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Connecting Health and Social Services for Patients with Complex Care Needs: A Pan-Canadian Comparative Policy Research Program

Relier services de santé et services sociaux pour les patients ayant des besoins complexes en matière de soins : un programme pancanadien de recherche comparative sur les politiques

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Services de santé, gestion et recherche de politique

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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.

CONTENTS

 Peer Reviewed

TABLE DES MATIÈRES

 Examen par les pairs

HEALTHCARE
POLICY
Politiques de Santé

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EDITORIAL

The Tangled Web of Integrating Health and Social Services in Canada

It is important to have all the pieces of health and social care systems working together to maintain and improve the lives and well-being of medically complex Canadians. Being medically complex means needing physical and mental healthcare for chronic conditions, addressing functional health limitations and adapting models of care to social vulnerabilities, such as rurality or cultural safety. This could happen to any of us or to our family members, at any time.

In practice, however, the pieces of provincial health and social care systems do not always mesh well together for the medically complex. When this happens, affected Canadians suffer unnecessarily through poorly coordinated care, unnecessary delays, reduced opportunities for social support and avoidable healthcare utilization.

In this special issue of *Healthcare Policy*, a team of researchers drawn from across Canada attempted to measure the degree of formal and informal integration between and within health and social care services. To do so, the team focused on two high-needs populations: children and youth and community-dwelling older adults with high functional health needs. The editorial team of *Healthcare Policy* supported the research team's efforts to share their findings since integrating health and social care services may lie on the causal pathway to improving patient-centred care and enhancing value for the provinces' spending.

There are eight manuscripts in this special issue, each penned by experts in their fields. The studies employed a comparative policy and program analysis that spanned ten provinces. The research compared the provincial structures that govern primary care, community-based social services and supports for the two high-needs populations. Then, the research identified facilitators and barriers to integrating primary care and community-based social services, and concluded with a description of macro-, meso- and micro-level policy barriers to data linkage and information sharing between health and social services.

Improving the integration between health and social services is a critically important task the outcomes of which will affect many of us. The contributions from this research will be integral to developing enduring national and provincial policies that work to avoid future breakdowns in care and meaningfully engage clinicians in care integration. I hope that you find the topic and manuscripts as meaningful as I do.

JASON M. SUTHERLAND, PhD
Editor-in-Chief

ÉDITORIAL

Le labyrinthe de l'intégration des services de santé et des services sociaux au Canada

Il est important que tous les éléments des systèmes de santé et de services sociaux travaillent de pair pour maintenir et améliorer la vie et le bien-être des Canadiens qui présentent des cas médicaux complexes. Présenter un cas médical complexe veut dire avoir des besoins en matière de soins de santé physique et mentale pour des maladies chroniques, faire face à des limitations en matière de santé fonctionnelle et devoir adapter les modèles de soins aux vulnérabilités sociales telles que la ruralité ou la sécurisation culturelle. Cela peut arriver à n'importe lequel d'entre nous ou aux membres de notre famille, et ce, n'importe quand.

Dans la pratique, cependant, les éléments des systèmes de santé et de services sociaux des provinces ne s'imbriquent pas toujours bien pour les cas médicaux complexes. Ainsi, les Canadiens touchés souffrent inutilement de soins mal coordonnés, de retards inutiles, d'un soutien social réduit et d'une utilisation évitable des soins de santé.

Dans ce numéro spécial de *Politiques de Santé*, une équipe de chercheurs canadiens a tenté de mesurer le degré d'intégration formelle et informelle entre les services de santé et les services sociaux. Pour ce faire, l'équipe s'est concentrée sur deux populations à besoins élevés : d'une part, les enfants et les jeunes et, d'autre part, les personnes âgées qui vivent dans la communauté et qui ont des besoins élevés en matière de santé fonctionnelle. L'équipe de rédaction de *Politiques de Santé* a appuyé les efforts de l'équipe de recherche pour faire part de ses conclusions, car l'intégration des services de santé et des sociaux sociaux peut mener à l'amélioration des soins axés sur les patients et à l'optimisation des dépenses des provinces.

Ce numéro spécial présente huit manuscrits, rédigés chacun par des experts dans leur domaine. Les études ont procédé à des analyses comparatives des politiques et des programmes dans dix provinces. La recherche a comparé les structures provinciales qui régissent les soins primaires, les services sociaux communautaires et le soutien pour les deux populations à besoins élevés. Ensuite, la recherche a identifié les facilitateurs et les obstacles à l'intégration des soins primaires et des services sociaux communautaires, et s'est conclue par une description des obstacles – de niveau macro-, méso- et micro-politique – au couplage de données et au partage de l'information entre les services de santé et les services sociaux.

Améliorer l'intégration entre les services de santé et les services sociaux est une tâche essentielle dont les résultats affecteront bon nombre d'entre nous. Les contributions de cette recherche seront essentielles à l'élaboration de politiques nationales et provinciales durables qui permettront d'éviter d'éventuelles défaillances dans les soins et de faire participer de façon significative les cliniciens à l'intégration des soins. J'espère que vous trouverez, comme moi, que le sujet et les manuscrits sont de grande importance.

JASON M. SUTHERLAND, PhD

Rédacteur en chef

INTRODUCTION

Connecting Health and Social Services for Patients with Complex Care Needs: A Pan-Canadian Comparative Policy Research Program

Relier services de santé et services sociaux pour les patients ayant des besoins complexes en matière de soins : un programme pancanadien de recherche comparative sur les politiques

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Abstract

Comprehensive primary healthcare for patients with complex care needs requires connections to other health services, social services and community supports. This descriptive comparative policy research program used publicly available documents and informant interviews to examine progress toward integrated comprehensive care through the lens of services needed by children and youth (0–25 years) and community-dwelling older adults (≥ 65 years) with high functional health needs. This article describes five projects. The following three findings emerged across all the projects: Canada indeed has multiple health systems; numerous integrated service delivery solutions are being trialled and most focus on medical services; and it is an ongoing challenge for ministries of health to engage physicians and physician associations in integration.

Résumé

Pour offrir des soins de santé primaire globale, aux patients ayant des besoins complexes, il faut établir des liens avec les autres services de santé, les services sociaux ainsi que le soutien communautaire. Ce programme descriptif de recherche comparative sur les politiques a recours aux documents publiquement accessibles et à des entrevues avec des clés informateurs pour examiner les progrès réalisés dans l'atteinte des soins intégrés globaux selon les services dont ont besoin les enfants et les jeunes (de 0 à 25 ans) ainsi que les aînés (≥ 65 ans) qui vivent dans la communauté et ont de forts besoins en matière de santé fonctionnelle. Cet article décrit cinq projets. Les trois constatations suivantes sont ressorties de chacun des projets : le Canada a effectivement plusieurs systèmes de santé; de nombreuses solutions intégrées de prestation de services sont mises à l'essai et la plupart sont axées sur les services médicaux; et il est toujours difficile pour les ministères de la Santé de faire participer les médecins et les associations de médecins aux initiatives d'intégration.

Introduction

Primary care in the Canadian healthcare system is responsible for first contact and ongoing care to a practice population undifferentiated by age, gender or disease status. Primary care should be organized to be the Patient's Medical Home for person-centred longitudinal care even when patients receive services elsewhere (CFPC 2011). The integrated care framework developed by Valentijn et al. (2013) posits that achieving comprehensive primary care for a defined population requires integration of services beyond the health sector to include social sectors and community-based organizations.

Primary healthcare, as defined aspirationally by the World Health Organization (WHO 1978, 2018), includes health, social and community services that meet the health needs of individuals throughout their life. Since the Canadian health system focuses predominantly on primary care, achieving primary healthcare requires integration of primary care (or the Patient's Medical Home) with other health services, social services and community supports. This special issue of *Healthcare Policy* presents eight linked articles that describe and compare policies and initiatives across Canada, which integrate services across health and social sectors from the perspective of primary care and especially for those with complex care needs.

Comprehensive, integrated primary healthcare is critical for all primary care patients but especially for those with multiple chronic diseases in addition to functional health limitations and social vulnerabilities, such as limited income or social isolation. Patients with complex care needs require smooth coordination and communication among primary care, specialised care, social services and community supports (Jones et al. 2020; Miller et al. 2009). Failure to connect (discontinuity) needed services leads to negative experiences for patients, caregivers and health professionals (Bayliss et al. 2015; Foglino et al. 2016; McCormack et al. 2008), as well as health deterioration, expensive healthcare interventions and costly social consequences (Hwang et al. 2013; Nolte and Pitchforth 2014; Paré et al. 2014).

The importance of integrating health and social services to achieve comprehensive and coordinated care is more often invoked than defined. A 2009 review of healthcare integration reported 175 definitions and concepts in 70 papers (Armitage et al. 2009). For this research program, we defined service integration policies as the governance, funding, strategic, organizational and programmatic directives that aim to facilitate coordination and collaboration among organizations and service providers whose complementary actions work together to achieve desired health outcomes for patients with complex care needs (Villeneuve 2017). Policies are statements of direction that result from decision-making processes. They guide action and are informed by data and evidence (Villeneuve 2017). Macro-level legislative policies, such as the *Canada Health Act* (1985), guide national or provincial authority and governance. Strategic policies such as the 2001 First Ministers Health Accord (Health Canada 2006) guide funding allocations to high-level priorities, such as primary care renewal or the COVID-19 pandemic. Meso-level or programmatic and operational policies pertain to organizations with complementary actions and facilitate connection, communication and

coordinated actions in pursuit of a common objective. An example of a common objective is avoiding institutional care for older adults through facilitated linkages of primary care, day hospitals and home care.

