identified data for quality improvement, public health surveillance, health system planning and research would be a prerequisite.

In the case of antibiotic prescribing for an RTI, EMR data analyzed by trusted third parties (e.g., CPCSSN in partnership with its network of practising primary care clinicians) could then partner with primary care practices and practice improvement organizations to deliver regular reports about prescribing for RTI at the practice, regional and federal levels. If the target audience was primary care practices, the reports could include Choosing Wisely antibiotic guidelines and alternative tools such as a viral prescription pad for clinicians to use when working with patients who have an RTI. If the target audience were regional or federal, policy makers could partner with primary care and public health leaders to develop strategies to incentivize appropriate prescribing (clinician behaviour) and public health media campaigns aimed at changing patient behaviour.

At the practice level, the ability for individual prescribers to see their own data compared with their peers' data can spur practice improvement. Clinicians' EMR data can be used to develop insights through a plan-study-do-act cycle. Practice teams can tailor treatment by delivering a viral prescription (Choosing Wisely Canada 2020) or other team-based care interventions to help patients meet their healthcare needs.

At the health systems level (provincial, territorial and federal) investment in a pan-Canadian primary care EMR repository develops an essential data source toward a public health communicable and non-communicable disease surveillance system containing data from the community. Primary care practice data could help public health professionals conduct surveillance and community assessments, while access to public health data for primary care team members allows them to observe information on community needs beyond the "micro" practice level and conduct proactive risk identification (Committee on Integrating Primary Care and Public Health et al. 2012). The primary care EMR data fill a gap because accurate measurement of antibiotic prescribing practices, for example, in primary care remains virtually nonexistent in Canada even though existing institutional programs are effective and have resulted in reduced antibiotic use and AMR (Cecchini et al. 2015; Price et al. 2018).

The EMR data ought to be linkable to other existing publicly funded administrative datasets (e.g., hospital discharge abstracts, dispensed medications) to provide additional value for health systems planning. Networks such as the Canadian Primary Care Research Network (<https://cpcrn-rcrsp.ca/>) and Chronic Disease Networks (CIHR 2022) play important roles in bringing together patients, clinicians and practice-based research learning networks (PBRLNs) and policy and decision makers to carry out further research and development. These networks can create virtual/online collaborative learning communities for PBRLNs (Westfall et al. 2019) where they use the data for learning purposes. For example, our work suggests antibiotic prescribing for RTI in the pre-COVID-19 pandemic period was heterogenous. These learning communities provide opportunities for clinicians and practices of provincial PBRLNs to learn and generate practice knowledge that could be tailored to their provincial context.

Limitations

This work should be interpreted with caution. The EMR data captures what is prescribed in participating practices. It is possible that patients could go elsewhere (e.g., walk-in clinics) to obtain prescriptions. This work captures only data from participating clinicians and clinics; therefore, potentially avoidable antibiotic prescriptions may be underreported. Some of the prescriptions deemed avoidable may, in fact, not be avoidable after considering clinical presentation. We, therefore, have used the term “potentially avoidable” throughout this work. The data are only as accurate as what is entered into the EMR by the clinician. It is possible that RTI was over-reported early during the COVID-19 pandemic. Lower antibiotic prescribing rates in primary care could have occurred given public health efforts to direct people to COVID-19 centres. Finally, EMR data quality efforts are relatively nascent when compared with administrative data. However, this large dataset has shown unique insights not possible with more developed administrative data sources.

Despite its limitations, this study provides evidence for the value of developing EMR data further as a pan-Canadian resource. This resource can be collected once and used by many. Clinicians and their practice staff could use these data for driving practice improvement. Individual clinicians can compare their own data with that of their peers in their practice or geographical area for purposes of individual reflection. Larger practices could work with a practice improvement lead to nudge improvements at the practice level. For example, practices could incorporate reports derived from their EMR data into a plan-do-study-act cycle on decreasing potentially avoidable antibiotic prescriptions for RTI. With appropriate approvals and permissions, researchers and health system planners could use data for directing resources upstream to primary care and public health efforts. One example is Hennepin Health in Minnesota, an accountable care organization with four partners: the Hennepin County Human Services and Public Health Department; the Hennepin County Medical Center; North Point Health, a federally qualified health centre; and the Metropolitan Health Plan, a non-profit, county-run, Medicaid-managed care plan. They all rely on EMR data linked to health plan billings and enrollment and social service records (Sandberg et al. 2014). Data are provided through an electronic dashboard tailored to team members’ needs. These data are also used by the care organization to stratify people into risk tiers and to have community health workers and social workers connect those at the highest risk to primary care and other medical, behavioural or social services.

Conclusion

In conclusion, this work uses the case of potentially inappropriate antibiotic prescribing for RTIs to illustrate the value of EMR data. Using these data to inform policies and practices aimed at altering the potentially inappropriate use of antibiotics in primary care can strengthen healthcare systems and improve individuals’ healthcare outcomes.

Disclaimer

The statements expressed herein are solely those of the authors and do not reflect those of the data source, the National Institutes of Health, the Department of Health and Human Services or the United States government; no endorsement is intended or should be inferred.

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Use of Electronic Medical Record Data to Create a Dashboard on Access to Primary Care

Utilisation des données du dossier médical électronique pour créer un tableau de bord sur l'accès aux soins primaires



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Abstract

Objective: This study aims to present a proof of concept of a dashboard on a set of indicators of access to primary healthcare (PHC) based on electronic medical records (EMRs).

Methods: This research builds on a multi-method design study including (1) a systematic review, (2) a pilot phase and (3) the development of a dashboard.

Results: Eight indicators were carefully selected and successfully extracted from EMRs obtained from 151 PHC providers. Indicators of access over time, as well as among providers and among clinics, have been enabled in the dashboard.

Conclusion: EMR data enabled the development of a real-time dashboard on access, giving PHC providers a reliable portrait of their own practice, its evolution over time and how it compares with those of their peers.

Résumé

Objectif : Cette étude vise à présenter une preuve de concept d'un tableau de bord sur un ensemble d'indicateurs d'accès aux soins de santé primaires (SSP) basés sur les dossiers médicaux électroniques (DME).

Méthode : Cette recherche s'appuie sur une étude de conception multi-méthodes comprenant (1) une revue systématique, (2) une phase pilote et (3) le développement d'un tableau de bord.

Résultats : Huit indicateurs ont été soigneusement sélectionnés et extraits avec succès des DME obtenus auprès de 151 prestataires de SSP. Des indicateurs d'accès dans le temps, ainsi qu'entre prestataires et entre cliniques, ont été activés dans le tableau de bord.

Conclusion : Les données des DME ont permis de développer un tableau de bord en temps réel sur l'accès, donnant aux prestataires de SSP un portrait fiable de leur propre pratique, de son évolution dans le temps et de sa comparaison avec celles de leurs pairs.

Introduction

Value in healthcare has been defined as “the contribution of the health system to societal wellbeing” (Smith et al. 2020: 3), which is the cornerstone of health, wealth and the healthcare system. It should be aligned with the values of patients, clinicians, decision makers and health organizations (Kuluski and Guilcher 2019; Wodchis 2019) to optimize patients' health outcomes and the allocation of resources (Porter and Lee 2013; Smith et al. 2020; Teisberg et al. 2020). One lever that has been proposed to improve value in healthcare is to strengthen primary healthcare (PHC). PHC is the cornerstone foundation of the healthcare system, where 80% of patients' needs are met (WHO 2018).

In Canada, access to PHC is one of the main challenges faced by the healthcare system. Resolving this issue is a priority for patients, clinicians and governments. Although the importance of PHC has been highlighted in the past decades, data on the delivery of PHC are underused (Wong et al. 2019). Indeed, access to and use of these data are necessary for practice improvement (Hogg and Dyke 2011) as measuring change is necessary to develop, sustain and spread improvements (Langley et al. 2009). Furthermore, to comprehensively evaluate PHC services and enable actionable decisions, multiple data sources should be linked to capture all relevant professional and organizational information. This may include electronic medical records (EMRs), administrative databases or patient surveys (including patient-reported experience and outcome measures [PREMs and PROMs]) (Wong et al. 2019). The implementation of EMRs in medical clinics over the past decade has provided an opportunity to measure and improve PHC. However, until now, EMR data have been underused in Canadian PHC, depriving the healthcare system of a rich source of timely data.

EMR data have previously been used in Canada to develop dashboards, which are visualization tools based on both text and graphic support, allowing for timely monitoring of clinical or organizational outcomes. Dashboards are quality improvement tools that can optimize the performance of health organizations, document patients' health needs and support timely decision making based on data made available in real time (Ehsani-Moghaddam et al. 2021; Singer et al. 2021). One example in which dashboards are used in PHC is the Canadian Primary Care Sentinel Surveillance Network, a population-level health surveillance system used to monitor chronic diseases in Canada based on EMR data (Williamson et al. 2014). Dashboards represent an invaluable source of information to improve PHC access because they capture the processes and outcomes of access as recorded by healthcare professionals and administrative staff.

This article presents a proof of concept of a dashboard on access to PHC based on EMR data. The specific objectives are to describe the key steps undertaken to develop such a dashboard, namely, to:

- map, conceptualize and validate a set of indicators of access to PHC;
- pilot the extraction and measurement of access indicators; and
- create a dashboard to enable comparisons of indicators longitudinally among professionals and across organizations to support reflective practice.

The findings demonstrate the feasibility and relevance of an access dashboard and inform decision makers and researchers interested in developing such a tool in order to assess the performance of organizations and evaluate large-scale reforms.

Methods

This study was based on a sequential multi-method design informed by (1) a systematic review of indicators of access and validation through expert consultations, (2) a pilot phase of data extraction from EMRs and (3) the development of a dashboard to compare data over time, both among professionals within a clinic and between clinics. Although there is no unique methodology to develop healthcare dashboards, we have followed the steps recommended by the Centers for Medicare and Medicaid Services (Centers for Medicare and Medicaid Services n.d.). These steps include identifying the goal of the dashboard, determining its audience, selecting key indicators to track, extracting data and interpreting findings. They may occur in a different order, iteratively or not, depending on the purpose of the dashboard and the availability of the data.

Objective #1: Map, conceptualize and validate a set of indicators of access to PHC

SYSTEMATIC REVIEW

First, we conducted a systematic review to map a comprehensive list of indicators on access to PHC. The search strategy was inspired by Rose et al.'s (2011) systematic review on

“Advanced Access Scheduling Outcomes.” We searched MEDLINE, HealthStar, PsycINFO and CINAHL databases for papers published between 2001 and April 2021 covering three key concepts: “advanced access,” “primary care” and “indicators.” The advanced access model is one of the most recommended models around the world to improve timely access (Breton et al. 2020). The model ensures that patients obtain access to the appropriate health-care services within a time frame dictated by their needs (Breton et al. 2022). The search strategy is outlined in Appendix 1 (available online at longwoods.com/content/27092). The twofold screening process was conducted independently by two analysts. Theoretical and empirical papers were retained, whereas commentaries, theses, protocols and policy briefs were excluded.

The first step, based on the reading of titles and abstracts, consisted of removing duplicates, papers in a language other than English or French and papers on irrelevant topics. The second step involved a detailed review of the remaining articles to identify papers reporting on access indicators. For systematic reviews, we returned to the original studies. Finally, the two analysts extracted all indicators that operationalize access along with their definitions and data sources. Indicators were then ranked by the number of occurrences.

EXPERT CONSULTATION

A committee of 17 experts was purposefully selected to validate the list of indicators identified by the systematic review. Participants were selected based on their expertise on access or healthcare indicators in general. All of the experts who were contacted, except for one, accepted the invitation. The committee was composed of five decision makers, six clinicians and six researchers with expertise on access in Quebec. A two-hour virtual meeting took place in June 2021. Participants were first presented with the results of the systematic review. The definitions of each indicator were then discussed. Participants were then split into two groups to participate in a structured brainstorming activity with a trained facilitator to generate additional indicators that could be used to appreciate access to PHC. The usefulness of each indicator and its feasibility and reliability based on the data available to generate the indicator were discussed.

Objective #2: Pilot the extraction and measurement of access indicators

The research team shortlisted the indicators based on the expert consultation and the data available in the EMRs. We extracted data and generated indicators collected from health-care professionals involved in another research project conducted by the research team (Gaboury et al. 2021). As part of this project, we had ethics approval to access available EMRs with the involved professionals. To further refine the assessment of the feasibility and reliability of each indicator, our research team manually extracted and measured the indicators on a weekly basis (Tuesday mornings before the clinic opened). Each EMR software tracks data differently and uses different definitions for its indicators. Furthermore, multiple clinics using the same EMR might register data differently within their own processes. Thus,

this step necessitated a thorough clean-up and organization of the extracted data to enable the translation of each EMR indicator and tracker into a single codebook and to ensure the quality of the extracted data.

Objective #3: Create a dashboard to enable longitudinal comparisons of indicators

We measured data through EMRs in real time to build the dashboard. Every week for 12 months (January 2022 to December 2022), our dashboard was filled in by eight clinics. The dashboard aims to compare indicators over time, as well as medians, means and standard deviations among professionals and among clinics. The visuals and the presentation of the data in the dashboard were improved through some iterations.

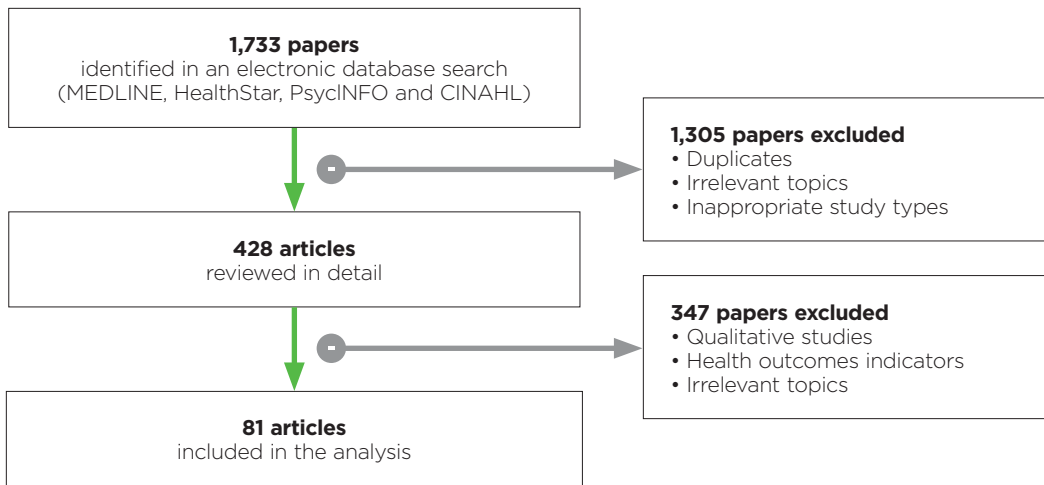
Results

Objective #1: Conceptualize and validate a set of indicators of access to PHC

SYSTEMATIC REVIEW

The initial search identified 1,733 citations, of which 1,305 were excluded based on title and abstract reviews (Figure 1). Of the remaining 428 articles, 81 were included in the analysis, representing 12 indicators of access.

FIGURE 1. Flow diagram of search strategy results



Of the 81 papers identified, 36 studies reported on several indicators. As shown in Table 1, the level of operationalization of the 12 indicators (i.e., providing a definition) varied across papers. Although the definitions were generally homogeneous, some indicators were presented without being formally defined or rigorously operationalized. The two most common indicators were “waiting time for appointment” and “no-show,” which were used in 38 and 36 articles, respectively. “Third next available appointment” and “continuity” each appeared

Use of Electronic Medical Record Data to Create a Dashboard on Access to Primary Care

TABLE 1. Twelve indicators of access based on the systematic literature review

No. of occurrences	Indicator	Definition	Data sources
38	Wait time for appointment	Time from the date of the request to the date of the service	Clinic logs, EMR
36	No-show	Whether the patient attend their scheduled appointment	Clinic logs, EMR
		An appointment that the patient does not attend or cancels with less than half a day's notice	
20	Third next available appointment	Average length of time in days to the third available appointment for a new patient's physical or routine exam or return visit	Clinic logs
20	Continuity	Percentage of visits with the patient's designated provider	Clinic logs, EMR Clinic's monthly patient survey Survey built by the authors Usual Provider Continuity Index Modified Modified Continuity Index Continuity of Care Index Continuity for the physician
		Patients responded "yes" to this: "Did you see the clinician that you preferred to see today?"	
		Continuation from the first through the fourth treatment session	
		Number of appointments a physician has with their assigned patients over the physician's total number of appointments	
		Number of providers providing service to a patient and the percentage of care provided by each provider	
		Dispersion between providers (based on the number of caretakers and number of visits only)	
14	Patient volume	Number of patients accessing the service in a determined period	Clinic logs
6	Productivity	Time taken per visit	Clinic logs, EMR
4	Cancellation	Provider's or patient's cancellation of the appointment	Clinic logs, EMR
2	Loss to follow-up	None	Clinic logs, EMR
2	Open slots	Percentage of open appointment slots at the beginning of the day	Clinic logs
1	Visits lost to outside providers	Visits lost to urgent care	Clinic logs
1	Patient seen on their day of choice	None	Clinic logs
1	Workload	Appointments made on five non-consecutive days, divided by the number of registered patients	Clinic logs

EMR = electronic medical record.

in 20 articles, and “patient volume” appeared in 14 articles. Indicators reported six or fewer times in the literature included “productivity,” “cancellation,” “loss to follow-up,” “open slots,” “visit lost to outside providers,” “patient seen on their day of choice” and “workload.” Appendix 2 (available at longwoods.com/content/27092) presents the details of Table 1 and a list of the references from the systematic review.