Among the initiatives to promote integrated health-related services in Canada, the pan-Canadian SPOR [Strategy for Patient-Oriented Research] Network in Primary and Integrated Health Care Innovations promoted cross-jurisdictional research and knowledge exchange "to accelerate the pace of integrated care solutions" (CIHR 2016). A priority that emerged across all provinces in 2016 was the need to identify, describe and compare initiatives across Canada to integrate services across health and social sectors for primary care patients with complex care needs.

Our pan-Canadian team (see p. 105) obtained funding from 10 different funders (see "Acknowledgment," p. 108) to conduct a comparative descriptive policy and program analysis with the following objectives:

- to describe and compare the structures and policies in Canadian provinces that govern primary care, community-based social services and community supports required for patients with complex healthcare needs;
- to identify exemplar publicly funded programs that connect primary care to health and social services and to community supports, and to assess facilitators and barriers to successful implementation and integration; and
- to identify recurring policy barriers to and facilitators of data linkage and information sharing across health and social services in key provinces.

This article is an overview of the research program reported in all the articles in this issue. We provide a brief description of the methods of the component projects and key findings that emerged across the different projects. Project-specific results are presented in the relevant papers of this issue.

Methodology

The research program presented in the articles of this issue consists of key projects, each uniquely focusing on aspects of healthcare integration in Canada since the 2001 First Ministers Health Accord that launched the renewal of primary care in Canada (Health Canada 2007). We focused on the 10 provinces for pragmatic and feasibility reasons reflecting the location of our research team. The majority of the data collection regarding policies and programs occurred during 2018 and into 2019.

The study team involved 46 researchers, clinicians, patient partners and decision makers from all 10 Canadian provinces. The five projects are:

- Consensus on the priority services to be connected for patients with complex care needs.

- Scanning of publicly available documents on macro-level policies that relate to the governance and scope of action of primary care and the priority services.
- Identification of exemplar programs for youth and children and the assessment of the degree of integration.
- Identification of exemplar programs for older adults and the assessment of the degree of integration.
- Comparative health reform analysis of selected exemplar programs.

Project leadership was distributed among principal investigators in Quebec (J. Haggerty, A. Quesnel-Vallée, Y. Couturier,), Manitoba (T. Stewart), New Brunswick/Prince Edward Island (S. Doucet, W. Montelpare), Nova Scotia (R. Urquhart), Alberta (C.M. Scott) and British Columbia (N.D. Oelke).

Study population

The focus of the research presented in the articles of this issue is patients who were managed in primary care clinics, although they had complex care needs that required connection to other medical, social and community-based services to maintain functional health or mitigate its decline. Functional health refers to a person's capacity to carry out activities of daily living that permit the achievement or maintenance of personal autonomy and social integration (Bierman 2001). This outcome is relevant to primary care because it transcends disease categories and encompasses physical, emotional and social dimensions of health. Inspired by the tracer condition methodology (Nutting et al. 1981), we examined the policy and programs through the lens of two patient subgroups: children and youth; and older adults. It is the expectation that policy and programs for these groups will be relevant to other subpopulations that require integration among primary care, social services and community supports.

CHILDREN AND YOUTH (0–25 YEARS) WITH HIGH FUNCTIONAL HEALTH NEEDS

Children and youth with complex care needs are those with one or more chronic physical, emotional, developmental, neurological or behavioural conditions (Cohen et al. 2012; Goyette et al. 2011), estimated as between 15 and 18% of North American children (Berry et al. 2011; Kaufman et al. 2007). They typically require a high volume of healthcare services, as well as social, educational and community supports, to optimize the development of autonomy and enhance social integration (Cohen et al. 2011, 2012; Kaufman et al. 2007).

COMMUNITY-DWELLING OLDER ADULTS (≥ 65 YEARS) EXPERIENCING FUNCTIONAL DECLINE

Older adults are living longer and over half have multiple chronic health conditions (CIHI 2011; Doupe et al. 2016). Services across the health, social and community sectors have to be mobilized – sometimes quickly in response to health or social crises – to prevent health decline and maintain community-dwelling autonomy for older adults as long as possible (Hébert 1997; Hoogerduijn et al. 2007).

Summary of Projects and Results

Project #1: Consensus on priority services to be connected

As a foundation for the research program, the team conducted a rapid consensus process, wherein all co-investigators and collaborators were invited to propose health, social and/or community services that should be linked to ensure integrated comprehensive primary healthcare for one of the two patient groups they best understood. A broad range of services were identified and defined separately for children and youth and for older adults using an electronic nominal group technique (Gallagher et al. 1993). After making an operational definition for each service, the team conducted a modified Delphi study to prioritize the service based on frequency of need and potential health impact of connecting to the service. The top 10 services for each group formed the backbone for the subsequent projects. As reported in the article by Dionne et al. (2023a), most of the top 10 priority services to be linked to primary care are traditional health services, but some are common to both patient groups and together represent a priority for integrating services.

Project #2: Scan of provincial governance and scope of primary care and priority services

Publicly available information from government websites was captured in a data-collection template for each province (Appendix 1, available online at www.longwoods.com/content 27186) that identified the then-current institutional authorities that governed primary care in each province and any relevant macro-level policies affecting primary care since 2001. The team also located the governance entity responsible for each of the top 10 priority services to be connected. The provincial data were transformed into a provincial narrative summary. Summaries were validated by key informants in each province, then analyzed independently by the senior investigators (JH, CS, YC) by the immersion–crystallization method to gather insights and discern patterns (Borkan 1999). The article by Scott et al. (2023) affirms that health service integration has been a persistent policy ambition across provinces. The article by Haggerty et al. (2023) on the prevalent and emerging primary care delivery models and their comprehensiveness reports that federal investments led to an ongoing process of primary care renewal that is more evident in some provinces than others, and that more comprehensive primary care models are the norm in at least five provinces. Policies and structures to integrate social care and community supports with healthcare are still nascent, however.

Project #3: Innovative programs for children and youth

All the co-investigators and collaborators were invited to identify programs in their own provinces that integrated health and social care for children and youth with complex care needs. From these, 16 were selected (at least one per province) as innovative and with potential for scalability. The team developed a tool to assign an integration score to each program to reflect the achievement of 10 principles of care integration (Suter et al. 2009) and

nine implementation facilitators (Damschroder et al. 2009). The team obtained information about the 16 programs from publicly available online documents and key informants. However, a lack of publicly available information precluded the application of the integration measure for a comparative analysis, an issue that is presented in more detail in the article by Stewart et al. (2023b), including the policy implications. The information that was available was used to create program summaries, and 14 of the children and youth co-investigators engaged in a deliberation conversation to identify pan-Canadian trends, as well as strengths and weaknesses that emerged across programs.

The article by Dionne et al. (2023b) reports on the findings, noting several programs that are exemplars of integration across the health and social divide.

Project #4: Innovative programs for older adults

The program identification and data collection was identical to that for children and youth and, again, the paucity of publicly available information posed a challenge to comparative program analyses. As reported in the article by Stewart et al. (2023a), integration pertained predominantly to services in the health system and formal linkage to primary care was rare.

Project #5: Comparative health reform analysis of selected innovative programs

For the comparative health reform analysis, the research team selected and obtained additional information about three programs in three provinces that addressed a similar issue. They identified the factors that influenced how and why each program started (Kingdon 2003), and how institutions, interests, ideas and external factors contributed to the program design (Bates and Andrew 2003; Hall 1997). Finally, the team identified the strengths, weaknesses, opportunities and challenges for implementation and program scale up. The selected children and youth programs focused on integration between primary care and social services but the analysis was not completed and is not included in this special issue. The older adults analysis compared three programs to integrate community-based care for major neurocognitive disorders and has been published elsewhere (Crowell et al. 2020). The findings of the comparative analyses echo the results of the children and youth programs (Dionne et al. 2023b) and the older adults programs (Stewart et al. 2023a). Their policy implications are coherent with other projects in the research program; namely, that building around existing institutional infrastructure and new primary care delivery models facilitates implementation, and that local champions are both critical and a source of fragility.

Common Findings across Projects

A common frustration and three findings emerged across all of the projects. The common frustration was the difficulty of finding information and how uneven information availability was across provinces. The difficulty of finding information about public policies and structures thwarted our original objectives in assessing the extent to which integration occurred in innovative programs and the lessons for implementation and scale up.

This frustration led to an unanticipated article on the paucity of publicly available information (Stewart et al. 2023b).

Among the three recurring findings, the first affirms the oft-repeated maxim that Canada has multiple health systems but also affirms the importance of federal and national policies in implementing and scaling up better and more equitable healthcare delivery options in all the health systems. A second – and hopeful – finding is the sheer number of integrated service delivery solutions and programs across the country; less hopeful is the limited scale up and cross-provincial learning. A third, if incidental, finding pertains to the policy and implementation challenge of engaging physicians and physician associations in comprehensive integrated care delivery solutions when they are outside the governance purview of the ministry of health.

Discussion

Here, we briefly discuss some policy implications of each of the three findings that emerged across the projects. We also refer readers to the other articles in the issue that address common challenges in integrating health and social services: multiple health systems, multiple innovations and the challenge of engaging physicians in integration.