The data sources for indicators varied from electronic forms, EMRs, clinic logs (i.e., non-electronic databases kept by health services), validated surveys such as the Usual Providers Continuity Index (Jee and Cabana 2006) and Continuity of Care Index (Bice and Boxerman 1977) to survey tools developed by researchers. Only 33% of the articles were based on EMRs, and these covered six indicators (wait time for appointment, no-show, continuity, productivity, cancellation and loss to follow-up).

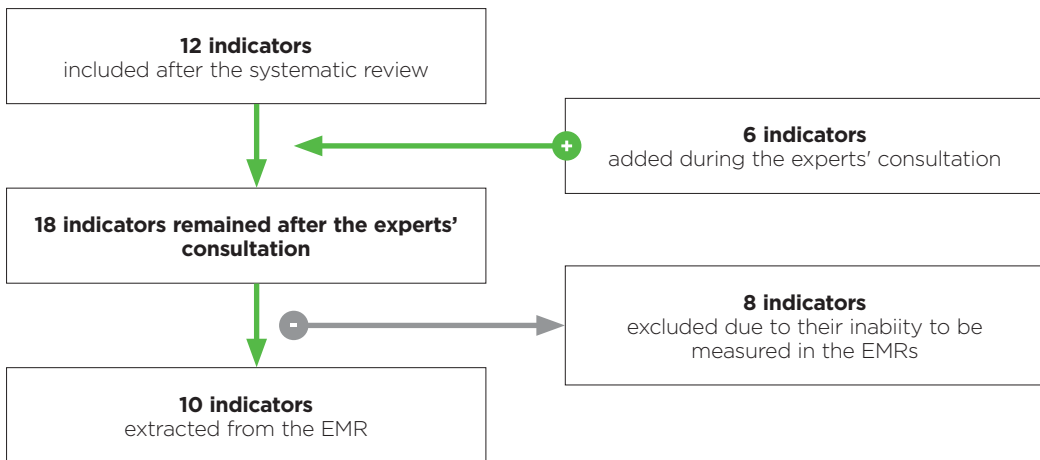
EXPERT CONSULTATION

The expert committee added six other indicators that could be derived from EMRs or administrative databases to the 12 indicators identified by the systematic review: (1) clinician supply, (2) patient demand, (3) consultations in other PHC clinics, (4) future capacity, (5) professional diversity of care and (6) use of walk-in clinics. The committee recommended adding characteristics of the supply and demand of each clinician to estimate balance. This consisted of creating a profile of registered patients by age and assigning them a vulnerability code to estimate the appropriate number of consultations. These two indicators support clinician reflection on the planning of service delivery.

Objective #2: Pilot the extraction and measurement of access indicators

From the list of 18 indicators, 10 were shortlisted by the research team based mainly on the capacity to measure them using EMR data (see Figure 2 and Table 2).

FIGURE 2. Flow chart of the selection of access indicators to be extracted from the EMR



EMR = electronic medical record.

Use of Electronic Medical Record Data to Create a Dashboard on Access to Primary Care

TABLE 2. Ten indicators on access to PHC selected for measurement through the EMR

Indicator	Operationalized definition
Clinician supply	Number of consultations within the previous year (can be broken down by patient type: registered, unregistered and unattached patients) to estimate the annual supply
Patient demand	Number of appointments within the previous year where a patient presented (can be broken down by patient type: registered, unregistered and unattached patients) to estimate the annual demand
Discontinued care for patients with chronic disease	Number of patients with a targeted chronic disease who have not visited any professional at the clinic within the previous years
Future capacity	Proportion of appointments still available within the next two and four weeks out of the total number of scheduled slots Slots dedicated to specific populations or cases (obstetrics, paediatrics, mini-surgeries, etc.) are not considered available slots Calculated every Tuesday morning
48-hour capacity	Proportion of appointments still available within the next 48 hours (urgent needs) out of the total number of scheduled slots Slots dedicated to specific populations or cases (obstetrics, paediatrics, mini-surgeries, etc.) are not considered available slots Calculated every day the clinic is open
Professional diversity of care	Among the registered patients of a given professional, the proportion of consultations offered by different types of professionals in the clinic (social workers, nurses, pharmacists)
Relational continuity	Among a physician's registered patients, the proportion of medical visits with the physician over the total number of visits with any physician, resident or nurse practitioner at the clinic
Third next available appointment	Number of days between the present and the third available appointment slot in each physician's schedule, excluding those dedicated to specific populations or cases (obstetrics, paediatrics, mini-surgeries, etc.) Calculated on Tuesday mornings
Use of walk-in clinics	Among the registered patients of a given professional, proportion of visits that were not pre-booked out of the total number of visits Could also be calculated for a resident or a nurse practitioner
No-show	Among registered patients, the number of appointments classified as "no-show" out of the total number of appointments made during the same period

EMR = electronic medical record; PHC = primary healthcare.

We piloted the extraction of the data for these 10 indicators. Discontinued care for patients with chronic diseases was a key indicator for the expert committee. However, there was no consensus on which chronic diseases to target. Moreover, the quality of the data entered for chronic disease status varied greatly across clinics and among professionals. For these reasons, we eventually stopped piloting this indicator. In addition, manually extracting data to measure future capacity was found to be quite labour intensive. Thus, the extraction of this indicator was put on hold during piloting and was not integrated into the final indicators.

Objective #3: Create a dashboard to longitudinally compare access indicators to support reflective practice

We developed a real-time dashboard structure based on eight indicators; two indicators related to characteristics of the clinical practice (clinician supply and patient demand) and six related to access (third next available appointment, relational continuity, 48-hour capacity, use of walk-in appointments, professional diversity of care and no-shows). We extracted and measured the eight indicators for 151 PHC professionals at eight clinics, including 123 family physicians, 16 registered nurses and 12 health professionals (psychologists, social workers, pharmacists) over 12 months (January 2022 to December 2022).

Clinician supply and patient demand are measured yearly, third next available appointment and future capacity are measured weekly and 48-hour capacity is measured daily. The remaining indicators are measured every month.

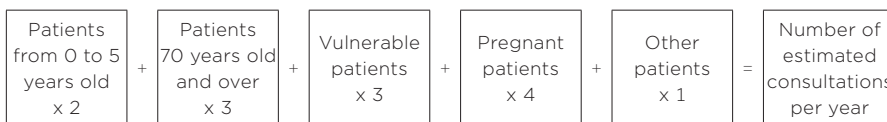
The dashboard was constructed for health professionals to compare data with others in their own clinics and with other professionals sharing the same type of practice in other clinics, and to compare data among clinics. This also helps show the effects of improvements or differences across regions.

ESTIMATED BALANCE

We calculated the yearly supply of each clinician based on the number of appointments given in the previous year. This indicator can be compared with the estimated demand of their practice based on the number and characteristics of their patients in order to evaluate if their practice is balanced or if they need to adjust their workload.

Demand is estimated based on the recommendations of the Fédération des médecins omnipraticiens du Québec (FMOQ), which establish a number of consultations per year for each patient based on a set of characteristics, such as age and vulnerability (Table 3). Patients were considered vulnerable if they were assigned at least one of the 19 vulnerability codes defined by Quebec’s Health Insurance Board, the Régie de l’Assurance maladie du Québec, based on the presence of certain diagnoses (e.g., diabetes, chronic obstructive pulmonary disease, mental health disorders) (Breton et al. 2015).

TABLE 3. Calculation of estimated demand



Supply is calculated for each clinician’s practice in the previous year (Table 4). Because many clinicians have diverse practices that include non-registered patients or walk-in patients registered with other clinicians at the same clinic, a detailed summary of the various types of appointments provided is included in the dashboard.

TABLE 4. Information provided about appointments during the previous year

	Estimated demand	Individual clinician supply	Clinic-wide supply
Patients registered with the physician	998	748 (46%)	50%
Other patients registered at the clinic	-	457 (28%)	43%
Non-registered patients	-	426 (26%)	7%
Total	-	1,631	-

These data can help each clinician adjust their practice. As seen in Table 4, the physician did not provide enough consultations for their registered patients in the past year but provided many more services to non-registered patients than the rest of the clinic. Based on these results, they may choose to focus their practice on their registered patients or transfer some patients to other clinicians at the clinic.

THIRD NEXT AVAILABLE APPOINTMENT

The third next available appointment is recognized as one of the key indicators of advanced access. Studying variations over a long period of time and comparing them with other clinicians at the same clinic can help clinicians make better decisions regarding their practices. In the example shown in Figure 3, the third next available appointment is available sooner with Dr. A than with the rest of the clinic. During summer, we have observed a longer delay.

FIGURE 3. Example of the visual provided to each physician to evaluate the third next available appointment

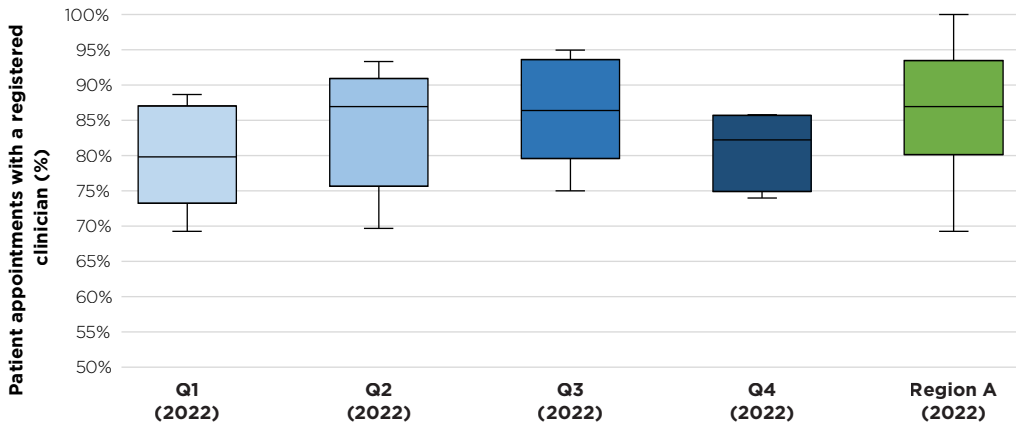


RELATIONAL CONTINUITY

Continuity is an important indicator for advanced access as it evaluates whether or not each clinician’s registered patients can obtain an appointment with their own registered clinician or if they have to consult other doctors, who are often less familiar with their health conditions. Comparing continuity of care across different clinics can help managers address issues within their establishments. The example provided in Figure 4 shows the distribution of

rational continuity at each quarter at a clinic compared with the region's average and distribution over the past year.

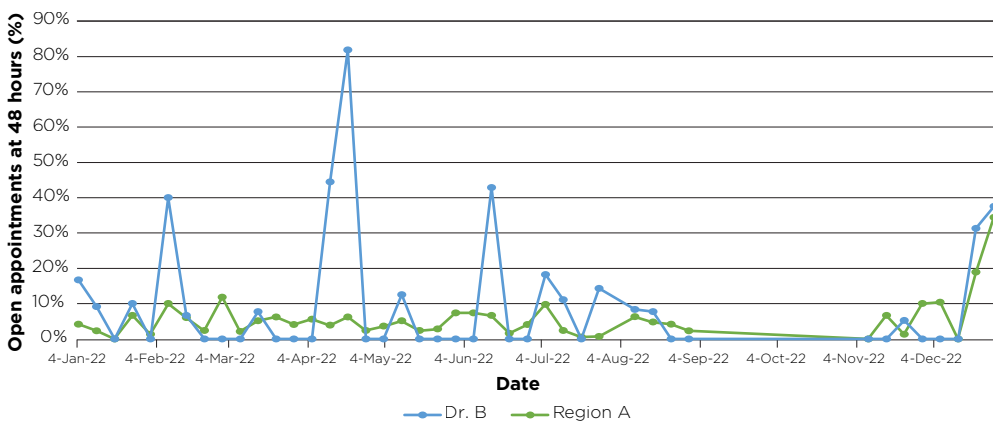
FIGURE 4. Relational continuity of an example clinic compared with all other clinics



48-HOUR OPEN APPOINTMENTS

The proportion of appointments available within 48 hours is a strong indicator of clinician availability for urgent care, another important part of the advanced access model. This indicator can be captured in real time on a daily basis, and comparisons of the individual results of each clinician with similar clinicians in their region can provide them with critical information to adjust to trends in data. Figure 5 shows that Dr. B has inconsistent availability for appointments at a 48-hour notice, having a high percentage of open appointments for some weeks and no open appointments for others.

FIGURE 5. Example of the visual provided to each physician to evaluate their 48-hour open appointments



Discussion

We demonstrated that it is possible to create a dashboard on PHC access based on real-time data extracted from different EMRs. We identified eight key indicators based on a systematic literature review, consultations with experts and piloting in eight clinics. Two more indicators were identified as relevant, “discontinued care for patients with chronic diseases” and “future capacity,” but required further efforts to ensure their validity and feasibility.

The indicators “third next available appointment,” “relational continuity” and “use of walk-in clinics” offer data related to the general availability of clinicians and insight into timely access to needed services. These indicators measure the number of patients who cannot access the physician with whom they are registered and have to resort to consulting other physicians at the clinic. Continuity and access to primary care are two important and connected concepts (Haggerty et al. 2003). In fact, a recent Canadian study reported that decreased PHC access was associated with a 6% reduction in a physician’s continuity of care and a higher number of emergency department visits (Cook et al. 2020). When access to a clinician or team who know the patient is impeded, it follows that the patient will seek services from another clinician or organization, which jeopardizes the continuity of services. Another study from our research team revealed that patients preferred waiting a few days for a consultation with a professional who knew them rather than having a more rapid consultation with any healthcare professional, even for urgent or semi-urgent needs (Breton et al. 2022). The main challenge becomes finding a way to improve both timely access to PHC and continuity with a professional and an organization that know the patient.

Two of the key indicators retained are designed to evaluate the level of day-to-day availability of clinicians for their patients. The indicator “48-hour capacity” represents the availability of primary care providers for urgent care for their patients, whereas “third next available appointment” quantifies the general week-to-week availability of doctors. The third next available appointment is the most accurate indicator for measuring timely access in PHC (Pickin et al. 2004). It reflects availability more accurately than the first or second available appointments as these can result from a recent cancellation or an unanticipated event (Breton et al. 2020). Along with “future capacity,” these indicators provide insights into whether patients can be seen at the right time with regard to their needs (urgent, semi-urgent or non-urgent) and whether a professional has a balanced schedule and can manage variations in demand over time.

“Professional diversity of care” is a good measure of quality rather than access and ensures that each patient is seen by the appropriate professional. This is central to a timely access strategy (Murray et al. 2003). Often patients default to seeing a physician for any of their healthcare needs, which is not always effective to ensure either the quality of care or an optimal use of resources. For example, prescription renewals for a condition deemed stable could be done by a registered nurse or a pharmacist. Some mental health consultations could also benefit from direct access to a social worker or a psychologist. Making sure that all

professionals at PHC clinics work in a way that maximizes their scope of practice is crucial to achieving high quality in healthcare.

The proportion of appointments where the patient was not present (i.e., “no-shows”) has been recognized in the literature as a good proxy for general access to care. Patients who cannot access quality care within a reasonable time frame are more likely to miss appointments because they no longer need treatment, have received care elsewhere or have simply forgotten. Therefore, an underlying timely appointment system leads to greater efficiency with fewer missed appointments. Of note, our study revealed relatively fewer no-shows (average 2%) and greater stability in this indicator when the implementation of timely access strategies was well underway. Paying attention to this indicator may, therefore, be more relevant during the early stages of the implementation of such strategies or when access is quite limited for a given clinician (Steinbauer et al. 2006).