Multiple healthcare systems and national policies

The structure and administration of healthcare in Canada rests jointly with federal, provincial and territorial governments. The oft-repeated maxim of 10 different provincial health systems became very evident in the scan of governance structures pertaining to primary care renewal and priority services. As pointed out in the article by Scott et al. (2023), even the nomenclature of hierarchical units in organizational charts for the provincial ministries of health was not comparable among provinces. There were striking similarities, however, in the names – and structures of services had been the object of federal or national policies such as the 2004 Health Accord on home care (Health Canada 2007) and the Mental Health Commission (https://mentalhealthcommission.ca).

Our findings point to the critical influence that policy decision making at a federal level or through cross-provincial accords has on the harmonized allocation of financing and service delivery in provincial and territorial jurisdictions. The integrated care programs for older adults with major neurocognitive disorders were initiated and sustained by the *National Strategy for Alzheimer's Disease and Other Dementias Act* (2017) (Stewart et al. 2023a). Ongoing investment by provinces in strengthening primary care is based on the initial federal investment in the Primary Health Care Transition Fund (Health Canada 2007; Hutchison et al. 2011). Guarantees in the *Canada Health Act* (1985) have created a sense of security among Canadians that they will have access to similar medical service coverage, regardless of jurisdiction. The *Canada Health Act* (1985) only addresses the criteria for transfers pertaining to publicly funded medical services, and it consequently defines comprehensiveness narrowly as "medically-necessary services." The recent experience with the COVID-19

pandemic highlighted to the Canadian public the differences in public health recommendations among provinces, the unequal health consequences between social and racial groups and the fragility of children and youth and of older adults. From our conversations with patient partners (Haggerty and Scott 2023), we think that the Canadian public expects more than just medical services from the health system and wants fewer, not more, differences between provincial health systems. We strongly recommend that it is time to revive federal and cross-provincial conversations to arrive at health accords that expand the definition of comprehensiveness to include health and social service integration, and ensure that Canadians receive the health and social services they require, regardless of jurisdiction.

So many integrated service delivery innovations, so little scale up

Our informal elicitation of exemplary integrated service delivery solutions and programs for both youth and children and older adults across the country revealed a surprisingly large number that started from 2001. This is a testament to the capacity for innovation and the relevance of integration for patients, caregivers, clinicians and policy makers. Programs for children and youth are often grounded in patients' needs and well supported by the community (Dionne et al. 2023b). But the implied sigh of "So much innovation, so little change" (Hutchison et al. 2001), alas, still holds true.

Many of the programs reviewed were pilot or research projects that did not survive end of funding, or they were local programs that were not spread or scaled up because they were so dependent on local champions. Formal program evaluation was rare and, even when available, did not address key dimensions of integration, such as information systems and financial management that are so important to policies for scale up (Stewart et al. 2023b). If our health-related services and system seem anachronistic and calcified, it is not for lack of innovativeness, lack of information or desire for change.

The capacity of provinces to learn from each other to spread and scale up innovations also requires a commitment to making relevant information more available. Inter-jurisdictional differences in regulations on privacy limit information sharing that can inform policy making to support allocation of financial and human resources to assist scale up within a province (Stewart et al. 2023b). It is time for a national dialogue on strategies to facilitate information sharing and to engage the public in understanding the implications of the status quo, much as was done for the Romanow Commission (Romanow 2002). Likewise, evaluation should be an expectation of any new program, especially programs that receive public funding, with the results publicly available in a program repository. The obligatory evaluation of the Primary Health Care Transition Fund may be part of the reason that provinces such as British Columbia, Prince Edward Island and Newfoundland and Labrador were able to trial primary care delivery models, such as the primary care networks, more than a decade after funding ended (Haggerty et al. 2023).

Engaging physicians and physician associations in integration policies

Canadians are justly proud of the policy achievement of universal no-cost coverage of

medically necessary hospital and ambulatory services under the *Medical Care Act* (Government of Canada 1966). However, the negotiated social contract with organized medicine to achieve the Act gave physicians the right to function as private entrepreneurs largely outside the purview of health system governance despite being publicly funded. Clinician integration has been recognized as a challenge even in integrated delivery systems where physicians have an employee–employer relationship (Shortell et al. 2001), so it is not surprising that clinician integration is such a challenge in Canada. An achievement of the many primary care renewal delivery models is that they not only increased comprehensiveness available to patients but also brought autonomous family practices within the governance and policy reach of the ministry of health (Haggerty et al. 2023). The strong network of primary care renewal models in Ontario provided an infrastructure for the spread of integrated programs for older adults with neurocognitive disorders, which was missing for a similar program in Saskatchewan (Crowell et al. 2020). This shows that the benefits extend beyond mere ministry of health influence. The emergence of competing family medicine models designed explicitly to align closely with the model promoted by the College of Family Physicians of Canada (CFPC 2011, 2019) rather than similar ministry of health models in New Brunswick speak to the challenge of fully engaging physicians in ministry of health solutions. The recurring support by physician associations of policies promoting a stronger presence of private healthcare is worrying and could undermine the comprehensiveness, universality, public administration, portability and accessibility guaranteed in the *Canada Health Act* (1985).

Implications for Policy

National policies such as the *Medical Care Act* (Government of Canada 1966), the *Canada Health Act* (1985) and the Health Accords (2001, 2004) (Health Canada 2006, 2007) and subsequent national initiatives, such as the Primary Health Care Transition Fund (2002–2006) (Health Canada 2007), have created a solid foundation on which to build policies for and collaborate on more comprehensive and integrated care for all Canadians and especially for those with complex care needs. Recent calls from provincial and territorial governments for the federal government to add more money to healthcare and support for more private healthcare have the potential to perpetuate the status quo of a narrow basket of medical care that ignores the social determinants of health and creates healthcare inequity.

Over 150 reports commissioned by governments to study the Canadian health systems have provided recommendations on what we can do better, but few of these recommendations have been implemented (Picard 2022). We do not need more national and provincial strategy reports, nor do we need to inject more money for more administrative restructuring. We need cross-provincial accords (through the Council of the Federation) in collaboration with the federal government, care providers and the public to identify a pathway toward integrated care. We have learned through the COVID-19 pandemic that policy making and changes in service delivery can be nimble when there is a crisis that transcends the interests of any one group.

This research program (with ambitious goals and a modest budget) responded to a felt need in a large group of Canadian health service and policy researchers and decision-making partners to have access to information to support cross-jurisdictional knowledge exchange and learning that would accelerate implementation of integrated care delivery solutions. We vastly underestimated the resources required to obtain even descriptive information. However modest, we hope that our results will be a stepping stone toward the creation of a Canadian repository of the ever-changing structures of our 13 Canadian health systems and also a directory of innovative programs and their evaluation. Meaningful learning and cross-jurisdictional spread of innovation depends on policy makers, researchers and patients having access to such information.

Conclusion

The articles in this special issue take stock of the integration of priority services for chronic illness in children and youth and older adults with high functional health needs. The findings in these two groups likely pertain to other patient groups, and they suggest that we have not yet achieved integration of medical services, let alone integration of health and social services. Addressing the growing need for chronic illness management in Canada demands better integration of health and social services and the mobilization of community supports. What is needed is a renewed health accord that intentionally complements the *Canada Health Act* (1985) using a social determinants of health lens to integrate health and social services.

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RESEARCH PAPER

Toward Comprehensive Care Integration in Canada: Delphi Process Findings from Researchers, Clinicians, Patients and Decision Makers

Vers une intégration complète des soins au Canada : résultats de la méthode de Delphes selon des chercheurs, des cliniciens, des patients et des décideurs

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Abstract

Introduction: From a larger study examining policy and program information on how Canadian provinces integrate care services, this study aimed to create "priority lists" of 10–15 services that are "absolutely needed" for care integration.

Methodology: A diverse group of over 50 Canadian stakeholders participated in virtual consensus-building using the nominal group technique and a modified e-Delphi method to identify services that focused on two different groups: children and youth with high functional health needs and older adults in functional decline.

Results: Three lists – containing services, processes and infrastructure elements – emerged: one per tracer condition group and a consolidated list. The latter identified the following five services as top priority for primary care integration: mental health and addictions services; home care; transition between urgent-emergency-acute care; medication reconciliation in community pharmacies; and respite care. No single social service was a clear priority, but those that mitigate material deprivation emerged within the top 10.

Discussion: This humble pan-Canadian study shows that priority services in health and social services are neither well integrated nor connected to primary care. It also suggests that effective policy strategizing for primary care integration for those with complex care needs may require thinking beyond the logic of services – given their siloed organization.

Résumé

Introduction : À partir d'une étude plus vaste qui examine l'information sur les politiques et les programmes visant l'intégration des services de soins dans les provinces canadiennes, cette étude avait pour objet de créer des « listes prioritaires » pour les 10 à 15 services qui sont « absolument nécessaires » pour l'intégration des soins.