The indicator of “discontinued care for patients with chronic diseases” is quite relevant in the context of implementing timely access strategies. Most often, such strategies rely on making patients responsible for booking appointments when they need them as opposed to maintaining a backlog or recall lists (Breton et al. 2017). Several professionals have voiced concerns with respect to losing some of their most vulnerable patients by not providing appointments in advance (Abou Malham et al. 2017). This indicator could then function as a balancing indicator and act as an unseen benefit to help avoid unintended consequences of such a care organization strategy.

The piloting of data extraction was done as part of a research project under the regulation of an ethics committee. Such a process was instrumental and essential to access nominal data to develop a dashboard. Creating a dashboard within a research project under the jurisdiction of a research ethics committee temporarily allowed us to circumvent regulatory requirements, a strategy that has been shown to be efficient for other innovation scale-up projects in PHC, such as eConsultation (Breton et al. 2019; Moroz et al. 2020). This facilitated the consent process, from the clinics’ perspective, to provide access to confidential and sensitive data. Access to nominal data is an important barrier to scaling up the use of a dashboard by policy makers.

Another barrier to gathering data into a single dashboard is the fact that the data must be extracted from various EMRs, which are under the governance of various private EMR providers. This is an important barrier to accessing and extracting data in a secure manner for a single repository. EMRs differ substantially within and between provinces, and the regulations surrounding data management and use may also vary. Standardizing data management policies would greatly facilitate the process of data extraction and comparisons within and among organizations and across provinces.

One of the success factors for clinics to adopt the dashboard was the offer of a personalized feedback report in the near future along with comparisons with similar individuals and organizations. We believe that providing each professional with a reliable picture of their own practice, its evolution over time and how it compares with those of their peers will contribute

to the implementation of key elements to facilitate an improvement process to increase access to and, more broadly, quality of care.

Another success factor was working in partnership with professional associations to provide continuing education credits following a reflective activity supported by the personalized feedback report. To do so, professionals will be invited to complete a brief continuous quality improvement activity and to document the experience (identifying areas for improvement, setting an improvement goal and identifying ways to assess whether the change resulted in improvement). For this project, the FMOQ will provide the equivalent of one hour of training to complete this reflective exercise.

The creation of a dashboard is an essential component to improve access and support professionals and decision makers in quality improvement projects. Investing in the development and implementation of such a dashboard is even more important considering that Canada is one of the worst countries on access indicators (CIHI 2017, 2021). The next step in the creation of a provincial dashboard will be to increase the number of participating clinics, which will be facilitated by using an automated extraction approach fed by various EMRs from all PHC clinics. An automated extraction software fed by five EMRs has been developed in collaboration with a specialized programming firm and is operational. We are in the process of obtaining accreditation from the Ministry of Health and Social Services in Quebec to authorize external connections between the automated extraction software and EMRs in compliance with safety standards.

Ultimately, the adoption of a provincial dashboard by professionals and practices will play a key role in establishing a comprehensive benchmarking system. Benchmarking can be defined as the process of measuring key indicators, identifying the organizations or settings that score most favourably on these indicators, understanding the characteristics and practices of these top organizations and spreading these practices to bring other organizations to the same level (Ellis 2006; Ettorchi-Tardy et al. 2012). Benchmarking is one of five approaches to instigate significant changes in healthcare. The next step is to spread the dashboard and create a benchmarking system to learn from the top-performing organizations and professionals.

Strengths and limitations

One of the strengths of this study is that it draws on several complementary methods to develop a valid, acceptable and reliable dashboard on PHC access. We have demonstrated that it is possible to connect different EMRs to a common dashboard in real time.

Another strength lies in our capacity to respect data privacy when producing comparative reports and our independence from any governing or decision-making bodies. Our research team has access to these nominal data with the permission of an ethics committee and the agreement of the clinicians. Data are always presented anonymously, even when comparisons are made at the organizational level.

At the current time, one of the main limitations of the access indicators extracted from the EMRs is that they do not allow for the evaluation of any indicators outside the clinic. Access to data on services used outside the clinic would make it possible to better grasp the trajectory of patients for access to PHC services.

Conclusion

Timeliness of data reporting could support quality improvement initiatives and add value to our healthcare systems. The use of EMRs embedded in organizations offers exceptional potential for appreciating and contributing to the improvement of access in real time. Access is a priority for health system improvements, and tools must be developed to assess PHC access in a contemporary and meaningful manner. The dashboard on access is a key step to support quality improvement. To support professionals and organizations to improve PHC, political authorities have to support and fund the creation of a provincial dashboard on PHC to fuel data-informed reflective practice.

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Patients Living with Social Vulnerabilities Experience Reduced Access at Team-Based Primary Healthcare Clinics

Expérience d'accès réduit aux équipes cliniques de
première ligne chez les personnes aux prises avec
des vulnérabilités sociales



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Abstract

Objective: This study aims to explore differences in access to care as experienced by patients registered in team-based primary healthcare clinics according to their social vulnerability profile.

Method: A total of 1,562 patients from four team-based primary healthcare clinics completed an e-survey conducted between June and November 2021. The social vulnerability index was used to compare the experiences.

Results: Patients with low vulnerability consulted at emergency rooms three times more often because their family physician was not available ($p = 0.006$) than patients with no vulnerability. Lack of continuity was reported two times more often by patients with low vulnerability related to team members not knowing their recent medical history ($p = 0.006$) and by patients with high vulnerability related to no one being in charge of their file ($p = 0.023$). Both vulnerable groups reported receiving contradictory information more often than patients with no vulnerability.

Conclusion: Patients with high vulnerability experienced more access difficulties related to continuity, interprofessional collaboration and communication with providers.

Résumé

Objectif : Cette étude a pour objectif d'explorer les différences d'accès aux soins vécues par les patients inscrits dans une équipe clinique de première ligne, selon leur profil de vulnérabilité sociale.

Méthode : Au total, 1 562 patients de quatre équipes cliniques de première ligne ont répondu à un sondage en ligne entre juin et novembre 2021. L'indice de vulnérabilité sociale a été utilisé pour comparer les expériences.

Résultats : Les patients à faible vulnérabilité ont consulté trois fois plus souvent aux urgences, parce que leur médecin de famille n'était pas disponible ($p = 0,006$), que les patients sans vulnérabilité. Le manque de continuité a été rapporté deux fois plus souvent par les patients à faible vulnérabilité parce que les membres de l'équipe ne connaissaient pas leurs antécédents médicaux récents ($p = 0,006$) et par les patients à forte vulnérabilité en raison de l'absence de prise en charge de leur dossier ($p = 0,023$). Les patients des deux groupes de vulnérabilité ont déclaré avoir reçu des informations contradictoires plus souvent que les patients sans vulnérabilité.

Conclusion : Les patients à forte vulnérabilité ont plus de difficultés d'accès liées à la continuité, à la collaboration interprofessionnelle et à la communication avec les prestataires de services.

Introduction

Access to primary healthcare is an essential element in reducing health inequities (CSDH 2008). Timely access is defined as patients being able to access care when they need medical

attention (Katz et al. 2017; Schoen et al. 2007). Lack of timely access to a primary healthcare provider is an important weakness frequently reported in various countries, including Canada. Lack of timely access has several negative effects on the healthcare system, such as increased emergency room (ER) use for non-urgent care needs (Kaplan et al. 2015; Schoen et al. 2004; Senn et al. 2019), increased unmet care needs, more inappropriate treatment and deteriorated health status (Bowen 2012; Haggerty et al. 2008, 2020; Harris et al. 2004; Harris 2012; Khandor et al. 2011; Lévesque et al. 2012; McCusker et al. 2017).

In line with the core elements of value-based healthcare, improving timely access requires the development of equitable interventions and arrangements centred on patients' needs (Gilmore et al. 2019; Richard et al. 2016; Smith et al. 2020). From a patient perspective, the experience of access to care is defined as a process with steps such as perceiving the need for care, seeking and obtaining care and benefiting from the services received (Lévesque et al. 2013). Multiple barriers to accessing care exist at different stages of this process, and certain population groups are disproportionately more likely to experience them (Corcadden et al. 2018; Haggerty et al. 2020).

Inequitable healthcare occurs when access varies by social characteristics rather than need (Haggerty et al. 2020; Lévesque et al. 2013). Social determinants of health – such as living conditions related to poverty, isolation, age, discrimination and the ability to speak the official languages (Nundy et al. 2022; Raphael et al. 2020; Seale et al. 2022) – have been associated with greater negative impacts on the experience of access to healthcare (Clark and Preto 2018; Nundy et al. 2022; Patrick et al. 2018; Raphael et al. 2020; Seale et al. 2022). The presence of one or more of these determinants creates vulnerabilities from the patient's perspective to access care (Haggerty et al. 2020). Low income and immigration status contribute more often to barriers to accessing primary healthcare (Corcadden et al. 2018; Davis and Ballreich 2014; de Looper and Lafortune 2009; Osborn et al. 2016; Schoen et al. 2010). When barriers to accessing care accumulate and interact, the use of urgent care for general access and for primary care increases (Cheung et al. 2012; Haggerty et al. 2020; Macinko et al. 2016; Shippee et al. 2012). Using a social vulnerability index that includes personal and social characteristics (e.g. financial, immigration status, social support) shown to impact the ability to access care may be relevant to explore the multiple barriers of accessing healthcare services (Haggerty et al. 2020).

Despite being essential to support quality improvement efforts at both the clinic and policy levels, vulnerable patient-reported experience and outcome measures (PREMs and PROMs) have not yet been sufficiently documented (Horne and Manion 2019; Sutherland 2019; Wong et al. 2019). The objective of this study is to explore the different access experiences of patients registered at team-based primary healthcare clinics according to their social vulnerability profiles.

Methods

Design and setting

This study is based on a cross-sectional e-survey hosted on a web platform (<https://www.surveymonkey.com/>) that was conducted between June and November 2021 in four team-based primary healthcare clinics in Quebec. These clinics are groups of primary healthcare professionals, including family physicians, nurse practitioners, nurses, social workers and pharmacists, among others, who can be consulted by all registered patients. The size of the clinics varied. Clinic A had 17 physicians for 8,200 registered patients, Clinics B and D had 10 physicians for approximately 7,700 registered patients and Clinic C had 14 physicians for 8,800 registered patients.

Content of the patient e-survey on access

The e-survey of 52 items covered various access features on four main dimensions, including the pre-booking and the appointment booking process (actions taken before and while booking an appointment), access to the clinic (reaching the clinic, obtaining healthcare or advice, opening hours, reasons to consult elsewhere) and care continuity (communication with team members, interprofessional collaboration). Most of the questions were developed based on existing questionnaires to document these four dimensions of access (Appendix 1, available online at longwoods.com/content/27091).

The organizational accommodation questionnaire (Haggerty and Lévesque 2017) and the generic measure of continuity of care questionnaire (Haggerty et al. 2012) were shortened to assess access, continuity, comprehensiveness, responsiveness and perceived outcomes of care received. We supplemented the questionnaire by mapping questions from the GP [general practitioner] patient survey (NHS 2020) to assess the pre-booking and booking experience, the Primary Care Assessment Survey (PCAS) (Safran et al. 1998) and the Patients' Insights and Views of Teamwork (PIVOT) (Henry et al. 2014). We also used existing questions from the social vulnerability index (SVI) developed by Haggerty et al. (2020, 2023) based on social support, perceived financial status, education, language spoken at home as a proxy for limited language proficiency and new arrivals.

Data collection

The questionnaire was distributed electronically by a secretary at each clinic to registered patients with an e-mail address who had consulted at the clinic within the past month. All patients over 18 years were invited to participate in the study. Respondents were asked to complete the anonymous questionnaire on a voluntary basis. The research team prepared an e-mail message for the secretary to invite patients to participate in the e-survey. The self-administered questionnaire took approximately 20 minutes to complete.

Analysis

We performed descriptive analyses to summarize participant characteristics (gender, years as a patient at the clinic, etc.) and response frequencies (% valid). The SVI composite score was calculated based on a maximum score of four (very vulnerable). Table 1 presents the indicators of the SVI index, which is generated by the sum of all four indicators.

TABLE 1. Social vulnerability index

Indicators	Vulnerability codification
Social support	1 = 0-2 persons 0 = 3-6 persons
Perceived financial situation	1 = Poor to very tight 0 = Tight to very comfortable
Education	1 = No high school diploma 0 = High school diploma and higher
Languages spoken at home	1 = Does not speak French or English 0 = Speaks French or English

We performed Kruskal–Wallis tests to assess whether the socio-demographic characteristics of the study groups differed based on the clinical context. We used logistic regression models to explore associations between vulnerability groups and features of the four dimensions of the patient experience. Three groups were created based on the SVI index: no vulnerability (SVI score = 0), low vulnerability (SVI score = 1) and high vulnerability (SVI score = 2–4). The categories were determined based on observations from Haggerty et al. (2020), who showed that the presence of at least two social vulnerabilities was associated with experiencing access issues. Multivariate regression models were adjusted for any imbalances in socio-demographic characteristics. Odds ratios (ORs) with 95% confidence intervals (CIs) were generated. The Bonferroni criterion was applied to assess the significance level; any result with a *p* value <0.002 (0.10/48 tests, considering the exploratory nature of the study) were considered significant. We used IBM SPSS (IBM SPSS Statistics for Windows, Version 26.0, released 2019) for all analyses. Incomplete responses were excluded from the analysis.

Ethics approval

This study was approved by the Research Ethics Committee of the Centre de recherche – Hôpital Charles-Le Moyne of the CISSS de la Montérégie-Centre (MP-04-2020-410). Participants were provided with information on the study, and they consented to participate before completing the survey.

Results

The participation rate was estimated based on the number of patients who received an invitation from the clinic secretary to participate in the study. The sample consisted of 322/2,012 respondents from Clinic A (16%), 779/3,387 respondents from Clinic B (23%), 180/718 respondents from Clinic C (25%) and 281/3,451 respondents from Clinic D (8%).

Of the 1,562 patients who responded to the e-survey, 60% had been patients at their clinic for more than five years, 70% were women, 58% were 50 years or older and 99% spoke one of the two official languages at home. On the SVI, 14% of the respondents had a low vulnerability score (SVI = 1, $n = 189$) and 2% had a high vulnerability score (SVI = 2 to 4, $n = 32$). The overall SVI varied between 0 and 3, with a median of 0. Results of comparisons of the characteristics of the respondents showed significant differences among the clinics in three socio-demographic components – gender, age and self-perceived health status (all $p < 0.001$) – that were included in the adjusted models. Table 2 presents the socio-demographic characteristics of the respondents.

The pre-booking experience

Overall, 82% of the respondents (95% confidence interval [CI: 79.5, 83.4]) had booked an appointment within the past 12 months, and almost two-thirds (64%; 61.0%, 65.9%) were worried about their health. The main actions taken by the respondents before booking an appointment were to search for information online (34%; 31.3%, 36.0%), to take no action to get information or advice (32%; 30.2%, 34.9%), to try to self-treat by taking medications they already had at home (25%; 22.6%, 26.9%) and to talk to a pharmacist (22%; 20.1%, 24.3%). The two actions related to the use of the emergency room (ER) were the least reported by respondents: using the 24/7 dedicated line to consult a nurse for non-urgent health problems (triage, referrals to appropriate resources to avoid overuse of the ER) (8%; 7.0%, 9.8%) and going to the ER before making an appointment (5%; 3.7%, 5.8%). The group with low vulnerability reported worrying about their health less often than the group with no vulnerability (adjusted odds ratio [OR] = 0.70; 95% CI: [0.50, 0.99]; $p = 0.045$). However, after correcting for multiple tests, no features of the pre-booking experience were associated with the vulnerability groups.

Booking experience

Overall, nearly half of the respondents were given a choice of time or day to book an appointment at their clinic (47%; 44.4%, 49.4%), 33% (30.8%, 35.5%) were not given a choice and only 5% (3.8%, 5.9%) were given a choice of the type of professional they wanted to see. Nevertheless, more than 80% (81.5%, 85.2%) of the respondents were satisfied with the appointment they obtained and reported a good booking experience. The booking experience was not significantly associated with the vulnerability groups after applying the Bonferroni correction. Table 3 (available online at longwoods.com/content/27091) presents the pre-booking and booking experiences of the three groups.

Access to the clinic experience

Overall, a large proportion of the respondents reported good opening hours for appointments (79%; 77.2%, 81.4%), 89% (87.5%, 91.0%) did not regularly have difficulty obtaining care due to lack of availability of their physician and 84% (81.5%, 85.6%) received the health services

Patients with Social Vulnerabilities Experience Reduced Access to Team-Based Primary Healthcare

TABLE 2. Socio-demographic characteristics of respondents, *n* (%)

	Total respondents (1,562), <i>n</i> (%)	Clinic A 322 (21)	Clinic B 779 (50)	Clinic C 180 (11)	Clinic D 281 (18)	<i>p</i> value
Patient of the clinic for						
≥5 years	944 (60)	192 (60)	473 (61)	105 (58)	174 (62)	0.740
1-5 years	574 (37)	111 (35)	185 (37)	74 (41)	104 (37)	
<1 year	42 (3)	19 (6)	19 (2)	1 (1)	1 (1)	
Sex						
Female	955 (70)	204 (73)	442 (66)	102 (66)	207 (81)	<0.001
Age group						
≥65 years	409 (30)	96 (34)	213 (32)	39 (25)	61 (24)	<0.001
50-64 years	387 (28)	80 (28)	209 (31)	42 (27)	56 (22)	
35-49 years	325 (24)	56 (20)	152 (23)	36 (23)	81 (32)	
18-34 years	240 (17)	50 (18)	99 (15)	38 (25)	53 (21)	
<18 years	12 (1)	2 (1)	4 (1)	0	6 (2)	
Self-perceived health status						
Excellent	75 (5)	12 (4)	40 (6)	5 (3)	18 (7)	<0.001
Very good	346 (25)	57 (20)	174 (26)	30 (19)	85 (33)	
Good	666 (49)	139 (49)	337 (50)	75 (48)	115 (45)	
Fair	234 (17)	61 (22)	103 (15)	38 (24)	32 (13)	
Bad	49 (4)	15 (5)	20 (3)	8 (5)	6 (2)	
Social vulnerability index						
Median, min, max	0, 0, 3	0, 0, 2	0, 0, 3	0, 0, 2	0, 0, 2	
Components						
Language spoken at home						
French or English	1,356 (99)	276 (97)	669 (99)	155 (99)	256 (100)	
Other language only	10 (1)	7 (3)	2 (1)	1 (1)	0	
Self-perceived financial status						
Comfortable	724 (53)	134 (48)	376 (56)	66 (42)	148 (59)	
Moderate	407 (30)	102 (36)	185 (28)	53 (34)	67 (27)	
Poor to tight	227 (17)	45 (16)	107 (16)	37 (24)	18 (15)	
Highest education level						
Post-secondary	979 (72)	187 (67)	480 (72)	109 (70)	203 (80)	
High school	288 (21)	69 (25)	144 (22)	36 (23)	39 (15)	
Less than high school	95 (7)	25 (9)	47 (7)	10 (7)	13 (5)	
Number of persons for social support						
5-6 persons	908 (67)	180 (64)	438 (65)	94 (60)	196 (77)	
3-4 persons	383 (28)	85 (30)	198 (30)	49 (31)	51 (20)	
0-2 persons	69 (5)	15 (5)	34 (5)	13 (8)	7 (3)	
Median, min, max	5, 0, 6	5, 0, 6	5, 0, 6	5, 0, 6	5, 1, 6	

they needed at their clinic. However, 31% (28.9%, 33.9%) felt abandoned by the healthcare system and 37% (34.2%, 39.4%) reported that it was not easy to obtain healthcare or advice from the clinic. Feeling abandoned by the health system was reported two times more often by respondents from the high-vulnerability group (adjusted OR = 2.3; 95% CI: [1.1, 4.8]; $p = 0.033$). The low-vulnerability group reported consulting at the ER because their family physician was not available three times more often than the group with no vulnerability (adjusted OR = 3.2; 95% CI: [1.4, 7.2]; $p = 0.006$). The same group also reported consulting at the ER almost three times more frequently because the next appointment was too far away (adjusted OR = 2.6; 95% CI: [1.1, 6.0]; $p = 0.023$). The access to the clinic experience was not significantly associated with the vulnerability groups after applying the Bonferroni correction. Table 4 (available online at longwoods.com/content/27091) presents the access to the clinic experience of the three study groups.

Care continuity experience

Overall, about 80% (81.5%, 85.2%) of the respondents did not report having the impression that no one was in charge of their file, receiving contradictory information, experiencing team members not being aware of decisions made by another professional on the team or experiencing team members not having access to test results. Also, about 72% (69.3%, 74.3%) did not report having to repeat information that should have been in their file or experiencing team members not knowing their recent medical history. However, 45% (41.1%, 48.0%) of the respondents reported that team members were not at all or were only sometimes aware of their case, and 37% (33.7%, 39.5%) did not receive any information on how the clinic team works. The results of comparisons of the three vulnerability groups showed that patients with high vulnerability reported that no one was in charge of their file more than twice as often as the no-vulnerability group (adjusted OR = 2.5; 95% CI: [1.1, 5.7]; $p = 0.023$), whereas those in the low-vulnerability group reported that team members did not know their recent medical history (adjusted OR = 1.7; 95% CI: [1.2, 2.5]; $p = 0.006$). Patients from both groups reported having significantly more difficulties in their experiences of continuity related to receiving contradictory information than patients from the no-vulnerability group, and this increased gradually with the vulnerability level. The continuity experience was not significantly associated with the vulnerability groups after applying the Bonferroni correction. Table 5 (available online at longwoods.com/content/27091) presents the continuity of care experiences of the three study groups.

Discussion

Equitable access to primary healthcare is crucial in the move toward value-based healthcare. A greater understanding of the patient experience, particularly of patients who experience multiple intersecting health and social vulnerabilities, is essential (Horne and Manion 2019; Wong et al. 2019). Our results showed that although very few respondents went to a hospital ER before booking an appointment and a large proportion reported being satisfied with their

booking experience, fewer were satisfied with the other dimensions of access. Patients from groups with a low or high vulnerability index reported experiencing more difficulties accessing the clinic and more difficulties related to care continuity than patients from the group with no vulnerability but on different features. For instance, consulting at the ER because their family physician was perceived as not being available or because the next appointment was too far away was reported three times more often by patients in the group with a lower vulnerability index, and they were more likely to report that team members did not know their recent medical history. In contrast, respondents from the high-vulnerability group more often reported feeling abandoned by the healthcare system and that no one was in charge of their file. Both groups reported receiving contradictory information more often than the no vulnerability group, and this increased gradually with the vulnerability level.

Our results are in line with concerns already raised about equity of access to primary healthcare for patients with continuity of care needs and the necessity to guarantee an appointment with a particular provider (Dixon et al. 2006). In our study, respondents with high vulnerability did not consult more often at the ER than those with lower vulnerability, but the main reasons differed between groups; those with lower vulnerability reported that they did so because of a lack of availability of their physician. Not receiving the healthcare that they need at their clinic, experiencing aggravated health problems due to a long delay in obtaining care and experiencing a lack of availability of their physician are the barriers faced by vulnerable populations in accessing primary healthcare as identified by Corscadden et al. (2018), resulting in avoidable ER visits, unmet care needs and deteriorating health status (Bowen 2012; Haggerty et al. 2008, 2020; Harris et al. 2004; Harris 2012; Khandor et al. 2011; Lévesque et al. 2012; McCusker et al. 2017).

Overcoming these barriers is crucial for value-based healthcare systems to contribute to societal well-being (Smith et al. 2020). In Quebec, the main model of primary healthcare clinics, Family Medicine Groups (FMGs), are the result of a 2002 policy initiative to enhance access by uniting groups of physicians working closely with other primary healthcare professionals to provide services in one clinic (Breton et al. 2011). The implementation of FMGs also aimed to affiliate patients with one regular family physician (Breton et al. 2013), a policy intended to foster a continuous relationship between physicians and patients (Collège des médecins de famille du Canada 2012). Having a regular physician has been proven to improve access to primary healthcare services (Dunlop et al. 2000; Lambrew et al. 1996; Ngo Bikoko Piemeu et al. 2021) and continuity (Smithman et al. 2022) and to reduce use of the ER (McCusker et al. 2012).

Our results suggest a greater need for patients with social vulnerabilities to see their family physician to reduce ER use. However, Quebec is the only province in Canada with a policy obligating physicians to dedicate a portion of their time to locally prioritized medical activities, such as the ER or long-term care facilities (Roy et al. 2016; Nji et al. 2022). Although an association has been demonstrated between increased access and a higher

number of hours worked by physicians in their practice (Paré-Plante et al. 2018), this policy and excessive administrative duties mean that new physicians have fewer hours available to care for their registered patients, with less than one-quarter of their practice time allocated to ensuring continuity of care (Roy et al. 2016). Increasing the hours spent in primary healthcare settings according to the vulnerability level of the patient population and/or socio-economics of the area could be a policy reform to improve patient access and continuity of care.

Successive healthcare policy reforms have been adopted in Quebec since 2002 to enhance the integration of care for patients with complex intersecting health and social needs (Katz et al. 2017; Nji et al. 2022). Despite these policy initiatives, socially vulnerable populations seem to continue to experience access inequalities due to difficulties in navigating an increasingly complex and constantly evolving healthcare system (Loignon et al. 2015; Ouimet et al. 2015). Navigation innovations designed to promote appropriate primary healthcare service utilization have been proven to be effective in reducing ER use (Enard and Ganelin 2013). Studies evaluating these innovations from the patients' perspective have highlighted the need to improve communication between providers and patients (to understand and express one's self and be heard) and to provide relational and emotional support (e.g., decision-making assistance, supportive listening), pragmatic information on existing resources and how the clinic functions and assistance in completing insurance forms, coordinating care (Viswanathan et al. 2010), finding transportation and scheduling appointments (Burns et al. 2014; Ngo Bikoko Piemeu et al. 2021). In line with these studies, our results on care continuity experiences showed that patients with a higher vulnerability index experience more difficulties related to patient-provider communication, as well as interprofessional communication and collaboration, that need to be considered when designing future navigation interventions. Navigation programs typically cost less than the savings from reduced ER visits (Enard and Ganelin 2013), and promoting this type of innovation could contribute to enhanced access and continuity for vulnerable populations.

These results also highlight challenges associated with clinic practices for patients with social vulnerabilities. Since 2015, primary healthcare clinics have evolved toward more interprofessional practice models, including family physicians, nurse practitioners, nurses, social workers and pharmacists, among others – and local health networks connecting health and social service providers have been promoted to enhance collaboration (Nji et al. 2022). A team-based primary healthcare clinic, in which patients are cared for by an interprofessional team rather than by the family physician alone, can ensure continuity and increase access (Abou Malham et al. 2017; Gocan et al. 2014; Martin-Misener et al. 2009; Oelke et al. 2021). However, challenges have been highlighted, such as a lack of clarity on interprofessional roles (Beaulieu et al. 2006), communication gaps when coordinating sequential actions between professionals, interprofessional sensemaking and working together to understand as a team (Fox et al. 2021).

Policies are required to increase the resources available to improve interprofessional collaboration and clear guidelines, care protocols and formal and informal consultation and guidance mechanisms are needed to determine the roles, scopes of practice and contributions of each professional (Breton et al. 2022). For instance, expanding the role of nurses to address common health problems (Abou Malham et al. 2020) could improve collaboration and communication among team members who tend to operate as separate primary healthcare providers (Lancaster et al. 2015). Innovations already exist that could guide future policies, such as integrated care in team-based primary healthcare clinics with an expanded nursing practice role. A recent study that measured patient-reported experiences of access, continuity, comprehensiveness, responsiveness and outcomes of care in six of these exemplary clinics showed a significant increase in reported care experience measures on all five dimensions (Duhoux et al. 2022).

Study strengths and limitations

One strength of this study is that it contributes to the literature on patient experiences of access, particularly for patients experiencing multiple barriers to accessing primary healthcare (Corcadden et al. 2018; Gilmore et al. 2019; Horne and Manion 2019; Sutherland 2019; Wong et al. 2019). Nevertheless, certain aspects of this study may limit the generalizability of the findings. First, it was conducted in four primary healthcare clinics in Quebec, including three that are university affiliated, which have particular characteristics, notably their teaching mission. Second, the data collection tool was based on existing questionnaires (cited in Appendix 1) in order to create a comprehensive report on access. We conducted a face-validity assessment of the survey, but we did not assess the construct validity for our questionnaire, mainly because our objective was not to assess a single abstract construct. Third, we sent the questionnaire only to patients with an e-mail address in their electronic medical record. This may have contributed to the low response rate. However, the response rate is similar to rates from other PREM/PROM studies – that is, between 11% and 47% (Corcadden et al. 2018; Tyser et al. 2016; Weir et al. 2021). Although this data collection method is low cost, it may have introduced a response bias, with patients with the highest vulnerability scores being underrepresented (Langer et al. 2021; UyBico et al. 2007). Recruitment strategies recommended to reduce these biases in future research include adapting the communication modalities for recruitment and data collection to occur close to where people are and when it is convenient for them (e.g., partnering with community organizations) and offering meaningful incentives (Langer et al. 2021). Finally, we were not able to identify patients with chronic diseases with this questionnaire. Concerns have been raised for these groups of patients with continuity of care needs since the implementation of advanced access in primary healthcare settings (Ahluwalia and Offredy 2005; Dixon et al. 2006; Murray and Tantau 2000; Murray et al. 2003; Salisbury 2008). Documenting immigration status will also increase knowledge of the concerns associated with higher use of the ER

among recent immigrants (Haggerty et al. 2020) and the effects of affiliation with a provider (Lasser et al. 2006). Future research should further investigate these vulnerability issues associated with access.

Conclusion

Access to primary healthcare is at the centre of efforts to improve health and reduce health inequities. Our study points to the need to focus on efforts to address specific access barriers for patients with a high vulnerability index. Several policy levers might improve care access among patients experiencing delays or difficulties associated with receiving the health services that they need at their clinic, continuity needs, patient–provider communication and interprofessional collaboration. Overcoming these barriers by increasing resources would allow physicians in Quebec to adjust their availability according to patients’ vulnerability and/or the socio-economics of the area, and policies could contribute to more rapid development of successful innovations (e.g., navigation, integrated clinics). Also, providing team-based primary healthcare practices with clear guidelines and care protocols to determine the roles and contributions of each professional is crucial for value-based healthcare systems to contribute to societal well-being.

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“A Band-Aid Solution”: Policy Maker and Primary Care Provider Perspectives on the Value of Attachment Incentives

« Une solution de fortune » : points de vue des décideurs et des fournisseurs de soins primaires sur la valeur des incitations à l’adhésion



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Abstract

Approximately 15% of Canadians are without a primary care provider (“unattached”). To address “unattachment,” several provinces introduced a financial incentive for family physicians who attach new patients. A descriptive qualitative approach was used to explore perspectives of patient access and attachment to primary care. Semi-structured qualitative interviews were conducted with family physicians, nurse practitioners and policy makers

in Nova Scotia. Thematic analysis was performed to identify participant perspectives on the value and efficacy of financial incentives to promote patient attachment. Three themes were identified: (1) positive impacts of the incentive, (2) shortcomings of the incentive and (3) alternative strategies to strengthen primary healthcare. Participants felt that attachment incentives may offer short-term solutions to patient unattachment; however, financial incentives cannot overcome systemic challenges. Participants recommended alternative policy levers to strengthen primary healthcare, including addressing the shortage of primary care providers and developing remuneration and practice models that support sustainable patient attachment.

Résumé

Environ 15 % des Canadiens n'ont pas de fournisseur de soins de santé primaires (« sans adhésion »). Pour lutter contre le « manque d'adhésion », plusieurs provinces ont mis en place un incitatif financier pour les médecins de famille qui accueillent de nouveaux patients. Une approche qualitative descriptive a été utilisée pour explorer les perspectives d'accès et d'adhésion des patients aux soins primaires. Des entrevues qualitatives semi-structurées ont été menées auprès de médecins de famille, d'infirmières praticiennes et de décideurs en Nouvelle-Écosse. Une analyse thématique a été effectuée pour identifier les points de vue des participants sur la valeur et l'efficacité des incitations financières pour promouvoir l'adhésion du patient. Trois thèmes ont été identifiés : (1) les impacts positifs de l'incitatif, (2) les lacunes de l'incitatif et (3) les stratégies pour renforcer les soins de santé primaires. Les participants ont estimé que les incitations à l'adhésion peuvent offrir des solutions à court terme au manque d'adhésion des patients. Cependant, les incitations financières ne peuvent pas surmonter les défis d'ordre systémique. Les participants recommandent des leviers politiques pour renforcer les soins de santé primaires, notamment en s'attaquant à la pénurie de prestataires de soins primaires et en développant des modèles de rémunération et de pratique qui favorisent une adhésion durable de la part des patients.