Méthode : Un groupe diversifié de plus de 50 intervenants canadiens a participé à l'établissement d'un consensus virtuel, à l'aide de la technique du groupe nominal et d'une méthode de Delphes en ligne modifiée, afin de déterminer quels sont les services prioritaires

pour deux groupes différents : d'une part, les enfants et les jeunes ayant de forts besoins en matière de soins fonctionnels et, d'autre part, les personnes âgées en déclin fonctionnel.
Résultats : Trois listes (contenant des services, des processus et des éléments d'infrastructure) se sont dégagées : une pour chacun des groupes de conditions de traçage ainsi qu'une liste consolidée. Cette dernière a permis d'identifier les cinq services suivants comme prioritaires pour l'intégration des soins primaires : les services de santé mentale et de lutte contre les dépendances, les soins à domicile, la transition entre les soins d'urgence et les soins de courte durée, le bilan comparatif des médicaments dans les pharmacies communautaires et, pour terminer, les soins de relève. Aucun service social n'était clairement prioritaire, mais ceux qui atténuent la défavorisation matérielle ont émergé parmi les 10 premiers.
Discussion : Cette humble étude pancanadienne montre que les services prioritaires en santé et en services sociaux ne sont ni bien intégrés ni reliés aux soins primaires. Elle suggère également qu'une politique stratégique efficace pour l'intégration des soins primaires pour les personnes ayant des besoins complexes pourrait nécessiter de penser au-delà de la logique des services, compte tenu de leur organisation cloisonnée.

Introduction

People with complex care needs benefit greatly from the integration of their care across health and social service sectors (Bayliss et al. 2015; Breneol et al. 2022; Jones et al. 2020; McCormack et al. 2008; Miller et al. 2009). We defined service integration policies as "the governance, funding, strategic, organizational and programmatic directives that aim to facilitate coordination and collaboration among organizations and service providers whose complementary actions work together to achieve desired health outcomes for patients with complex care needs" (Haggerty et al. 2023: 12; Villeneuve 2017; see Appendix 2, available online at www.longwoods.com/content/27181). However, it faces complex structural and infrastructural challenges, notably when care services are organized in silos as in Canada. Patients with complex care needs also often depend on the interprofessional collaboration of those with a multiplicity of expertise (Hutchison et al. 2001). Unfortunately, these complexities have not been properly addressed by healthcare managers and policy makers (Atun and Menabde 2008). Identifying which health, social and community services are critical starting points of integration to primary care for patients with complex care needs is a useful first step in the assessment and development of multiservice integration programs, interventions and policy priorities.

This article is an attempt to make that first step. Here, we describe the methods and results of a consensus development process that took place in 2017, designed to identify, at a minimum, the most important health and social services to integrate with primary care to ensure the provision of comprehensive care for patients with complex care needs. The method chosen was applied to two different groups of such patients: children and youth (0 to 25 years) with high functional health needs and community-dwelling adults (≥ 65 years) experiencing functional decline[1]. These groups were chosen to illustrate how,

through this method, a consensus among a diverse group of stakeholders from across Canada could be developed and used to better understand the challenges facing service integration in this country. The study was conducted with 50 stakeholders who were, at the time, members of the Canadian Primary Care Research Network (CPCRN) – an interdisciplinary and intersectoral network involving a diversity of stakeholders across sectors, including citizens and service users, who collaborate in generating solution-focused innovations in primary healthcare delivery. The CPCRN's mission is to develop and support "provincial and territorial practice-based research and learning networks" (PBRLNs) (CPCRN n.d.). Patients, clinicians, decision makers and researchers from the CPCRN represented all 10 Canadian provinces.

Methods

Study design

To develop consensus on health and social service categories to be integrated with primary care, we used a two-phase virtual process. First, we used the nominal group technique to generate a list of candidate services for each tracer group (Delbecq and Van de Ven 1970; Gallagher et al. 1993; McMillan et al. 2014); then, we prioritized this list using a modified e-Delphi method (Crisp et al. 1997; Linstone and Turoff 1975). The Delphi method is a widely used and accepted technique well-suited for consensus building. We used a modified Delphi method (Miller and Crabtree 1999) with the goal of using an iterative process with community members to narrow topics to a practical priority list for which there is general consensus (not unanimous agreement) (Addison 1999). This two-phase process was completed in parallel for each tracer group and was integrated at the end of each of the two stages (the end of the nominal group process: to agree on service categorization, labels and definitions; the end of the consensus process: to compare the resulting lists of prioritized services, commonalities and differences). This entire process took place over a compressed time window of 12 weeks (between June and August 2017) to ensure maximal participant engagement. The study received research ethics approval at St. Mary's Research Centre in Montréal. All group members provided participant consent.

Participants

All participants (n = 40), representing Canada's 10 provinces, were invited to participate on the basis of their expertise in or experience of service integration in their respective provinces. Each participant had expertise in research, clinical practice (n = 28) or policy making (n = 9) or they had experiential knowledge as patients or caregivers (n = 3). For this study, the study partners were asked to participate in the tracer condition group (children and youth or older adults) in which they had expertise/experience. For each of the two groups, the entire process was run in parallel with a different set of stakeholders and research teams. All materials were prepared in both French and English, and participants were able to select their language of preference. All communication with participants was electronic and asynchronous via e-mail, an online discussion forum and online surveys.

Data collection and analysis

NOMINAL GROUP PROCESS

During a shared forum that lasted 10 days, participants were asked to name the health and social care services that, according to their area of expertise/experience, should be connected to primary care to meet the health and social needs of patients with each tracer condition. To prompt participants to think widely and inclusively about these needs, they received two patient vignettes per tracer condition that described, in a short narrative format, the lived experience of one member of this patient group. The vignettes did not aim for exhaustiveness of experiences or to already name the services a person may need. Rather, they encouraged our participants to think about "people," and needs in relation to the person's experiences and aspirations (from the point of view of persons, rather than fragmented needs). These vignettes were developed with the study's patient partners and validated by our other study partners with lived experience (either as patients, caregivers or health professionals). Participants were also asked to think beyond the vignettes with their own personal or professional lived experiences using a person- and family-centred perspective. The goal here was to be as inclusive as possible.

ANALYSIS OF THE NOMINAL GROUP PROCESS

The data for each tracer condition were analyzed in parallel by two different research teams composed of two senior researchers, two to three research assistants (graduate studies) and two to three non-research partners (patients, caregivers or health professionals) in order to extract all nominated services and consolidate those that were similar. This team completed an immersion-crystallization phase in which they reviewed the data to identify themes for organization (Borkan 1999), develop a specific coding structure, code text segments according to this structure (Huberman and Miles 2002; Miller and Crabtree 1999), identify patterns and relationships across codes and themes, connect themes and patterns to existing knowledge (Miller and Crabtree 1999) and then corroborate/legitimate the data by seeking out additional data to confirm or refute insights from the initial analysis. Then, using the responses of the participants (n = 23) and relevant information produced by international and national health organizational bodies (World Health Organization and Health Canada websites), all the information provided by participants was analyzed, collapsed into 31 distinct service category labels and labels as well as definitions and examples were provided. This list was then used for the second phase (see Appendix 2, available online at www.longwoods.com/content/27181, and the "Results" section below).

MODIFIED DELPHI

We used Qualtrics, an online service platform, to complete four rounds of an e-Delphi process and prioritize services. This was done by rating and then ranking the service categories.

In the first round, participants (n = 36) were asked to indicate, on a scale of one (not at all) to five (completely), the extent to which they agreed with the service categories (label/name,

definition and example). If they did not agree, they were asked to propose modifications, which were integrated by the research teams. The list was considered "accepted" when it was approved by all participants.

In rounds two and three, participants (n = 31, n = 30) were asked to rate the importance of integrating or connecting each service category to primary care by using a RAND scale of one to nine based upon (1) the frequency at which the service was needed by each tracer group and (2) the time-sensitivity required for the connection to avoid negative consequences. Services with mean values between one and three were categorized as "low priority services" (rarely needed or with flexible timeliness). Services scoring between seven and nine were considered "high priority" – either the frequency or time sensitivity was judged critical. Scores were averaged over all participants.

The final round presented participants (n = 40) with the resulting top 15 prioritized services for each tracer condition and asked them to validate the following:

1. the top five services for each tracer condition as a comprehensive and appropriate top-priority service list that would subsequently be used to inform the next studies within the larger research program;
2. the top 15 services per tracer condition;
3. a consolidated list integrating both tracer conditions using the top 10 priority services that emerged from both virtual processes;
4. the comprehensive list of service categories that included validated labels and definitions by all participants; this list emerged from the nominal group process.

With regard to the first three lists, they were asked "Can you live with this list of priorities?" Once finalized and approved, a final report and the lists were shared with all research participants and stakeholders in the study (this took place in the fall of 2017).

Results

The nominal group process yielded 100 services[2] for children and youth and 31 for older adults. Taken as a distinct service category, we found that no single social service emerged as frequent or time sensitive for either patient group (e.g., educational services, financial services, legal services, etc.). In order to reconcile the need to ensure full consideration of social services with our study design of generating a list of top 10 priority services, social services were grouped into the need they address – that is, material or social deprivation (see Appendix 2, available online at www.longwoods.com/content/27181).

Table 1 presents the top 15 services for children and youth. In the service identification and prioritization exercise, telehealth and information-sharing systems were the two highest-priority services rated by children and youth stakeholders. Yet they are not services, per se: health information systems refer to infrastructure while telehealth is a virtual care modality.

These were collapsed into a single category of "information-technology enabled care" to render visible the high importance placed on this mechanism for integrated care for children and youth with high functional health needs.

TABLE 1. Top 15 priority services to be integrated with primary care for children and youth (0–25 years) with high functional health needs

Rank	Top 10 priority services
1.	Health information–enabled care (information follows patient, telehealth)
2.	Mental health and addictions services
3.	Timely transition between urgent, acute and emergency care
4.	Prenatal and postnatal care
5.	Education support programs and services
6.	Health promotion and disease prevention programs and services
7.	Medication reconciliation programs at community pharmacy programs (integrated with primary healthcare)
8.	Home care
9.	Respite care
10.	Services to mitigate material deprivation in social determinants of health • Housing programs • Community nutrition services • Transportation services • Labour, employment and income services • Legal counselling
Other top-priority services	
• Child development services • Navigational services/patient navigators • Child and family services • Disability resource centres and organizations	

See Appendix 2 for complete descriptions, available online at www.longwoods.com/content/27181.

Table 2 presents the top 15 services for older adults, including the ranking of the top 10 services. Eight of the top 10 services are clearly in the traditional health (or medical) domain. Regrouping social services into services addressing material and social deprivation allowed the importance of social services to emerge for this group. The most important material deprivation services are the same for older adults as for youth.

Five services were ranked in the top 10 for both children and youth and older adults: (1) mental health and addictions services, (2) home care, (3) timely transition between urgent, emergency and acute care, (4) medication reconciliation in community pharmacy programs and (5) respite care. All but one (mental health and addictions services) are in the traditional health domain, but they represent a broad range of needs.

Finally, we created a *consolidated list* of the top 10 services for both groups by averaging the mean ranking across groups and then re-ranking them (e.g., mental health and addictions: second for children and youth and fifth for older adults = 2 + 5 = 7 / 2 = 3.5 overall).

Mental health and addictions services emerged as the top priority across both groups by a significant margin (Table 3). However, the most important services to be connected to primary care are in the traditional health domain.

TABLE 2. Top 15 priority services to be integrated with primary care for older adults (≥ 65 years) experiencing functional decline

Rank	Top 10 priority services
1.	Chronic disease management programs and/or services
2.	Home care
3.	Respite care services
4.	Medication reconciliation in community pharmacy programs
5.	Mental health and addictions services
6.	Palliative care
7.	Navigational services/patient navigators
8.	Timely transition between urgent, acute and emergency care
9.	Services to mitigate material deprivation in social determinants of health • Housing programs • Community nutrition services • Transportation services • Labour, employment and income services • Legal counselling
10.	Services to mitigate social deprivation in the social determinants of health • Community and recreational activities • Outreach programs to identify marginalized people or people with a limited support network • Translation services/interpreters • Immigration services
Other top-priority services	
• Disability resource centres and organizations • Health promotion and disease prevention programs and services • Geriatric day hospitals • Dental services • Translation services	

TABLE 3. Consolidated top 10 priority services to be integrated with primary care for both children and youth and older adults

Top five services in approximate order of priority
Mental health and addictions services (#1 priority across both groups)
Timely transition between urgent, acute and emergency care
Medication reconciliation in community pharmacy
Home care
Respite care
In the top 10 but with different priority across groups
Chronic disease management programs and/or services
Diverse services to address material and economic deprivation
Health information systems and telehealth
Health promotion and disease prevention programs and services
Navigational support/patient navigators

Discussion

Before we begin our discussion of points of relevance to policy making, we have three remarks to formulate.

Firstly, this study was conducted before the COVID-19 pandemic. This crisis has illustrated the need for service integration and provided examples of how this can be done through increased use of information technology services and telehealth initiatives. However, such integration has not been optimized and in some cases, the move to new methods to deliver healthcare has exacerbated problems integration seeks to address. The method employed and the consensus reached in this study remains relevant to identifying the top priority services that should absolutely be integrated or systemically connected with primary care in order to respond to the needs of patients requiring complex care and to support their flourishing.

Secondly, an important discussion that animated this entire study concerns the significant differences in the lexicon and terminology used across Canadian provinces. This proved a conceptual challenge, at first, because even the definition and understanding of "primary care" differed (see Haggerty et al. 2023). This challenge highlights the importance of coming to an informed agreement on the definitions and labels used to identify each service category. This, in our view, suggests that cross-provincial and territorial conversations are needed to achieve care integration, notably given the mobility of Canadians who often need to travel or relocate to other provinces.

Finally, during the nominal group process, participants often identified elements for integration that were not, in fact, *services* but rather *processes*, *types of professional titles*, *programs* and even *elements of infrastructure*. In our view, this suggests that we should not think about the integration of comprehensive care solely from the point of view of *services*. As Kreindler et al. (2022) remark, services are organized in overly *siloed* ways, and starting from their purview may hinder a truly imaginative process to rethink comprehensive care. Working from patients' needs, rather than from existing services, may be a more fruitful approach to developing care models and orienting policy.

Policy recommendations

Three main findings from this study can, in our view, help inform change in policy and practice. First, five of the top 10 priorities were the same for both groups, and these are all medical services (under the purview of ministries of health). Second, *mental health and addictions services* emerged as a priority both for children and youth and for older adults. Third, the high priorities placed on home and respite care entail the need for caregivers located outside traditional health service sites (e.g., hospitals, clinics, etc.).

Despite our explicit focus on prioritizing health and social services, our consolidated list of services shows that five of the top 10 priorities are *health* services under the purview of health ministries. In our view, the continuing predominance of traditional health services illustrates two things. This suggests a continued dominance of downstream rather than

upstream thinking by policy makers and service organizations. The effect is that the organization and prioritization of services are done from the purview of *managing illness* (or health consequences) rather than *preventing their emergence*. Thinking about integration from a life perspective, rather than from the point of view of short-term acute care for persons with complex needs, may be a more promising and innovative approach to comprehensive care that includes consideration for health promotion and prevention.

The continued dominance of traditional health services also attests to the fact that regardless of recent primary healthcare reforms and policy discourse concerning services and care, the Canadian context of services continues to be organized in silos while primary care is expected to play the role of integration. Yet given this *siloing*, integration remains an individual, *ad hoc* and piecemeal task at best, one that falls on the shoulders of primary care providers. The premise that it is the role of primary care to be the nexus where prioritized services are connected (the "medical home"), which is supported by the literature (Cooley 2004; Perrin et al. 2007; Valentijn et al. 2013), was questioned by study participants, specifically in terms of how viable this approach may be in the long term. This concern, which has been highlighted by the ongoing impact of the COVID-19 pandemic, has been echoed in the literature (e.g., Hutchison et al. 2011; Kearon and Risdon 2020; Snelgrove et al. 2022a, 2022b).

The consolidated priority list illustrates the high priority given to mental health and addictions services and highlights important considerations for policy makers. Increased attention has been drawn to mental health and addictions issues in the general population during the COVID-19 pandemic in tandem with the opioid crisis, which predated the pandemic (Gadermann et al. 2021; Regehr et al. 2021; Schmitz et al. 2020; Shatla et al. 2020; Xiong et al. 2020). The stressors experienced by the general population are exacerbated when combined with the challenges that patients with high functional health needs and their caregivers face on a day-to-day basis as they navigate complex health concerns through complex and fragmented health and social systems. We also know from practice and through the scientific literature that unaddressed or unresolved mental health needs may have dire long-lasting effects on patients' or caregivers' health, negatively affect their access to proper healthcare and/or force them to avail themselves of services that would not have otherwise been needed, thus placing an additional burden on the healthcare system (Kieling et al. 2011; Mesidor et al. 2011; Murphy et al. 2017; Patton et al. 2012). Across Canada, strategies to address burgeoning mental health and addictions issues among youth reflect an awareness that an integrated, contextualized health and social services response is required. Such integrated service models provide examples to guide future action (Abidi 2017; Fusar-Poli 2019; Halsall et al. 2019; Mathias et al. 2022; Settipani et al. 2019).

Finally, high rankings for home care and respite care in both groups reflect the dependence of those who live with high functional health needs, regardless of age, on the work of caregivers, be they personal attendants, family members or others (e.g., friends, colleagues). It is erroneous to assume that such support is readily available through existing family and

friend networks. Many are without significant others or a personal network, and for those who have relationships, it is not a given that these people are both available and capable to provide the physical and/or psychological support required for adequate care. When the burden to provide such care falls upon understaffed professional care providers or friends and family members – as is more often the case for more marginalized populations who lack access to such services – it can lead to negative health and economic consequences for them, which could have been prevented if they were better supported (Berglund et al. 2015; Berry et al. 2017; Kadowaki et al. 2015; Kok et al. 2015; Kokorelias et al. 2020; Stall 2019; Vandepitte et al. 2016). It should be noted that this burden has only increased in light of the COVID-19 pandemic. In light of this, policy makers should reflect on the demand that is made on patients to equip themselves with a private and personal support network and prioritize the formalization and organization of the support and services provided to all types of caregivers to ensure that they can perform what is demanded of them.

Limitations

There are a number of limitations to this study and on the impact and applicability of our findings. The consensus process was conducted over a short period to maximize engagement and maintain momentum, but this may have entailed some sacrifice of representation from relevant stakeholders. For example, we were unsuccessful in including stakeholders from the Territories (Yukon, Northwest Territories and Nunavut). Additionally, while all provinces were represented, participants from Ontario and Saskatchewan ($n = 4$) joined the study toward the end of the nominal group process and contributed to the approval of the final lists but not their initial creation.

Secondly, the list was used as the backbone for other components of our research program and continued to be scrutinized and clarified over the life of the research. We did not censor nominated services or activities, and consequently not all "services" can really be classified as services that can be the object of inter-organizational operating policies to integrate care. However, we are confident that the results reflect the importance of different aspects of integrated care for our stakeholder groups. The fact that few individual social services emerged as priority services may show that our initial patient vignettes did not reflect the social determinants of health strongly and may have induced our participants to think more about health issues than about functional capacity more broadly. In the process of consolidating services under a common broad category to render visible social services as a priority for integration with primary healthcare, the importance of specific services may have been diluted and many compromise specificity for policy action.