Introduction

Health system policy makers prioritize the notion of “value” or making the best use of available resources (Lewanczuk et al. 2020; Smith et al. 2020). Canadian provincial and territorial health systems are allocated a substantial but finite amount of resources, and they ration these resources across appropriate investments to address health system priorities (e.g., health outcomes, patient/provider experience, access) (Forest 2020; Lewanczuk et al. 2020). Ideally, the health system contributes to collective or personal well-being by ensuring health improvement priorities, including responsiveness, financial protection, efficiency and equity (Smith et al. 2020). Policy makers can use a variety of policy levers to address these priorities, including considerations of funding allocation, promoting the use of evidence and strengthening primary healthcare (Smith et al. 2020).

Primary care is vital for ensuring population health and reducing health disparities (Starfield et al. 2005). Countries that have made substantial investments in primary care (e.g., the UK, the Netherlands) perform well in terms of access to care and equity, suggesting that strengthening primary care can be an effective and valuable investment (Hutchison 2013; Schneider et al. 2021). According to Commonwealth Fund rankings of Organisation for Economic Co-operation and Development countries, Canada ranks poorly in access to care (ninth among 11 countries; Schneider et al. 2021). Many Canadians struggle to access a regular doctor and are more likely to visit the emergency department, compared to those from peer countries (Schneider et al. 2021). Challenges in accessing a primary care provider may be partially attributable to the fact that approximately 15% of Canadians are unattached, meaning that they do not have a regular primary care provider (Statistics Canada 2020).

Attachment to a primary care provider is a core value of and a substantial challenge faced by health systems across Canada (Marshall et al. 2022). To support the attachment of Canadians to primary care, several provinces have established monetary incentives for family physicians who attach new patients (Breton et al. 2015, 2019). In April 2018, the Government of Nova Scotia and the Nova Scotia medical association (Doctors Nova Scotia) announced the creation of the Patient Attachment Incentive Trust (Government of Nova Scotia 2020; Nova Scotia Medical Services Insurance 2018). The introduction of this Trust coincided with a rise in the number of unattached patients in Nova Scotia. Between 2015 and 2019, Nova Scotia saw an increase from around 11% of the population reporting being unattached to 14%, while other provinces saw a decrease in unattachment (Statistics Canada 2020). For this Trust, \$6.4 million was allocated to provide family physicians with a \$150 incentive for each patient they enrolled into their practice from the centralized primary care waitlist (known as the “Need a Family Practice Registry” in Nova Scotia) or by any other means, including referrals from retiring physicians or emergency departments (Nova Scotia Medical Services Insurance 2018). The one-time financial incentive was to be billed at the first visit between the patient and family physician and required family physicians to retain the patient for at least one year (Nova Scotia Medical Services Insurance 2018). Patient retention was defined as “keep[ing] the patient in your practice and maintain[ing] an open chart for at least a year” (Nova Scotia Medical Services Insurance 2018: 2). When the incentive rolled out, around 5% of the population (45,500 patients) was publicly reported to be enrolled in the Need a Family Practice Registry (Nova Scotia Health Authority 2018). Between April 2018 and January 2020, 627 physicians claimed the incentive and accepted 61,086 patients into their practice for a total of ~\$9.2 million spent via the incentive (Government of Nova Scotia 2020). The incentive ended in March 2020 with approximately 5.1% of the population (47,956 patients) on the registry (Nova Scotia Health Authority 2020; Nova Scotia Medical Services Insurance 2019). The proportion of people on the registry did not change as an almost equivalent number of people enrolled as were taken off.

Health system actors have historically relied on the same policy “levers” (e.g., payment incentives; McKay et al. 2022) despite the range of levers that exist (e.g., education, evidence-based care; McKay et al. 2022; Smith et al. 2020). However, there is evidence to suggest that there are limits to the efficacy of financial incentives to change the behaviours of primary care providers, including the promotion of patient attachment and access to primary care (Glazier et al. 2019; Lapointe-Shaw et al. 2017; Lavergne et al. 2018; Sempowski 2004). Regardless of the limited effectiveness, several Canadian provinces have used financial incentives to encourage patient attachment to primary care (McKay et al. 2022). There are data to suggest that these incentives may only have modest efficacy, and there is a need to understand *why* these incentives are not working as intended to create evidence for novel policy intervention. To do this, our study explores the perspectives of family physicians, nurse practitioners and policy makers on the value of a financial incentive to promote patient attachment to a primary care provider.

Methodology

A qualitative descriptive study design was used to elicit the experiences and perspectives of family physicians, nurse practitioners and policy makers in Nova Scotia related to patient attachment and the administration of, use of, and access to the Need a Family Practice Registry. Semi-structured interviews were conducted as part of the “Problems in Coordinating and Accessing Primary Care for Attached and Unattached Patients Exacerbated during the COVID-19 Pandemic Year (the PUPPY Study)” (Marshall et al. 2021). The interview guides (Appendices 1–3, available at longwoods.com/content/27090) were developed by the multidisciplinary team using findings from a policy scan and analysis and input from members of the study team, which included representatives from various stakeholder groups (e.g., clinicians, policy makers). The interview guides included questions on the use of incentives to encourage patient attachment. Family physician and nurse practitioner participants were asked this question: “What are your thoughts on providers being offered financial incentives to take on new patients from the centralized waitlist?”

Policy maker participants were asked two questions about the use of incentives:

- Before COVID-19, if you thought about attaching patients to primary care providers in this province, what key policies, strategies or incentives would you consider, and how would they impact attachment?
- Before COVID-19, what were the rules, regulation and incentives that posed obstacles for providers in taking on new patients? Which ones made things easier?

If policy makers did not mention the attachment incentive within their response, the interviewer used probes to ask about financial incentives for attachment. All stakeholders were asked questions in which there may have been the opportunity to mention the financial

incentive. For example, interviewees were asked: “What sort of supports or resources would you like to see offered for providers to better execute the effectiveness of the centralized waitlist?”

Purposeful and snowball sampling methods were used to recruit participants. Purposeful sampling ensured that participant characteristics such as role (i.e., family physician, nurse practitioner, policy maker), gender and region (e.g., urban/rural, health zone) were represented. Potential participants were identified by knowledge users on the research team, the research team’s network of primary care stakeholders and other participants (i.e., snowball sampling). Invitations were also distributed to potential participants via partner organizations (e.g., physician and nursing professional associations, relevant university departments, primary care clinics) and social media (e.g., Facebook, Twitter). Interested participants were directed to contact the research team by e-mail or phone. Some knowledge user members ($n = 4$) of the research team also agreed to take part in interviews as participants. Informed consent was obtained from each participant before their participation.

Semi-structured, in-depth interviews took place via Zoom (Zoom Video Communications Inc.) or telephone between October 2020 and July 2021. There were three interviewers for this study; each interviewer was primarily responsible for conducting the interviews with a single stakeholder group. The interviews were overseen by the PhD-trained nominated principal investigator (EGM) of the study. Interviews were digitally recorded and transcribed verbatim; personally identifiable information was removed. The interviewers recorded their initial reflections following the interview within their field notes. The interviewers and members of the research team had ongoing conversations and debriefs to identify early themes from the interviews. Once the interviewers and members of the research team felt that no new themes were being identified, two additional interviews were conducted. When no new themes were identified within those interviews, it was determined that thematic saturation (Guest et al. 2020) had been reached and recruitment concluded.

Data were managed using NVivo software (QSR International Pty Ltd., 2018). Data were coded to identify when participants were responding to the questions about the attachment incentive and to identify interview excerpts mentioning the incentive (e.g., when participants spoke about the incentive in an unrelated question). Two trained qualitative research analysts conducted thematic framework analyses to manage and analyze the data (Gale et al. 2013). The framework method involved creating a matrix of cases (participants) and themes, with in-between cells housing key quotes or summaries of the data. For the purpose of this paper, relevant themes were identified by research analysts, and consensus on the names and descriptions of the themes was reached through a discussion between the analysts and the primary investigator. Themes and subthemes were shared with members of the research team and knowledge user partners to ensure validity. Data were analyzed for variation in perspectives by participant role (i.e., family physician, nurse practitioner or policy maker). Ethics approval was obtained from the Nova Scotia Health Authority Research Ethics Board (File #1022763).

Results

Twenty-one family physicians, seven nurse practitioners and ten policy makers participated in this study (Table 1).

TABLE 1. Participant attributes

Attributes		Family physicians (n = 21)	Nurse practitioners (n = 7)	Policy makers* (n = 10)	Number of participants* (n = 37**)
Self-identified gender	Man	9	0	N/A	9
	Woman	12	7	N/A	19
	Other	0	0	N/A	0
Rurality	Rural	8	5	N/A	13
	Urban	13	2	N/A	15

*Due to concerns regarding identification, no demographic information was collected for the policy maker participants.

**One participant had dual roles of family physician and policy maker, and has been counted in both columns.

We identified three overarching themes, each with subthemes, that were salient to participants: (1) positive impacts of the incentive, (2) shortcomings of the incentive and (3) participant recommendations for alternative policy levers to strengthen primary healthcare.

Positive impacts of the incentive

Participants identified several positive impacts of the financial incentive. Participants felt that the incentive was effective at reducing the number of unattached patients, compensated the administrative work involved in accepting a new patient into one’s practice and was helpful for data validation of the Registry for primary care attachment.

“FORTUNATELY OR UNFORTUNATELY, MONEY DOES CHANGE PRACTICE”

Family physician and policy maker interviewees perceived an increase in patient attachments that occurred while the incentive was in effect. Participants felt that the incentive could encourage the attachment of patients in need of a provider, such as newborns and those on the Need a Family Practice Registry.

Adding that little incentive might just make a small difference ... maybe they’ll take five or ten patients every couple of months for a little bonus. I don’t think it’s the worst idea ... I think it could help a little bit with movement on the [Need a Family Practice Registry]. (Family physician, FFS [fee-for-service])

“IT PAID US FOR THE WORK WE HAVE TO DO”

Family physicians emphasized the value of the incentive in remunerating “some of the time that you would need to take when you do start with a new patient” (family physician, APP [alternative payment plan]). Although the incentive is “not equivalent to ... your billable

hours,” physician interviewees found the incentive to be helpful as it compensated them for the time it took to complete the necessary tasks when taking on a new patient, such as a lengthy first visit with a complex patient and accessing and reviewing the patient’s medical records, which can “take hours and hours.”

“IT WAS REALLY HELPFUL FROM A DATA VALIDATION PERSPECTIVE”

Policy maker participants identified the value of the incentive in helping to validate the number of attached patients on the registry. Physicians who attach a new patient would need to submit a billing claim to receive the incentive. The billing claim would be associated with a patient’s health card number; thus, administrators “could remove those [patient] names from the [registry]. It was really helpful for us from a data validation perspective” (policy maker). Using the incentive billing also allowed policy makers to “get a count on how many patients had found providers with that incentive” and understand whether patients were being attached from the registry.

Shortcomings of the incentive

Participants identified several shortcomings of the incentive, such as money not being the most important consideration in attaching patients, the potential of the incentive to negatively impact patient care and access, the ethics of the incentive, criticism of the incentive as a political idea and the inability of the incentive to address systemic challenges in primary care.

INCENTIVE MONEY CANNOT OVERCOME SYSTEMIC CHALLENGES

Many participants stated that the incentive could not overcome larger issues in primary care. Participants explained that providers are currently “overburdened” with their current panel size and “it’s not really the money that matters so much” (family physician, FFS). Participants explained that they have other obligations, such as “hospital work” and “learners,” that limit “the number of patients that we can serve and manage in a timely manner.” The providers who did have the capacity for new patients would accept patients regardless of the incentive, and they were “happy to accept the incentive for taking on the patient. But it didn’t really make [them] do anything [they] wouldn’t have done anyway” (policy maker).

“I DON’T THINK IT EQUATES TO BETTER CARE”

Interviewees expressed concern that funding physicians to take on additional patients may lead to poorer quality of care. As one family physician said “...if you can’t get in [to your family doctor] for a number of months ... you don’t really have a family doctor.” Interviewees said that offering a financial incentive to take on additional patients is problematic:

If I’m compelled to take [on] more patients because I want the money, but the patients that I take on don’t have access to quality care, are we really doing a good thing? (Family physician, FFS)

“I THINK IT’S UNETHICAL”

In addition to concerns about impacts on patient care and access, participants were also concerned about “...certain potential abuses...” of the incentive. One nurse practitioner described an experience where changes were made to the practice so that family physicians collected the incentives for patients cared for by nurse practitioners or family practice nurses, which they “did not agree with at all.” Participants also expressed concern for other unethical behaviours related to “supplier-induced demand” and the incentive leading to “cherry-picking” of “easier” patients, instead of more complex patients.

“A POLITICAL, TERRIBLE IDEA”

Participants described the attachment incentive as largely “political,” perceiving that it was used as a tool to “pacify anger in the patient and physician community.” Participants felt that the provincial government wanted to show that patients were becoming attached because it “...looks good on paper if the numbers [of people waiting for a primary care provider] are low.” Furthermore, participants felt that the incentive was “dropped too quickly...” without “...looking at what the value of the [incentive] was” and “...how it could be used to... help with attachment [of certain populations]” (family physician, APP). Nurse practitioner participants expressed disagreement with the choice to only offer the incentive to family physicians because nurse practitioners are a group who could also contribute to greater patient access and attachment to primary care.

Participant recommendations for alternative policy levers to strengthen primary healthcare

Participants made several suggestions for improving patient attachment to primary care providers, such as incentivizing “priority” patient populations, addressing the “shortage of primary healthcare providers,” addressing the need for different models of practice and remuneration and identifying an appropriate patient panel size.

INCENTIVES FOR “PRIORITY” PATIENT POPULATIONS

Participants expressed support for “incentives for rostering people who are defined to be priority” (family physician, APP). Interviewees identified a need to define “priority” but mentioned that complex patients, such as patients with cancer, and “babies” might fall under the definition of priority. As one participant explained, an incentive for priority patients might be worthwhile because there are “professional or personal disincentives to take on sicker people” (family physician, APP).

ADDRESSING THE “SHORTAGE OF PRIMARY HEALTHCARE PROVIDERS”

As one participant said “...we just need more family physicians” (family physician, APP) and that the attachment incentive did not address the larger issue of a lack of providers to care for unattached patients. Many participants felt that there is a need for more primary care

providers to “share the burden. We don’t need to keep dumping it on the existing ones that are burning out” (family physician, APP). Nurse practitioner participants suggested that there is a need to “increase the nurse practitioner population of providers as a way to get people off that list ... rather than incentivizing physicians” and that nurse practitioners should be “provided the same opportunities ... as physician providers.”

THE NEED FOR DIFFERENT MODELS OF PRACTICE AND REMUNERATION

Participants recommended changes to practice models, including collaborative practice teams and sessional fees with no overhead as models, which would encourage family physicians to accept unattached patients into their practice. Sessional fees are “attractive” because there is “no overhead” when paid hourly and providers “don’t have to worry about whether [patients are] going to show up or not” (policy maker). Changes to the existing fee structure, such as adding a fee for the first visit with a patient and allowing for differentials in this fee based on patient complexity “would be a better use of funding as opposed to just an incentive to take people off the list” (family physician, APP). From a policy maker perspective, one participant mentioned that collaborative family practice teams offer oversight regarding the number of patients being accepted, allowing for “consequences” if agreements are not followed.

IDENTIFYING AN APPROPRIATE PATIENT PANEL SIZE

A few participants recommended developing a method to measure a family physician’s capacity so that the appropriate patient panel size could be identified and supported. As one policy maker described:

We don’t have tools or measures to assess capacity within a primary care provider’s office. We’ve ... deferred to [using] 1,350 patients [as the recommended panel size for] family practice, with no measure of health status or demographics or from a determinants of health approach – let alone provider practice styles and preferences and things like that. We have to really develop some practical key metrics. (Policy maker)

Such metrics could help ensure that family physicians are not taking on too many or too few patients but rather are providing care to an appropriate number of complex and non-complex patients, recognizing that not all patients require the same amount of care.

Discussion

Participants described the positives and shortcomings of the attachment incentive and made recommendations for alternative policy levers to strengthen primary healthcare. Among the positives, participants felt that the incentive was somewhat effective at encouraging providers to attach patients and compensated family physicians for the administrative work involved with taking on new patients. However, many participants felt that the incentive did

not change the attachment behaviours of family physicians and did not equitably support attachment. Interviewees identified alternative policy levers to reduce patient unattachment, including incentives for attaching priority populations, addressing the shortage of primary healthcare providers and expanding the types of remuneration and practice models that are available in the Nova Scotia health system.