Furthermore, it remains unclear, with our data, whether the priority given to mental health and addictions services reflects the prevalence of mental health and addictions issues among the patient groups or mental health and addictions issues that develop among patients, families and caregivers due to inherent challenges in providing care to people with high functional health needs or both. Whatever the origin, it is impossible to dismiss the

enormous societal ramifications of limited access to much-needed mental health and addictions services and the importance of their integration with primary care and other health and social services (Kieling et al. 2011; Rehm et al. 2006).

Conclusion

The results of this pan-Canadian prioritization of health and social services for integration underscores the need for cross-jurisdictional, national and interprovincial dialogue and decision making to achieve health accords on fundamental health and social infrastructure to ensure equitable access to services for all Canadians. The 2004 Health Accords on home care were a good start (Health Canada 2004), but as demonstrated during the COVID-19 pandemic, huge policy gaps left many of the most vulnerable of our population in extremely precarious, if not life-threatening, situations. We believe a similar process of developing priority lists should include policy makers, professionals, patients and their families from a wider array of sectors. This requires a deeper understanding of patients' lived experiences, their service trajectories and the barriers and facilitators they experience in meeting their day-to-day needs. While innovative approaches to these issues abound, the political, organizational and professional will to transform our approach to health prevention, management and service delivery is required to move beyond firmly entrenched institutional boundaries that stand in the way of achieving health for all.

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Notes:

1. Functional health refers to the capacity to carry out activities of daily living that permit the achievement or maintenance of personal autonomy and social integration.
2. Much of what was named by participants, notably for our children and youth tracer condition, included programs, types of health professionals and professional activities (such as breastfeeding programs, midwives, postnatal care).

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RESEARCH PAPER

Inconsistent Governance Structures for Health and Social Services Limit Service Integration for Patients with Complex Care Needs

Des structures de gouvernance incohérentes pour les services de santé et les services sociaux limitent l'intégration des services pour les patients ayant des besoins de soins complexes

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Abstract

This paper describes how health and social services are governed and organized across Canada for two patient groups. Governance configurations and governance proximity between primary care and priority health and social services varied markedly between provinces. While the need for integrated service delivery has been made a clear priority during the COVID-19 pandemic, the potential of Canada's healthcare systems has not yet translated into coordinated and integrated care for health services, much less for health and social services. It is time to act on the policy recommendations from commissioned reports over the past two decades that focus on comprehensive, community-based care.

Résumé

Cet article décrit comment les services de santé et les services sociaux sont régis et organisés au Canada pour deux groupes de patients. Les configurations de gouvernance ainsi que la proximité de la gouvernance entre, d'une part, les soins primaires et, d'autre part, les services de santé et sociaux prioritaires varient considérablement d'une province à l'autre. Bien que la nécessité d'une prestation de services intégrés ait été clairement établie comme une priorité pendant la pandémie de COVID-19, le potentiel des systèmes de santé du Canada ne s'est pas encore traduit par des soins coordonnés et intégrés pour les soins de santé, et encore moins pour les services de santé et sociaux. Il est temps de donner suite aux recommandations stratégiques des rapports commandés au cours des deux dernières décennies, lesquels mettent l'accent sur les soins communautaires complets.

Introduction

In 2016, researchers within Canada's Primary and Integrated Health Care Innovations Network were looking to spread or scale up integrated care delivery solutions across provincial and territorial jurisdictions, but could not find any current description of how health and relevant social services were governed and organized in different Canadian provinces. The aim of this paper is to address that gap by describing and comparing the formal macro-level governance structures and strategic policies in Canadian provinces that pertain to comprehensive (i.e., a range of health and social services), integrated (i.e., support linkages and exchange) care for patients with complex care needs.

From the multiplicity of definitions of integration (Armitage et al. 2009), we used the following working definition: service integration refers to the ensemble of policies and procedures that support linkages and efficient exchange among institutions that deliver complementary services. Originating in business and manufacturing – where service integration gave major players a competitive economic advantage – service integration has become a sought-after goal to achieve both cost savings and effectiveness in health systems since the 1980s (Goldsmith 1994). An early assumption in the healthcare integration literature is that common governance in a single-payer or single-owner system makes it easier to align

different entities or providers (vertical integration) (Conrad and Shortell 1996; Goldsmith 1994; Robinson and Casalino 1996; Shortell et al. 1996).

The concepts of integration in healthcare have shifted from focus on the acute care hospital as the organizing entity toward community-based services (Evans et al. 2013; Kodner 2009). Reflecting on this shift, Valentijn et al. (2013) posit that primary care is the appropriate locus to conceive comprehensive healthcare integration because primary care is the point of first contact and purports to use a person-focused and biopsychosocial approach. In Canada, achieving comprehensive primary healthcare requires the integration of primary care (predominantly medical) with other health services, social services and community supports. The ensemble of policies and procedures at a macro level (system-level integration) provides a starting point for other forms of integration among organizations (meso) and service providers (micro) (Valentijn et al. 2013).

In its broadest sense, "governance" is defined as clarifying "who does what (or who should do what), which people and roles are involved, their areas of authority and responsibility, and how decisions are made" (Villeneuve 2017: 1). We assume that authority and responsibility are reflected through formal governance structures and that service integration is facilitated when services are in proximate governance units. We indicate the provincial-level governance structures that pertain to primary care and priority services identified for two target populations: children and youth (0–25 years) with high functional health needs and community-dwelling older adults (≥ 65 years) experiencing functional decline (Dionne et al. 2023). In keeping with the principle of vertical integration, we assume that service integration will be facilitated when services share strategic and operational policies under the same governance authority (proximal governance) and will be more challenging when they operate under different governance structures (distal governance).

Providing a descriptive portrait of the governance structures of the provinces is intended to identify governance environments that are likely to be supportive of integrated delivery solutions that link health, social and community services and to facilitate cross-jurisdictional learning and comparative research.

Methodology

Between September 2017 and September 2018, team members (NF, SZ) conducted a scan of government websites in the 10 Canadian provinces to identify the formal ministerial governance structures and any strategic policies that pertain to primary care and integration between health and social services (Appendix 3, available online at www.longwoods.com/content/27185). These websites were used as there are no existing databases that consolidate this information. We included any information about provincial governance structures and strategic policies that was feasibly accessible from public government websites and was relevant to priority services for the two target populations. The information for each province was summarized and presented to a key government informant. Key government informants were identified by the research team members in each province and were usually the decision

makers within the provincial ministry of health. Interviews were brief (30 minutes to 1 hour, approximately) and were focused on confirming the summary and identifying any gaps in the description. Based on these interviews, the information was amended to reflect the situation at the time the information was collected.

A second scan, from June 2019 to January 2020 (AA), focused on the "governance distance" between primary care and the 15 priority services for our two complex care target populations of children and youth and older adults. These are populations managed in primary care clinics, requiring connection to health and social services to optimize functional health but whose care processes are likely to be relevant to other patient groups (Dionne et al. 2023). One member of the team (AA) obtained the detailed organizational chart (organigram) of each provincial ministry of health closest to September 2018. The organigrams were predominantly obtained from publicly available websites. When they were not available from public websites, they were obtained from key informants from the ministry of health (we use "ministry of health" to refer to this generic function, recognizing that the proper name differs by province). Priority services that were in the same organizational unit as primary care were considered "very proximal," those in different organizational units but under the same level of hierarchical authority as primary care were "proximal" and those under a different hierarchical authority were "distal." Services that fell under the authority of another ministry were "very distal."

The provincial summaries were generated by research associates and were read independently by three senior team members (JH, CS, YC) who immersed themselves in the summaries and then crystallized observations to detect cross-provincial similarities, differences and patterns pertaining to integration of services (Borkan 1999). Initial insights were challenged to ensure that they were based on the available data and not pre-existing positions or personal knowledge. The senior team members summarized the similarities and differences as they related to priority service areas for the two target groups. The findings were presented to the larger research team to assess the accuracy of the results. This study received ethical approval from the Research Ethics Committee of the Centre intégré universitaire de santé et de services sociaux de l'Ouest-de-l'Île-de-Montréal.

Results

The quantity and detail of publicly available information on government websites varied substantially across provinces. The information was most easily accessible (i.e., little effort to find and retrieve from websites) and up to date (in decreasing order) in British Columbia (BC), Quebec (QC), New Brunswick (NB) and Ontario (ON); somewhat accessible in Alberta (AB), Saskatchewan (SK) and Newfoundland and Labrador (NL); and the least accessible in Prince Edward Island (PEI), Manitoba (MB) and Nova Scotia (NS).[1]
Key informants consistently remarked that the summaries based on the websites were out-of-date and might not reflect current structures.

The publicly available organigrams also varied considerably in detail. The most detailed organigrams were in BC, QC and NB and the least detailed were in PEI. According to our key informants in PEI, the lack of detail reflected an intentional policy orientation toward health promotion rather than disease management. It was challenging to find the entity responsible for overseeing the provision of some of our priority services in organigrams.

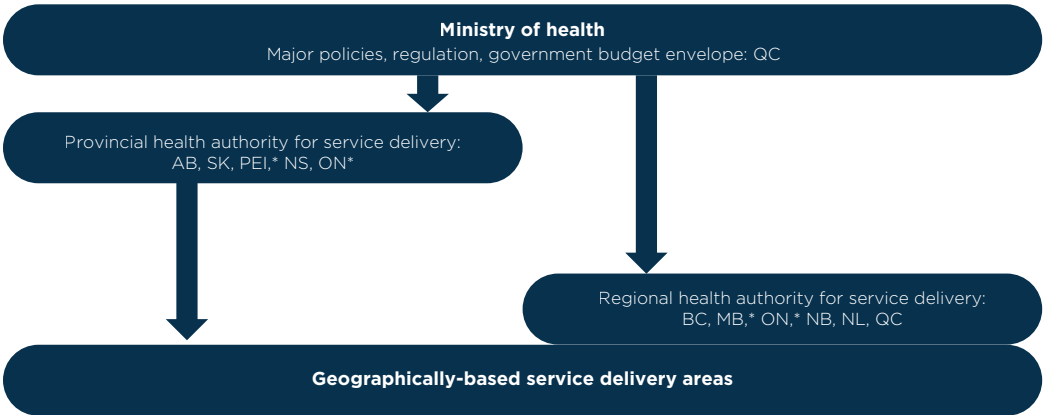
Centralized vs. decentralized structures of macro-governance

All the provincial ministries of health maintained a distinction between health system oversight (regulatory and funding allocation) and governance of health service delivery. Sometimes these distinct functions were assumed by separate governance entities. For instance, Alberta Health had the regulatory function and Alberta Health Services oversaw health service delivery. In MB, PEI and ON, health service delivery was under crown corporations that were accountable to the ministries of health but were independent entities with their own governance structure. In QC, both oversight and governance of service delivery were centralized within the Ministère de la Santé et des Services sociaux.

Integration of services was a recurring policy concern across provinces. Historically, the focus has been on the integration of medical services from primary through tertiary levels. The main policy instrument used in all provinces was geographic zoning of service delivery. In some provinces, the intention to integrate was reflected in the naming of the zones: Integration Areas (SK); Local Health Integration Networks (ON) and Centres intégrés de santé et de services sociaux (QC). The scope of service delivery governed geographically pertained mostly to medical care, but in rural service delivery areas, the scope could extend to medical and social services as we observed in SK, MB and QC (e.g., in SK, an executive director of primary healthcare in rural areas may also have the authority and responsibility for broader services, including home care, public health and mental health).

In some provinces, in addition to macro policies at the ministry level, there were regional authorities with the authority for funding allocations and priority setting for the geographic zone and regional organization of service delivery (devolution). There seemed to be an increasing trend toward consolidating health authority at the provincial level with only service delivery being zoned geographically. AB was the first province to replace regional health authorities with a province-wide health authority in 2008. Several provinces followed suit: PEI in 2010, NS in 2015, SK in 2017 and ON in 2019 (outside the study period). QC also abolished the 18 regional health authorities in 2015 and concentrated authority at the Ministère de la Santé et des Services sociaux but did not create a new governance entity; planning, delivery and resources were decentralized to 34 geographically zoned Centres intégrés de santé et de services sociaux. The use of crown corporations as the accountable organizations for health services delivery in MB, ON and PEI was also a mechanism for concentrating authority at the ministry of health. Figure 1 illustrates the provinces that had consolidated vs. regionalized health authority in 2019.

FIGURE 1. Structure of provincial health authority and regionalization of service delivery in 2019



The 2019 structure of governance, authority and health service delivery shows provinces with authority consolidated at the provincial level (left), provinces with regional authority at the geographic delivery zone (right) and provinces with governance delegated to an independent crown corporation (*).

A governance innovation in BC in 2013 created a First Nations Health Authority that was not geographically bounded and that designed, managed and funded the delivery of First Nations health programs and services, including the federal services formerly provided by Health Canada. Another non-geographic health authority oversaw and coordinated province-wide agencies and programs with specialized health missions (e.g., cancer, autism, emergency services).

Governance oversight for primary care

Table 1 names the ministry of health for each province. The name of the provincial ministry of health in six of 10 provinces suggests governance scope beyond classic medical and public health services: wellness (PEI, NS), social services (QC), community services (NL) or long-term care (ON). MB's Ministry of Health, Seniors and Active Living (since 2016) suggests the broadest scope. If we presume that broader scope of governance suggests potential for broader service integration, then MB's governance environment should be conducive to the integration of health, social and community services, at least for older adults.

Table 1 also names the entity where primary care is located. Although all ministries of health refer to primary healthcare, the scope refers to the first-contact community-based delivery models that we identify as primary care. The organizational nomenclature of governance oversight differs from province to province. We, therefore, use the generic terms first, second and third level to denote the different hierarchical levels of governance oversight. For instance, in NL and NS, the "department" is the highest level of governance (equivalent to ministry), whereas in others, "department" refers to a sub-unit. In BC, branches are under divisions, whereas in SK and NL, divisions are under branches. Primary care is usually located at the third level of governance, except in BC and PEI, where it is at the second level of governance suggesting higher importance within the ministry of health.

TABLE 1. Names of provincial ministries of health and levels of hierarchical governance for primary healthcare in 2018

Province	Name of ministry of health (first level of governance)	Second level of governance	Third level of governance
British Columbia	Ministry of Health	Primary Care Division	Primary Care Strategy, Policy and Quality
Alberta	Alberta Health	Health Workforce Planning and Accountability Division	Primary and Community Health Branch
Saskatchewan	Ministry of Health	Connected Care Services Branch**	Primary Health Services Branch
Manitoba	Health, Seniors and Active Living (2016)	Mental Health and Addictions, Primary Health Care and Seniors	Primary Health Care Branch
Ontario	Ministry of Health and Long-Term Care**	Mental Health and Addictions, Primary Health Care and French Language Services**	Primary Health Care Branch
Quebec	Ministry of Health and Social Services	Direction générale des affaires universitaires, médicales, infirmières et pharmaceutiques	Direction générale adjointe de l'Accès, des Services de proximité et des Effectifs médicaux
New Brunswick	Department of Health	Health Services and Francophone Affairs Division	Primary Health Care Branch
Nova Scotia	Department of Health and Wellness	System Strategy and Performance Division	Primary Health Care Branch
Prince Edward Island	Ministry of Health and Wellness	Regional Family and Community Medicine and Hospital Service	Primary Care and Chronic Disease Branch
Newfoundland and Labrador	Department of Health and Community Services	Population Health Branch	Primary Health Care

**Time stamped to 2018 – names changed subsequently.

The vast majority of primary care services in Canada were delivered privately by autonomous physician-led family practices and were not under the purview of the ministry of health. We observed, however, that several provinces had governance mechanisms that facilitated the engagement of physician leadership in primary care service delivery. Both BC's Divisions of General Practice and QC's Direction régionale de médecine générale provided a forum for physicians to organize the planning and delivery of primary care around local practice priorities. In AB and SK, leadership of primary care networks and integration areas was assured jointly by the ministry, zone (AB) and physician leads. MB engaged physician leaders and other health professionals in governance through an entity called Shared Health.

Governance proximity between primary care and priority services

Most of the services ranked as priority services for children and youth and older adults fell under the governance of the ministry of health. Notably, five services ranked in the top 10 for

both groups: home care; mental health and addictions services; timely transitions between urgent, emergency and acute care; respite care; and medication reconciliation by community pharmacies. Medication management in community pharmacies falls under the governance of professional associations rather than under the ministry of health, so we excluded it from further analysis. Table 2 shows the governance distance for the nine remaining services, grouped by overall governance proximity to primary healthcare (though proximity varies by province). We present the results and their implications for integration by governance proximity.

The priority services most proximal to primary care were chronic disease management; home care; mental health and addictions services; and urgent, emergency and acute care. In most provinces, integrated care solutions should be the easiest for these services, and their similarity across provinces should facilitate the spread of innovations. Home care is often subsumed under the label of "continuing care" but the description corresponds to home care, which was under the same second-level governance as primary care (i.e., proximal) in four provinces (MB, ON, NS, PEI). In the other five out of 10 provinces, home care and primary care were under different second-level governances (distal). Home care and primary care governance locations needed to be inferred for SK. The provinces with the greatest overall governance proximity between primary care and priority services were MB, ON, NB, NS and PEI. If common governance facilitates operational integration, then these provinces may be the most supportive of integrated care solutions for both elders and children and youth.

Chronic disease management was the priority service most consistently proximal to primary care across the seven provinces where it was named explicitly. This was also an explicit policy priority in the Maritime provinces. Chronic disease management was also a professional competence of primary care health professionals, which may support clinical integration across organizational boundaries.

It is striking that mental health and addictions services was usually a stand-alone unit in most organigrams, and was proximal to primary care in MB, ON, NS, NB and NL. Although the notations in Table 2 indicate low proximity in BC and AB, both provinces had a governance entity for mental health and addictions at a high level to provide broad authority and oversight. BC had a dedicated Ministry of Mental Health and Addictions in addition to the unit for mental health in the ministry of health. AB had a dedicated office for an associate minister under the Ministry of Mental Health and Addiction, who reported directly to the minister of health, in addition to its unit for addiction and mental health (distal from primary care).