Equity should be valued within universal healthcare as the application of equity concepts ensures that need determines access to care (Smith et al. 2020). Certain groups of people are underserved by the health system (e.g., patients who require opioids, people with lower incomes and transgender people [Asada and Kephart 2007; Marshall et al. 2017, 2019; Vermeir et al. 2018]) and face more challenges in obtaining attachment to a primary care provider. Prioritizing the attachment of these equity-deserving patients may help to address barriers to primary care access. Jurisdictions across Canada struggle to provide equitable access to care based on patient needs. Provinces such as British Columbia, Ontario and Quebec prioritize patient attachment from centralized waitlists based on the patient's assessed vulnerability or complexity (Breton et al. 2019). Thus, in addition to a targeted incentive, Nova Scotia would benefit from applying an equity lens to prioritize patients' attachment to a primary care provider from the centralized primary care waitlist, thereby ensuring that patients with the most need would have timely access to preventative care, a valuable function of the health system (Smith et al. 2020). Furthermore, payments could be used to appropriately compensate physicians for the time it takes to onboard new patients, considering the additional time required for complex or vulnerable patients. Prioritizing patients most in need may lead to calls for adjusting provider payments based on patient complexity, and provincial decision makers should prepare for such calls from medical associations and patient advocates.

Financial policies, including incentives, are commonly used to encourage change within primary care practices in Canada (McKay et al. 2022). Financial incentives may change the behaviours that are being incentivized and result in small, short-term improvements but may not create long-term changes (Lavergne 2017; Mendelson et al. 2017). For example, a financial incentive might increase patient attachment but might not lead to good access as attachment to a busy, overburdened provider is not likely to result in good access. In addition, incentives aimed at increasing the attachment of patients in greater need have shown that providers will choose to take a smaller amount of money and enroll *a greater number of* patients who require *less* care as opposed to a greater amount of money for enrolling patients who require more care (Breton et al. 2015; Glazier and Redelmeier 2010). If health system decision makers wish to promote greater patient attachment, they must take a systems approach and consider the various factors that contribute to poor access and attachment. Practice and funding models are known to influence providers' willingness to attach patients (Breton et al. 2021). Providers who are employed directly by the health system or who are working in interdisciplinary teams may have an increased willingness to attach new patients. Canadian health systems could invest in strategies that have proven successful in other

countries, such as neighbourhood-based clinics that are designed to meet the needs of their community and have the capacity to provide attachment to the surrounding population (Kiran 2022).

There is a need to understand provider panel size in a more nuanced way. Quantity measures, such as the number of patients enrolled in a practice, do not account for the quality of care patients receive or the care needs of individual patients (Ashcroft 2014), particularly across varying care models (e.g., FFS, collaborative care teams). Doctors Nova Scotia, in cooperation with the provincial government, has begun rolling out an accountability framework that will help to ensure that physicians paid by APP are maintaining an appropriate panel size (Doctors Nova Scotia 2022). This framework accounts for patient age and socio-economic status, is designed to support physician management of their practices and allows provincial stakeholders to better understand primary care capacity in the province. Such metrics of provider capacity are needed to inform policy initiatives directed at improving patient attachment and access to primary care. Without this broader health system planning, a financial incentive for attachment alone is likely insufficient to overcome systemic challenges in supporting appropriate physician compensation and patient access to timely care.

Strengths and limitations

Qualitative interviews with participants from three stakeholder groups – policy makers, family physicians and nurse practitioners – provided rich, in-depth perspectives from various stakeholders in primary care. The end of the incentive coincided with the beginning of the COVID-19 pandemic; therefore, we cannot draw associations between the ending of the incentive and the marked increase in the number of patients on the registry since that time.

Future directions

Patient perspectives on attachment and access to primary care, specifically related to meeting perceived needs, would be a valuable qualitative follow-up. Quantitative analyses could be used to triangulate the perspectives of the participants of our study. Future analysis of administrative data may help indicate whether there were changes in provider behaviours during the period when the incentive was available. In addition, the incentive only required physicians to maintain an open file for the patient for one year following the initial visit. Analysis of billing data may show if patient attachment was maintained once the incentive obligations ended. Furthermore, an analysis of visits to other providers and emergency departments would help show the attachment incentive's financial value.

Conclusion

From 2018 to 2020, Nova Scotia used a financial incentive to encourage the attachment of patients to family physicians. While some participants perceived short-term benefits of

the incentives, generally, the incentive was not perceived as either valuable or effective in addressing the underlying causes of patient unattachment and raised ethical and professional concerns. Participants identified alternative policy levers that may be effective in strengthening primary care in Nova Scotia. Encouraging greater patient attachment to primary care may require addressing systemic problems, including targeted interventions to address challenges related to equitable access and team-based models of primary care. These investments may better support patients accessing the right care from the right provider at the right time, reducing the overall health system burden.

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A North Star Vision: Results from a Deliberative Dialogue to Identify Policy Strategies to Improve Value in Healthcare

Vision à long terme : résultats d'un dialogue délibératif visant à identifier des stratégies politiques pour améliorer la valeur des soins de santé



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Abstract

We hosted a deliberative dialogue with citizens ($n = 3$), policy researchers ($n = 3$), government decision makers ($n = 3$) and health system leaders ($n = 3$) to identify evidence-informed policy options to improve the value of Canadian healthcare. The analysis resulted in three themes: (1) the need for a vision to guide reforms, (2) community-based care and (3) community-engaged care. Results suggest the need for a new paradigm: community-focused health systems. Such a paradigm could serve as a North Star guiding healthcare transformation, improving value by aligning citizen and healthcare system goals, prioritizing spending on services that address the social determinants of health and improving quality and equity.

Résumé

Nous avons organisé un dialogue délibératif avec des citoyens ($n = 3$), des chercheurs en politiques ($n = 3$), des décideurs gouvernementaux ($n = 3$) et des dirigeants du système de santé ($n = 3$) afin d'identifier des options politiques fondées sur les données probantes pour améliorer la valeur de soins de santé au Canada. L'analyse a abouti à trois thèmes : (1) la nécessité d'une vision pour guider les réformes, (2) les soins communautaires et (3) les soins engagés dans la communauté. Les résultats font voir la nécessité d'un nouveau paradigme : des systèmes de santé axés sur la communauté. Un tel paradigme pourrait servir de guide pour transformer les soins de santé, pour améliorer la valeur en alignant les objectifs des citoyens et du système de santé, pour accorder la priorité aux dépenses consacrées aux services qui traitent des déterminants sociaux de la santé et, finalement, pour favoriser la qualité et l'équité des soins.

Introduction

The Canadian healthcare system ranks second to last in overall performance among 11 comparable nations across five domains (i.e., access to care, care process, administrative efficiency, equity and healthcare outcomes) (Schneider et al. 2021). Notably, Canada also ranks second to last in performance compared with spending (Schneider et al. 2021).

Improving the value of healthcare involves improving quality, equity, health outcomes and patient and provider experiences while simultaneously containing or reducing healthcare costs (Conrad et al. 2016; Porter 2010). Since the establishment of Medicare, there has been no shortage of policy proposals to improve these key dimensions of health and healthcare (Advisory Council on the Implementation of National Pharmacare 2019; Romanow 2002; Lalonde 1974; Government of Canada 1997), yet there has been limited change (Lazar et al. 2013).

Healthcare reforms often succeed as a result of timing or context changes, such as fiscal or perceived crises or actions taken by new governments (Lazar et al. 2013), and when patients and providers are engaged in the policy process (Culyer and Lomas 2006; Usher et al. 2021). The COVID-19 pandemic has been an unprecedented crisis. It has exposed and deepened health, race and gender inequities; crystalized new challenges (e.g., access to virtual healthcare, mental healthcare, long-term care [LTC] and provider burnout) that require immediate action; and opened the window for healthcare reform (Béland and Marier 2020; Dozois and Mental Health Research Canada 2021; Haworth-Brockman and Betker 2020; Moroni et al. 2020; Ndumbe-Eyoh et al. 2021; PHAC 2021; The Conference Board of Canada 2020; Wake et al. 2020; Wang et al. 2020; Webster 2020). In an effort to build a more sustainable future for Canada's health systems at this critical moment, the Centre for Health Policy at the O'Brien Institute for Public Health launched a Health System Sustainability Initiative (<https://obrieniph.ucalgary.ca/centre/health-policy/health-policy-initiatives/the-health-system-sustainability-initiative>). The initiative is guided by the Quadruple Aim (improving population health, value, patient experiences and provider experience) (Bodenheimer and Sinsky 2014) and equity. The goal of this initiative is to design evidence-informed health policy options to improve health system sustainability in Canada by improving performance while maintaining or reducing costs. We brought citizens, policy researchers, government decision makers and health system leaders together to participate in a deliberative dialogue at a Health Policy Forum to identify policy options to improve the value of Canadian healthcare.

Methods

Participants

Twelve individuals representing health policy researchers ($n = 3$), citizen groups ($n = 3$), governmental decision makers ($n = 3$) and health system leaders ($n = 3$) participated in the dialogue. The group included five women and six men from six provinces and two territories. The participants had expertise in patient and citizen engagement, digital health, healthcare

administration, rural healthcare, social work, healthcare funding and payment, evidence-informed policy development and implementation and primary care, as well as access, quality, safety and equity. All the participants had experience with health and/or social policy, including designing, implementing or evaluating public health and healthcare policies at different levels of the health system. The participants were divided into three discussion groups, each containing a representative from the four stakeholder groups.

Deliberative dialogue

A one-day deliberative dialogue was held on June 27, 2022, at the University of Calgary in Calgary, AB. A deliberative dialogue is a group process informed by research evidence that leads to recommendations reflecting both the knowledge, experience and values of individual participants and the consensus that emerges after reflecting on evidence and others' perspectives (Boyko et al. 2014; Culyer and Lomas 2006). The aim of the dialogue was for the participants to develop evidence-informed recommendations that address health policy priorities that have the potential to improve value for money and have historically been challenging to overcome. The dialogue was led by three facilitators and included research presentations and a series of small- and large-group discussions.

RESEARCH EVIDENCE

Participants considered evidence from three research studies. The first presentation addressed Canadians' perspectives on potential reform to the healthcare system (Parsons Leigh et al. 2023). This interview-based study reported results from interviews with public citizens, healthcare leaders, academics and political decision makers on the structure of the healthcare system, healthcare processes and strategies to improve short- and long-term population health outcomes. The second presentation provided results on two knowledge syntheses of international health system reform, including a literature review on the history of reforms in Organisation for Economic Cooperation and Development countries that identified drivers of reform (Farkas et al. 2023) and a concept analysis to develop a model of successful health system reforms (Minion et al. 2023). The third presentation reported findings from interviews with members of federal health advisory groups since the 1990s, as well as interviews with implementers of the group's recommendations (Quinn et al. 2023). Implications for implementation strategies based on barriers and facilitators identified in the sociopolitical context, characteristics of recommendations and collaborations (e.g., stakeholder engagement) of the National Forum on Health, the Romanow Commission and the Advisory Council on the Implementation of National Pharmacare were discussed.

We undertook these three studies to present participants with data to inform the deliberative dialogue. Our intention was that these studies would identify effective health reform strategies and targets in Canada and similar countries, identify barriers and facilitators of reform implementation in Canada and identify stakeholders' needs emerging from the COVID-19 pandemic.

FACILITATION

Three sequential small-group discussions addressed the following: (1) defining a vision for the future to identify opportunities for improvements within the healthcare system, (2) defining priorities for change and corresponding goals and outcomes for reform and (3) identifying barriers that have historically made it challenging to address these priority areas and drafting policy recommendations to achieve identified goals. Each facilitator was partnered with a note-taker who took detailed notes and recorded the group's conversation on prepared templates. The note-takers were instructed to capture the discussion on the templates in a visible, accurate and comprehensive way. The first discussion preceded the research presentations, while the second and third discussions followed the presentations. During the second discussion, facilitators reviewed key findings from the presentation on Canadians' priorities for reform and invited participants to suggest their priority areas. The group was asked to narrow down their list to two priorities through consensus and then identify goals and outcomes for each priority area. In the third discussion, facilitators prompted participants to integrate information from the presentations relating to their identified priority areas and discuss barriers and strategies to achieve their proposed goals. After each small-group discussion, one forum participant (not a facilitator) from each table reported to the rest of the forum on their table's discussion using the prepared templates. Afterward, a large-group dialogue (with all 12 panellists) was facilitated by a moderator.

Analysis

Two authors (AEQ and RD) conducted a reflexive thematic analysis (Braun and Clarke 2006, 2019; Byrne 2022) underpinned by a relativist ontological and subjectivist epistemological stance. Reflexive thematic analysis is a theoretically flexible type of thematic analysis to identify patterns of meaning that are not concerned with coding reliability or structured codebooks. It involves a process of data familiarization, data coding and theme development and revision. Themes, created from both codes and researchers' active engagement with data, are the output of the analysis.

Proceedings were audio recorded, transcribed, de-identified and imported into NVivo 12 software (QSR International). AEQ and RD participated in the deliberative dialogue and independently reviewed the transcripts to develop an initial list of codes. Both the authors discussed the initial codes and agreed upon a first-draft codebook. They both independently coded the transcripts, iteratively refining the codebook as necessary. Both of them also discussed the evolving codebook and initial themes. Coding was predominantly inductive. We utilized questions asked during the dialogue to guide coding. The PROGRESS tool (O'Neill et al. 2014) was used to guide coding related to characteristics typically associated with discrimination and disparities to ensure that an equity-focused lens was adopted. As themes were defined, themes and subthemes were revised and recoded. During the analysis process, AEQ and RD maintained open communication about their interpretation and positionality to challenge their assumptions of the dialogue and to ensure that participants'

experiences were reflected in the results. All quotations that appear in the Results section are from the deliberative dialogue. Quotations are not attributed to specific individuals as they reflect group discussions resulting from the facilitation process.

This study was approved by the University of Calgary Conjoint Health Research Ethics Board (REB22-0491).

Results

A vision to guide us from the healthcare system of today to the healthcare system of the future

The participants identified five priority areas for reform to improve our current healthcare system. These priorities emphasized community-based care models and the leadership and structural changes needed to support these models: (1) develop leadership and vision, (2) restructure coverage and funding, (3) reimagine primary care, (4) improve LTC and (5) advance equitable and community-based care. A summary of potential policy strategies and views on how action in these areas could improve value is presented in Table 1 (available at longwoods.com/content/27089).

The need for a guiding vision for the healthcare system that all stakeholders could understand and work toward was raised repeatedly. This vision could serve as a North Star, to galvanize needed reforms identified repeatedly by Canadian policy experts and to guide future reforms and evaluations of delivery processes and outcomes. The Quadruple Aim was proposed by some participants as a North Star.

When we talked about what we'd like to look at for healthcare in the future, we felt we already know a lot of this, but that we need to really articulate it. And that the vision could be a North Star [that] we could make our decisions against.

There was discussion of the need for leadership from the federal government, provincial and territorial governments and municipalities to achieve reform. Roles for each of these levels of government were apparent as the group discussed the need for expansion of medicare-covered services (e.g., LTC, mental health and substance use services), care management, publicly delivered community-based care, new payment models that motivate desired healthcare processes and outcomes and community engagement at all levels of the health system.

Conversations about how to support these needed changes were complex, including discussion of capital and human resources, growth of healthcare spending and the performance of the system compared with what is spent. Some participants stated that the current system was not sustainable due to poor infrastructure and a lack of resources. Others described the system as *too* sustainable as there is a continuous inflow of money from governments with limited requirements or expectations. Participants proposed either increasing taxes or utilizing current funding more efficiently or effectively to fund potential reforms. Other sources of

revenue were not discussed. Participants discussed the importance and challenge of estimating the impact of proposed reforms, including the need to be transparent about winners and losers resulting from new funding and payment models, as well as the need to develop mitigation strategies to address anticipated budget impacts.

Community-based care in the healthcare system of the future

The necessary delivery system reforms that were discussed shared common threads of improving equitable access to care and being located in the community as opposed to institutional settings. Community-based care or “care closer to home” could include primary care, home-based care (as opposed to hospital-based care and LTC facilities) and public health interventions, such as developing housing connected to community health centres. By focusing on “care closer to home,” one group explained:

I think the outcome we would like to see is better quality of life for everybody, particularly those who are older and have high healthcare needs.

Primary care was identified as a key component of the healthcare system that needed reform to improve system-wide value for money due to insufficient investments, access issues and outdated models of care characterized by fee-for-service payments and private care delivery by individual or small-group providers. Participants highlighted that access to primary care providers remains a long-standing challenge. One group described their vision for a re-imagined model as “respectful, responsive care that is accountable and directly reflective of a defined community’s needs.” A strategy proposed to be reflective of a defined community’s needs was establishing publicly funded primary care delivery sites that serve a designated catchment area alongside existing private facilities.

LTC was also highlighted as an area that requires reform in order to increase the long-term quality of life of older adults and to decrease institutional stays and alternative levels of care days in hospital. Increased home-based care services was suggested as the primary strategy. One group suggested that new LTC facilities should no longer be built or, alternatively, municipalities could lead the delivery of new care models for older people.

Pay attention to the life trajectory and care for older people. And that’s deliberately chosen vocabulary because it’s not just about better clinical care for the elderly. It’s about the total trajectory based on a philosophy that drives it, which is that this is about a system that cares about older people and believes in enabling their capacities to pursue high quality of life.

Many individual and social characteristics, such as place of residence, age, gender, occupation, language and socio-economic status, were discussed as being associated with disparities in health opportunities and outcomes. These factors were typically viewed as barriers to

accessing care. Community-based care could increase access to prevention and treatment services because it would be closer to patients' homes. However, there are also risks that a focus on home care could increase caregiver burden, which would likely affect women more than men.

Community-engaged care in the healthcare system of the future

Equitable, community-based care was described as reflecting and responding to the needs and voices of the community. Thus, engaging patients and citizens in health systems was perceived as essential to implement community-based care and to overcome historic barriers to healthcare reform. The historic barriers identified were (1) lack of a guiding vision, (2) the intertwining of politics and policy, (3) lack of transparency and accountability, (4) limited public information and knowledge, (5) lack of community voice and (6) inadequate funding and infrastructure. Each barrier is defined and corresponding strategies for change are presented in Table 2 (available at longwoods.com/content/27089).

Participants discussed both broad principles of reform and specific strategies related to community engagement. Two principles of reform discussed were universality and trust. The concept of universality reflected the need to strive for a system with a high level of equity and accountability where all Canadians are included, regardless of need, age and socio-economic or other circumstances. Participants described the importance of trust between patients and healthcare workers, as well as trust among healthcare workers in future reforms. Many of the implementation strategies described by participants involved "a shift in some decision making and control toward community that might start to address those structural considerations of power and voice within health systems."

There was a substantial focus on strategies to include the community voice across the healthcare system (in policy development, administration and delivery) in order to empower citizens. This would require including patients and citizens in non-tokenistic roles in governance committees and other decision-making bodies across the system to increase their influence. There was also discussion of "conversations" with patients and citizens as vehicles for specific performance improvements, as well as to generate a narrative to inspire increased community advocacy. "Safe spaces" in the healthcare system would be necessary to have these conversations. Increasing community engagement would also require educating the public to reduce misinformation and misunderstanding about the healthcare system, particularly regarding funding and payment models, government priorities and roles and the vision for healthcare. Furthermore, increasing the transparency and accountability of the government and delivery systems could also play an important role in communicating with patients and citizens regarding health system performance.

Discussion

A deliberative dialogue of cross-national citizens, researchers, delivery system leaders and decision makers was held to identify evidence-informed priorities and strategies for

healthcare reforms that improve value for money. Based on our interpretation of the priorities and strategies discussed, we identified three themes: (1) the need for a vision to guide us from the healthcare system of today to the healthcare system of the future, (2) a future system of community-based care and (3) a future system of community-engaged care. A future healthcare system focused on community-based care would emphasize primary care, care for older adults in the home, home-based hospital care and public health services. Strategies to overcome historic barriers to create a healthcare system focused on community-based care predominantly involved a shift in decision making and control away from payers and providers toward communities through community engagement and government and delivery system transparency and accountability. These reforms can improve value by aligning citizen and healthcare system goals, prioritizing spending on services that address the social determinants of health and improving quality and equity.

The need for a guiding vision, a North Star, for healthcare administration, management, funding and delivery system reform was a dominant point of discussion. The concepts of community-based care and community-engaged care point to a vision of community-focused health systems that could serve as the North Star. Participants also indicated that the Quadruple Aim could serve as a North Star, just as the Triple Aim originally intended (Berwick et al. 2008). Furthermore, equity was identified as an important component of future reforms. Taken together, community-focused health systems could serve as a North Star vision representing where we hope to get, while the Quintuple Aim (improving population health, value, patient experiences, provider experience and equity [Nundy et al. 2022]) could represent pillars of that vision. These pillars would signify what we hope to achieve within community-focused health systems.

A community-focused health system would include three key features: (1) co-led and co-designed by community members alongside healthcare payers and providers, (2) focused on primary and community-based care and (3) built upon supportive funding and delivery mechanisms. Similar concepts have been proposed in Canada for decades. However, little progress has been made. Federal health advisory groups have prioritized citizen engagement (Advisory Council on the Implementation of National Pharmacare 2019; Romanow 2002; Government of Canada 1997), including calls to shape the healthcare system “around health needs of individual patients, their families and communities” (Romanow 2002: 50). Because of the COVID-19 pandemic – an unprecedented crisis – there may currently be a window of opportunity to introduce community-focused solutions as a new paradigm for reform.

There is evidence from Canada that community-based care that emphasizes primary care can improve health system performance. A systematic review of primary care reforms in Alberta, Ontario and Quebec found that team-based care and disease management reforms were associated with improved utilization and health outcomes (Carter et al. 2016). Payment reforms were associated with changes in the utilization of services but not necessarily quality improvement (Carter et al. 2016). The concepts of primary care health teams and alternative payment models have been advancing in Canada, with renewed calls as access to primary care

has been even more challenging since the COVID-19 pandemic (Kiran 2022). Coalitions of physicians and patient and citizen partners could lead the development of alternative delivery and payment models in order to overcome historic barriers to reform. Alternatively, regional health authorities could advocate for the ability to directly contract with physicians.

A big challenge for Canada would be developing and implementing performance evaluation frameworks to ensure that new community-based care delivery and payment models were contributing to improved value (Fletcher et al. 2021) and meaningfully engaging the public (Abelson et al. 2016). Participants suggested that provincial/territorial governments could be responsible for managing providers similar to private health plans in the US or, alternatively, that providers or professional societies could monitor their performance. Another option could be developing new governance structures for primary care in parallel to regional health authorities that support empowerment and accountability for population-based primary care. In a community-focused health system, public reporting of performance would be critical to foster trust with patients and citizens.

The main findings from our deliberative process echo many of the themes developed by authors in the recent *HealthcarePapers* series on value from healthcare –particularly stakeholder engagement, population health, measuring what matters to patients and alternative funding and payment models that support new models of care delivery (Logan and Sutherland 2020; Mathies 2020; Strumpf 2020; Sutherland 2020a, 2020b; Wodchis and Reid 2020). Our work also echoes much of the broader policy conversation that has called for significant attention to LTC, primary care and community-based care (Dass et al. 2022; Key and Lewis 2018; Kiran et al. 2020; Lee et al. 2021; McKay et al. 2022; O’Neill et al. 2020; Pulok and Hajizadeh 2022; Usher and Denis 2022; Wilson et al. 2022). However, our work extends the current body of literature by focusing on the healthcare system writ broad as opposed to individual aspects of it and considers high-level reform. Our work also integrated multiple stakeholders across the system, which has not been done at a macro-system level since the Romanow Commission (Romanow 2002).

There are limitations to this analysis. The deliberative dialogue and reflexive analysis process reflect the interpretations of individual participants and individual researchers. Thus, the results may be influenced by the participant recruitment process, specific questions asked during the meeting and the knowledge and experience of the researchers. Other participants and questions may have offered alternative ideas for reform options and strategies.

Conclusion

Collectively, the results of the deliberative dialogue address the need for a new paradigm: community-focused health systems. Such a paradigm could serve as a North Star to guide healthcare transformation, providing both a vision for value-based Canadian healthcare and a path to achieve it. A community-focused health system would include three key features: (1) co-led and co-designed by community members alongside healthcare payers and providers, (2) focused on primary and community-based care and (3) built upon supportive funding and

delivery mechanisms. While questions of governance would still need to be answered by co-leaders, empowering Canadians to be more actively engaged in healthcare could improve the value of care by aligning citizen and system goals.

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Results from a Deliberative Dialogue to Identify Policy Strategies to Improve Value in Healthcare

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Psychedelics to Relieve Psychological Suffering Associated with a Life-Threatening Diagnosis: Time for a Canadian Policy Discussion

Thérapie psychédélique pour soulager la souffrance
psychologique associée à un diagnostic menaçant la vie :
discussion en cours sur les politiques canadiennes



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Abstract

In Canada, the conversation to enable access to therapeutic psychedelics is under way. With recent federal initiatives, Canadians can request access to psychedelic-assisted therapies (PATs) to alleviate enduring and intolerable psychological suffering (EIPS) associated with

life-threatening conditions on a case-by-case basis. The resurgence of past research concerning the therapeutic potential of PATs, promising preliminary results from contemporary clinical trials, public and media interest and the recognition of traditional Indigenous use of psychedelics have facilitated a change in the popular narrative around these stigmatized substances. A lack of access to PATs for treating EIPS, especially at end of life, is a public policy problem worth addressing.

Résumé

Il y a actuellement, au Canada, un débat entourant l'accès aux thérapies psychédéliques. Grâce aux récentes initiatives du gouvernement fédéral, les Canadiens peuvent demander, au cas par cas, l'accès à des thérapies assistées par des psychédéliques (TAP) pour soulager les souffrances psychologiques persistantes et intolérables (SPPI) associées à des conditions potentiellement mortelles. La résurgence des recherches passées concernant le potentiel thérapeutique des TAP, les résultats préliminaires prometteurs des essais cliniques contemporains, l'intérêt du public et des médias ainsi que la reconnaissance de l'usage autochtone traditionnel des substances psychédéliques ont favorisé un changement dans le discours populaire sur ces substances stigmatisées. Le manque d'accès aux TAP pour atténuer les SPPI, en particulier en fin de vie, est une question de politique publique qui mérite d'être abordée.

Introduction

In recent years, Canadian perceptions of controlled substances have shifted along with changes in drug policy, including provisions for access to medical cannabis (Fischer et al. 2016). More changes are anticipated. Global drug policy is also shifting. The United Nations has removed cannabis from its strictest control (UN 2020), enabling federal shifts in policy. Research and conversation about the therapeutic use of psychedelic substances abound internationally and nationally. Canada's leading medical journal reported that the medicinal use of psychedelics was "just around the corner" (Dyck 2015: 1080), "opening clinical and therapeutic doors long closed" (Tupper et al. 2015: 1059). Over 50 terminally ill Canadians have received legal access to psilocybin-containing mushrooms to alleviate psychological distress at end of life (EOL). Canadian healthcare professionals have acquired access to psilocybin for training in psychedelic-assisted therapies (PATs) (Dubinski 2020). Canadians, including policy makers and medical practitioners, are interested in exploring psychedelic options to improve quality of life (QOL) at EOL and to reduce psychological disturbances more generally.

We use the term *psychedelics* to refer to lysergic acid diethylamide (LSD), ketamine, psilocybin, 3,4-methylenedioxymethamphetamine (MDMA), N,N-dimethyltryptamine (DMT) and N,N-dipropyltryptamine (DPT). Each of these have been – to varying degrees – the most researched for safety and efficacy within an EOL care context. PAT refers to the use of psychedelic substances as an adjunct to a psychotherapeutic modality.

Enduring and Intolerable Psychological Suffering

The Medical Assistance in Dying (MAID) legislation (Bill C-14) in 2016 marked the creation of a clinical condition called enduring and intolerable psychological suffering (EIPS) as an indication for MAID (Government of Canada 2016). The original provision conceptualized EIPS as a form of suffering arising when coping with an incurable and terminally advanced physical disease. The text of the Bill states that patients may have cause for MAID if “that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable” (Government of Canada 2023: 286).

As a construct defined within a legal and political framework, EIPS does not correspond with recognized psychiatric disorders, contributing to a lack of information about the condition’s determinants and diagnosis. Nonetheless, the construct of EIPS points to a condition long recognized by clinicians in palliative care, hence the historical use of palliative sedation as a last-resort intervention for terminally ill patients. Some have referred to EIPS as existential distress, death anxiety or demoralization in an EOL context, which has been treated with conventional treatments such as pharmacotherapies and psychotherapies (Bauereiß et al. 2018; Vehling and Kissane 2018). Existentially oriented distress is a condition both immemorial and new that has come under the radar of psychiatric nosology.

Research on MAID has found that most requests are motivated by existential suffering associated with a life-threatening diagnosis (Cha 2017; Downar et al. 2020; Li and Kain 2018), which is neither inadequate pain or physical symptom control nor, strictly speaking, a desire for death. Rather, MAID may allow individuals to have control over the timing and manner of their death, alleviating some death and dying-related concerns.

Though EIPS may not have a high prevalence, it is difficult to manage when it does occur. The first line of treatment may involve conventional pharmacotherapy or psychotherapy or their combination, but for those who do not respond to them, MAID is the next legally accessible option – the second line of treatment. We propose that PATs may be well suited to alleviate existentially oriented psychological suffering and can be an effective option (Schimmel et al. 2022; Yaden et al. 2021).

Palliative Sedation and MAID

MAID signalled a change in public perception that it is acceptable to have the right to die and to determine the medical options that would promote dignity in death at EOL. Before MAID, EIPS at EOL may have been controversially addressed for some with palliative sedation – an intervention to sedate a person that may hasten death as a secondary effect but is not the primary intent. The use of palliative sedation has been extended to include the alleviation of non-physical symptoms such as fear, anxiety and psycho-existential distress (Heijltjes et al. 2020), and in some jurisdictions, it can be the sole reason for the request for palliative sedation. The legal status of palliative sedation, particularly for the indication of psychological suffering, is unsettled in Canada. There is no legislation addressing it, and no court cases have tested it.

Despite calls for caution (Laupacis 2020), access to MAID continues to broaden rapidly. As of 2024, eligibility will include those whose sole diagnosis is a mental illness (Karel 2021; van Veen et al. 2022). Given the finality of MAID or palliative sedation and the pace of cultural change, stakeholders may welcome the inclusion of PATs as an alternate or additional treatment option.

Are PATs Safe and Effective Enough?

Contemporary clinical trials examining psilocybin and MDMA in patients with life-threatening illnesses have demonstrated physiological and psychological safety in a medical setting (Griffiths et al. 2016; Grob et al. 2011; Ross et al. 2016; Wolfson et al. 2020). Psilocybin-assisted therapy led to a decrease in depression, anxiety and existential distress and an increase in QOL and life meaning sustained at six months (Griffiths et al. 2016). In one study, participants requested additional sessions to reinforce clinical benefits (Grob et al. 2011). These results are promising and remarkable, though the evidence is preliminary. The clinical trials were relatively small, the populations were heterogenous and the initial research did not have the statistical power or methodological rigour to definitively demonstrate efficacy within EOL populations. More studies are needed to clarify both indications and contraindications and to continue to explore the safety of PATs.

However, the large effect sizes, amount of clinician and researcher commentary and increasing public engagement should not be ignored. A decision logic that supports good enough evidence that improves QOL at EOL may be helpful, especially given that the regulatory and medical boundary includes MAID. EOL care decisions that are clinically relevant may be the ones that (1) consider patient-relevant benefits that outweigh any harms, (2) apply to the patients being treated and (3) are the best available options (Howick 2011).

A tempered approach may be appropriate. The findings so far probably do not support the immediate widespread rollout and unmitigated access to PATs. However, providing funds to facilitate the study of psychedelic interventions can be recommended as can easing administrative restrictions to provide streamlined case-by-case access for those experiencing EIPS within a MAID context. We also recommend that policy discussions begin now about how to meet the demand for PATs (see Table 1).

Approval Processes

There may be several approval processes for the therapeutic use of psychedelics. A recent example is by way of requesting subsection 56(1) class exemption of the *Controlled Drugs and Substances Act* (CDSA) (1996). Approval and access to illicit substances and last-resort interventions for therapeutic purposes, typically for conditions that have not responded to conventional therapies, have a long-standing history in Canada's medical and legal landscape. The scope of use for palliative sedation was expanded under the umbrella of compassionate care using the principles of informed consent and potentially life-shortening symptom relief (Downie and Liu 2018) to include EIPS as an indication. The approval process for MAID

TABLE 1. Three overarching questions to guide the policy discussion

Question 1	Who can be allowed to facilitate a therapeutic experience with a patient undergoing a psychedelic intervention?
	This question may raise follow-up questions about training and certification processes, healthcare professional affiliations, Indigenous and other traditional ethnocultural healers and types of clinical or healing approaches that would fulfill the psychotherapeutic or facilitation portion.
Question 2	Where can a patient undergo a psychedelic intervention?
	Issues raised may include the location of psychedelic administration (e.g., hospital, home, community clinic, Indigenous and other traditional ethnocultural contexts), the necessary physical and aesthetic elements within the setting (e.g., furniture, décor, temperature, sound) and questions about accessibility.
Question 3	Which psychedelic substances can be administered?
	Issues raised may concern the decision about which psychedelics will be part of a medicinal treatment model, including substances that have been more researched (e.g., psilocybin, DPT, LSD) or those with a history of use in traditional healing practices (e.g., ayahuasca). There may also be questions about production and methods of procurement.

DPT = N,N-dipropyltryptamine; LSD = lysergic acid diethylamide.

was the subject of judicial consideration, the law was changed and policies were created to make MAID accessible.

Cannabis has undergone a complex approval process and may offer insight into how psychedelics could pass this process. Similar to psychedelics, cannabis had a '60s stigma that produced an enduring negative counterculture image. There was mixed scientific evidence for its therapeutic properties and discouragement of medical research based on it. Some cannabis products were made accessible for medical use before the *Marihuana Medical Access Regulations* (2001) and the *Marihuana for Medical Purposes Regulations* (2013). Examples of these products included nabilone, which was approved in 1982 for chemotherapy-induced nausea and vomiting not responding to conventional therapy, and in 2005, Canada became the first country to approve Sativex – a cannabis-derived prescription medicine used for multiple sclerosis neuropathic pain and cancer pain.

Precedents for the Therapeutic Use of Psychedelics

There are a few legal means to access psychedelic substances at EOL. Each avenue provides a different potential for medical support and involves various methods of procurement of the substance. Clinical trial enrolment is the most common and the long-standing method of access. More recently, the Public Prosecution Service of Canada issued a revision to simple possession offences under the CDSA (1996), whereby law enforcement is advised to avoid prosecuting simple drug possession cases unless there are significant public health and safety concerns and only when prosecution serves the public interest (Public Prosecution Service of Canada 2020). This directive allows individuals at EOL to procure and consume psychedelics without criminal prosecution. Outside a clinical trial context, the only legal provision for

“medical” access is the case-by-case basis subsection 56(1) class exemption of the CDSA (1996). It has been used to give patients access to psilocybin-containing mushrooms since August 2020.

On January 5, 2022, Health Canada announced its amendment to the Special Access Program (SAP), allowing practitioners with prescription privileges to request access to restricted drugs (including psychedelics such as psilocybin, LSD and MDMA) within a model of PAT for Canadians experiencing mental disorders unrelieved by existing treatments. Through subsection 56(1) class exemption of the CDSA, healthcare workers were provided case-by-case access to PAT training. In February 2022, Health Canada began denying subsection 56(1) exemptions to terminally ill Canadians and healthcare workers seeking access to psilocybin for medicinal and training purposes. This decision has not been publicly explained, and lobbying to grant exemptions continues (Office of the Commissioner of Lobbying of Canada 2022). The Centre for Addiction and Mental Health (CAMH) has recently received Canada’s first federal grant from the Canadian Institutes of Health Research (CIHR) to study psilocybin’s effects on treatment-resistant depression (CAMH 2022). The federal funding agency has also issued a request for proposals to support early phase clinical trials exploring the use of psilocybin-assisted psychotherapy to treat mental health disorders and substance use, including at EOL (CIHR 2022). Perhaps support can be expanded to consider innovative trial designs.

In the US, outside of approved clinical trials, there is an expanded access program that provides a pathway for seriously ill patients to access investigational drugs (Darrow et al. 2020). However, increased access to legal psilocybin therapy began as an Oregon state-led initiative to provide medically available psilocybin services for a two-year period, activated by special interest and lobby groups (Investing News Network 2022). During this period, information will be gathered on this experimental policy to inform how and whether to create a comprehensive regulatory framework for providing this service. Taking a different approach, Australian medical regulators have rejected an application to have psychedelics legalized for clinical use due to a lack of clinical scientific evidence (Landis-Hanley 2021). To back this evidence base, the Australian government has provided millions of dollars to fund psychedelic research by the country’s universities. Meanwhile, the European Medicines Agency is conducting large-scale trials of psilocybin to alleviate treatment-resistant depression.

Pan-Canadian Rollout: Issues to Consider

The federal aspect is well developed at this point, with recent changes to the SAP enabling access to psychedelics. However, there are no approaches to access that are province- or territory-specific. The first steps to establishing such pan-Canadian approaches would entail regulatory changes, legislative changes and consultation with key stakeholders, including the government, scientific and clinical communities, drug development companies and special interest and patient groups. To expand the current policy discussion that is under way, there are three questions that will need to be discussed (see Table 1).

Many issues will be similar to those related to the medicalization of cannabis. However, there are important exceptions – namely, that a licensed health professional will likely be required to administer the psychedelic within a supervised psychotherapeutic setting. Issues with product licensure, production and manufacturing may follow a similar pathway as the one for cannabis. As such, four points will need to be considered: (1) the licensing and certification of the providers, (2) the creation of appropriate settings for administration and follow-up, (3) funding models and payment schemes within an EOL context and (4) the evaluation of outcomes.

There may be provincial and territorial variations in creating access to medicinal psychedelics. British Columbia has several initiatives that model potential ways of delivering psychedelic therapies, including training programs for those interested in providing PAT. Historically, Saskatchewan and Ontario were at the forefront of research on mescaline and LSD in Canada. Current Canadian research is largely under way in Ontario, Quebec and British Columbia, exploring psilocybin's effects on mood disorders and EOL distress, ketamine's antidepressant effects and MDMA's potential to alleviate post-traumatic stress disorder. These provinces may be the first to tackle issues of creating access to medicinal psychedelics for EOL care and to establish working models that other provinces and territories can adapt. It is worthwhile to consider the diversity both ethnoculturally and clinical-professionally, especially as it relates to Indigenous Peoples' right to traditional healing modalities and their use of traditional Indigenous medicines (Muscat et al. 2021). Thus, it is important to recognize that diversity in the licensing and certification process for providers of PAT may need to exist, which is consistent with existing variations in the licensure for health professionals across Canada. Provinces and territories may also consider establishing training programs open to certifying various professionals beyond those with a regulated clinical designation.

EOL Psychedelic Use: There Is Little to Lose and a Lot to Gain

With municipal discussions to decriminalize controlled substances for personal consumption, access to MAID for those who are not close to their natural death and upcoming changes to MAID's eligibility criteria that will enable access for persons whose only medical condition is a mental illness – the potential clinical benefits of making PATs accessible as part of palliative care may outweigh the risks. The most recent changes to Bill C-7 may not adequately address Canada's commitment to providing access to acceptable and alternative options (Government of Ontario n.d.). Since palliative care aims to improve QOL at EOL, alternative interventions addressing a person's psychological suffering and loss of life's meaning in the face of death should be made accessible. Psychedelics may constitute such an alternative. Canadians have the right to access all treatment options available and should not have to choose between a legal but, for some, inadequate solution and an illegal but potentially more effective one.

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Commentary: Access to Psychedelics for Psychological Suffering at the End of Life – Prioritizing Our Priorities

Commentaire : Accès aux thérapies psychédéliques pour soulager la souffrance psychologique en fin de vie – mettre de l'ordre dans nos priorités

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Abstract

We agree with Kratina et al. (2023) that the problem of psychological suffering at the end of life deserves attention from a policy standpoint and that psychedelic therapies show promise in this clinical context. However, we argue the following in this rejoinder: (1) disproportionate attention to psychedelics may overstate the current evidence base, potentially diverting resources away from existing evidence-based programs; (2) a more pressing policy priority related to this public health problem is to address population-level inequities in accessing high-quality, early and holistic palliative care, including psychosocial care; and (3) discussions about expanded access to psychedelics must also foreground equity issues.

Résumé

Nous convenons avec Kratina et al. (2023) que le problème de la souffrance psychologique en fin de vie mérite une attention politique et que les thérapies psychédéliques sont prometteuses dans ce contexte clinique. Cependant, nous soutenons ce qui suit dans la présente réplique : (1) une attention disproportionnée aux thérapies psychédéliques pourrait exagérer le fondement des données actuelles, en détournant les ressources des programmes existants qui sont fondés sur des données probantes; (2) une priorité politique plus urgente liée à ce problème de santé publique est de remédier aux inégalités des populations en matière d'accès à des soins palliatifs précoces et holistiques de haute qualité, notamment les soins psychosociaux et (3) les discussions sur l'élargissement de l'accès aux thérapies psychédéliques doivent aussi mettre de l'avant la question de l'équité.

Introduction

Psychedelic research is enjoying a re-medicalization renaissance. Early findings from trials on psychedelic therapies using compounds such as psilocybin and 3,4-methylenedioxymethamphetamine (MDMA) are promising for a range of conditions, including major depressive disorder and post-traumatic stress disorder. One area that has received considerable attention is palliative care, with recent trials suggesting that psychedelic-assisted therapies (PATs) may reduce psychological suffering common to people with advanced disease.

As an author team actively engaged in the field of PAT research, as well as its ethics, we welcome the policy conversation initiated by Kratina and colleagues (2023). Indeed, we welcome new, safe, effective and compassionate approaches that not only help to promote patient well-being but also help healthcare professionals achieve the *telos* of medicine – that is, the alleviation of pain and suffering. This is particularly important given the context of medical assistance in dying (MAID) in Canada, as the authors note, where the presence of intolerable suffering is a key criterion (Kratina et al. 2023). However, we do not believe that the lack of access¹ to psychedelic therapies at the end of life (EOL) – or as an alternative to MAID – is as urgent a health policy priority as the authors suggest. In our view, this line of argumentation distorts the policy landscape in two important ways. First, it may lead to the misperception that PAT is the best – or even the *only* – intervention available to alleviate psychological distress among dying patients, which may divert attention and resources away from existing evidence-based interventions and clinical programs. Second, it does not address what we believe should be a higher policy priority, which is to reduce existing population-level inequities in accessing high-quality, early and holistic palliative care, including psychosocial care. Furthermore, any potential PAT rollout must not reproduce similar inequities.

MAID and the Public Health Problem of Psychological Suffering at EOL

The authors state that Canadian MAID legislation in 2016 “marked the creation of a clinical condition called EIPS [enduring and intolerable psychological suffering] as an indication for MAID” (p. 136) and define this as an extreme form of demoralization/existential distress/

death anxiety. Attention to the clinical problem of psychological end-of-life distress (EOLD), and research focused on its treatment, has a long history that coincides with the rise of the palliative care field, although it has received less attention relative to physical distress (Kaasa et al. 2018). Most research on psychological EOLD has focused on depression and other common clinically recognized outcomes rather than assisted dying requests, and there are many evidence-based interventions available to treat those outcomes (Breitbart and Chochinov 2022).

The authors' framing of MAID as the "second line of treatment" (p. 136) for EIPS is not quite accurate. The push to legalize assisted dying came largely from outside traditional healthcare, spurred by advocacy groups and public pressure (Li et al. 2017), rather than from within healthcare as treatment for an identified clinical problem. The drivers of MAID requests and potential prevention strategies remain poorly understood, partly because MAID remains relatively uncommon; a small proportion of patients with advanced disease make these requests, and an even smaller proportion follow through with a MAID intervention (Li et al. 2021; Vehling and Kissane 2018). It remains an empirical question whether psychedelics may decrease MAID requests, with some evidence that ketamine treatment of depression may not consistently reverse these decisions (Berens and Kim 2022; Rosenblat and Li 2021). Given the demographic similarities between those receiving MAID and those receiving PAT (Michaels et al. 2018; Redelmeier et al. 2021; Sellers et al. 2018) – that is, they are more likely to be white, with higher education and of higher socio-economic status – it is possible that PAT and MAID may appeal to the same population on the basis of personality, class or commonly held western liberal values favouring individual autonomy and independence.

We agree that the broader clinical problem of psychological EOLD is an important one and argue that what is needed is more research focused on this problem, as well as improved knowledge of and consistent access to existing evidence-based interventions.

Psychedelics and EOLD: The Story So Far

Psychedelic therapies appear to be safe for some patients with life-threatening illnesses, both from physiological and psychological standpoints (Maia et al. 2022). To our knowledge, no serious adverse events attributable to the study drug have been reported in contemporary trials using psilocybin, MDMA and lysergic acid diethylamide–assisted therapies in this patient population. With respect to efficacy, both quantitative and qualitative data from recent early-phase studies of PAT suggest tremendous promise for the rapid and enduring alleviation of symptoms of depression and anxiety associated with life-threatening illness along with improvements in quality of life, spiritual well-being, death anxiety and existential distress.

However, these broad conclusions must be followed by strong caveats. Trials to date have had stringent inclusion and exclusion criteria, limiting the generalizability of the findings to community practice. The heterogeneity of study participants with respect to disease status also limits the conclusions drawn about safety in this patient population; some participants had curable cancers, and some participants were enrolled while their disease was in

remission. We do not yet know how safe PAT is among people with more limited prognoses, people in hospice care or homecare settings, people with complex comorbidities, or in other specific cases (e.g., those with metastatic disease of the central nervous system).

Similarly, it is likely that participants in these early trials were highly motivated, and many had prior psychedelic experience(s). While the same may be true for some patients wanting access to PAT in the community, it is also likely that some patients, desperate for relief from their suffering, may seek these treatments because of the considerable hype surrounding psychedelics (Yaden et al. 2022), which often paints these substances as miracle pills that lead to instant cure through a “brain reset” (Watts 2022). The reality is that psychedelic therapies are complex and often intense interventions, of which the psychedelic substance is only one part. Trial therapy protocols have involved considerable support for participants (e.g., many hours of preparatory therapy, the presence of two therapists throughout the intervention and aftercare in the form of structured integration sessions), and study therapists have been highly trained.

Further research is needed to address important knowledge gaps that remain in this field (Beaussant et al. 2021). In the meantime, we are concerned that in the accelerated pace to grant widespread access to psychedelic therapies, patients may be at risk of harm because clinical best practices and standards regarding clinician competency are simply not yet in place.

Prioritizing Our Priorities: Inequitable Access to Palliative and EOL Care

Palliative care is critical for promoting quality of life for people with advanced disease and their families, including at EOL. While access to palliative care has improved in Canada, there continue to be population-level inequities in access to palliative and EOL care. Members of structurally disadvantaged groups, such as those experiencing poverty and homelessness, face the most barriers (Costante et al. 2019; Stajduhar 2020).

Depending on how PAT is regulated, policy makers must ensure that its implementation does not intensify existing inequities, particularly those that exist in the current context of lack of publicly funded psychotherapy and no universal pharmacare. For example, it would be problematic from a health equity perspective if decriminalized psychedelics are regulated solely in the private sector where access is determined based on the ability to pay – as is the case for many medications and psychotherapy available outside of hospital settings (Rea and Wallace 2021).

The focus on expanding access to PAT – provided that favourable evidence concerning its safety and efficacy profile continues to emerge – without due attention to reducing population-level inequities may provide great benefit to a small, privileged population with profound psychological suffering at EOL. This should not be discounted. However, prioritizing the expanded access goal in health policy discussions should not divert attention or scarce resources away from the complex socio-structural factors that make high-quality and holistic palliative and EOL care, including psychosocial care, out of reach for many individuals. Policy decisions should not entrench inequities.

Conclusion

Kratina et al. (2023) have provided the opportunity for an important conversation at the intersection of experimental interventions, health and drug policy and palliative and EOL care. While we remain excited about the possibilities for PAT, we have underscored the *tempered approach* surrounding the policy question of prioritizing expanded access to medicalized psychedelic therapies, given our concern that these efforts could divert the policy focus away from ensuring equitable access to high-quality, early and holistic palliative care. This is particularly so in the case of psychosocial palliative care, which has received less attention relative to interventions targeting physical symptoms. Calls for expedited access to psychedelic therapies for people with life-threatening illness must also come with a careful analysis of the safety and efficacy of these interventions, an acknowledgment of critical knowledge gaps and attention to equity concerns.

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Note

1. At the time of writing this article, eight Canadians with support from the psychedelic non-profit advocacy group TheraPsil had filed a Charter challenge, arguing that lack of access to psilocybin and PAT violated their Section 7 Charter rights to life, liberty and security of the person (TheraPsil n.d.).

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