The findings that acute and emergency care was proximal to primary care in QC, NS and NB need to be interpreted with caution because the priority expressed was for a timely and smooth continuum of services between urgent, emergency and acute care. Urgent care services are usually a function of primary care with no governance unit named "urgent care"

TABLE 2. Governance proximity between primary healthcare and priority services for children and youth and older adults with complex care needs

	Most proximal overall				Proximal			Most distal	
Province	**Chronic disease management**	**Home care**	**Mental health and addictions services**	**Urgent, emergency and acute care**	**Pre/postnatal care**	**Respite care**	**Palliative care**	**Telehealth**	**Health information systems**
British Columbia	***	*	*/X	*	*	*	*	**	**
Alberta	*	*	*/**	*	*	*/X	*	~	*
Saskatchewan	**	*	*	*	*	*	*	X	X
Manitoba	***/**	**	**	*	~/*/X	**/X	*	~	*
Ontario	**	**	**	*	*	**	**	X	*
Quebec	*	*	*	**	*	*	*	~	*
New Brunswick	***	*	**	***/**	X	*/X	**	*	*
Nova Scotia	**	**	**	***	*	**	***	*	*
Prince Edward Island	***	**	*	***	**	**/X	**	*	*
Newfoundland and Labrador	**	*	**	*	*/X	*	~	X	*/X
Ranking in target group	Child #n/a Older #1	Child #9 Older #2	Child #3 Older #5	Child #4 Older #8	Child #5 Older #n/a	Child #10 Older #3	Child #n/a Older #6	Child #1 Older #n/a	Child #2 Older #n/a

Governance proximity: *** = very proximal; ** = proximal; * = distal; X = very distal (in another ministry); ~ = information could not be inferred; / = governance shared.
Child = children and youth; older = older adults.
Shaded cells = information needed to be inferred.

within their scope of services. Governance of pre/postnatal care, respite care and palliative care was also generally proximal to primary care but with large variances between provinces, and often needed to be inferred (shaded cells).

The services most distal from the governance of primary care were health information systems including telehealth, a priority service for children and youth. The governance location of telehealth could not be inferred in five out of 10 provinces (AB, MB, QC, NS, PEI), but its governance was in a separate ministry in SK, ON and NL, and within the ministry of health for BC and NB. Not surprisingly, the largest governance distance from primary care was for social services that were mostly governed by other ministries. Nonetheless, we did see some priority social services within ministries of health of different provinces: adult day programs (in all provinces except MB, NB), educational support programs (ON, PEI), housing (AB, ON, MB) and nutrition support programs (MB, QC, NB).

Discussion

Our intent was to understand formal provincial-level governance structures to facilitate the scale and spread of integrated service delivery solutions across provincial and territorial jurisdictions. In attempting to understand these governance structures, we experienced many limitations. Firstly, our underlying assumption that service integration will be facilitated when services share strategic and operational policies under the same governance authority has theoretical merit but has yet to be definitely demonstrated with empirical evidence. Our intent to review governance structures and strategic policies as publicly displayed on government websites was limited due to the quantity, level of detail and accuracy of the information on websites (Stewart et al. 2023). There was inconsistent access to current organigrams on government websites and inconsistent detail and nomenclature in the organigrams and strategic policy descriptions across provinces. Due to resource constraints, we were unable to conduct more extensive searches or additional key informant interviews in each province to improve the accuracy of the findings. What we were able to discern may, therefore, not have reflected current governance structures. Despite these limitations, this high-level snapshot of the provincial-level governance structures for community-based health and social services illustrates the oft-quoted axiom of Canada having 14 different health systems (i.e., 10 provincial and three territorial health systems and one federal health system for Indigenous populations). We observed not only different governance configurations but also continuous major restructuring of governance, which makes it challenging to create up-to-date cross-provincial portraits. Nonetheless, this snapshot shows that service integration is a common and enduring concern in the health sector, with geographic zoning being the principal policy instrument for service integration. In 2000, health authority was mostly devolved to the geographic zone level, but since 2008, we observed a trend toward consolidation of authority at the provincial level. We also observed considerable variation between provinces in governance proximity of primary care to priority services for children and youth with complex care needs and older adults experiencing functional health decline. We discuss these further below.

While there was consistency across provinces in the use of geographic zoning to address service integration, we observed considerable experimentation with the sizing of geographic zones and centralization versus geographic devolution of governance authority. Regional health authorities were instituted across Canada in the 1980s and 1990s to consolidate the services offered in a territory, to shift from hospital-based to community-based care and to be more responsive to the needs of the population (Lewis and Kouri 2004; Marchildon 2015, 2016). Geographic zoning has led to improvements in service coordination, although the promise of integration has yet to be achieved (Barker and Church 2017; Bergevin et al. 2016). AB led the way with centralizing authority but decentralizing service delivery to geographic zones, but the size of geographic zones is far from stable. Even ON – the latecomer to regionalization in 2006 – moved to even smaller sub-zone delivery areas in 2015, only to be restructured yet again in 2019 under a single new authority providing oversight to five geographic regions. Fierlbeck (2016) argues that regional governance restructuring meets

political ends more than policy ends by disrupting the influence of established stakeholders: more churn than change. Perhaps government experimentation with geographic zoning of authority and service delivery and finding cost efficiencies deflects from the consideration of policy instruments, such as integrated budgeting (Shortell et al. 2014), or investing in interoperable health information systems (Kizer and Dudley 2009) that would support improvements in care.

One development in governance structures that we observed was the engagement of physician leadership in BC and QC through general practice geographic delivery areas and the engagement of physician leaders at executive levels for service delivery areas in AB and SK. Although community-based care was a stated objective of regionalization, the delivery of many services through autonomous physician-led family practices left primary care out of the regional equation. The integration of physicians into health system structures is one of the thorniest issues in achieving service integration (Bergevin et al. 2016; Shortell et al. 1996). Physician governance falls to the associations that govern the profession and to provincial colleges that issue licences to practice. Yet, within provinces where primary care renewal models are the norm (AB, ON, QC and NB) (Haggerty et al. 2023), the ministry of health had a greater role in governance and leverage for service integration. Despite AB's success in involving more than 90% of physicians in primary care networks (PCNs) and engaging physician leaders as co-executives of PCNs, recent attempts by the government to impose payment changes on physicians (Lee and Anderson 2020) point to the ongoing tension between ministries of health and physician organizations that negotiate on behalf of their members.

There are encouraging governance and strategic policy shifts in various provinces that are expected to enhance the connection between health and social sectors. MB's Shared Health (established in 2018) had a broad purview that included recruitment and retention of health human resources (including physicians), information and communication systems and clinical coordination and planning. The restructuring of PEI's health system reflected a policy intention to de-silo health services delivery from upstream determinants of health including social services. NL's Health-In-All-Policies approach for all ministries may have created a supportive governance environment for innovative programs that integrate education support, housing and income support with primary healthcare and other community-based services.

What can we discern from our analysis of governance proximity between primary care and priority services for our target populations? If our premise is true that more proximal governance contributes to common governance oversight for unified operational policies in the single-payer Canadian health systems, then our findings would suggest that MB, ON, NB, NS and PEI offer provincial governance environments that might be more conducive to testing integrated care solutions across health and social services. Integrated care solutions should also be the easiest between primary care and chronic disease management; mental health and addictions services; home care; and urgent, emergency and acute services, which are consistently in close governance proximity. Delivery solutions that integrate

care for these services may also have the greatest potential for cross-jurisdictional learning because they appear consistently in provincial organigrams and they share a legacy of federal policy initiatives (Health Canada 2006; Kirby and Keon 2006; Romanow 2002). We also acknowledge that our focus on formal provincial-level governance proximity is only one consideration among many (e.g., physical and social geography) in finding successful integrated care solutions.

Conclusion

We recognize that we have created an impressionistic and static 2019 portrait of governance structures that are in constant flux. Comparative information was not simple to obtain; details varied across provinces, and it was often out-of-date; and the level of detail varied across provinces. Although we validated the summaries with key informants in each province, in some cases this was a single person. It was challenging to base our findings only on available data in 2018, and it gave us a deep appreciation for the importance of data and information availability. If getting detailed and up-to-date information was difficult for a research team with dedicated (if limited) resources, what must it be like for citizens to understand their own health system or for policy makers who want to engage in cross-jurisdictional learning? Integrated care solutions in one province may require considerable governance re-arrangements to function in another. The only current mechanism for exchanging ideas for health system improvement is through federal, provincial and territorial ministerial meetings, and these meetings are highly politicized. If we are to advance cross-jurisdictional learning, there is a need for a less politicized forum for sharing innovation among provinces. Looking at this through the lens of two different target populations with complex needs allowed us to circumscribe the priority services that needed to be connected, but the priority services do not always correspond to identifiable governance units. The impact of inconsistent health and social governance structures across provinces has been brought into sharp relief during the COVID-19 pandemic.

Policy recommendations from commissioned reports over the past five decades have reflected a public commitment to the principles of the *Canada Health Act* (1985) (i.e., comprehensiveness, universality, public administration, portability and accessibility), while embracing the understanding that achieving health for all Canadians requires integration of health and social services, shifting from institutionalized to community-based, interprofessional care (Epp 1986; Health Canada 2006; Lalonde 1974; Romanow, 2002). Despite these calls for change, the hospital-based, physician-centric system of care has remained intact. The status quo of hospital-based systems is not meeting the needs of people with complex and chronic conditions, and adding more funding to existing healthcare structures and administrative systems is not a solution. There are no quick fixes. But what is clear from our results is that continuous administrative restructuring of health systems that fails to align health and social services under proximate governance structures is unlikely to achieve the long-standing policy goal of integration.

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Note

1. All provinces will be named in order of west-to-east geographic location unless indicated otherwise. Not all provinces are identified in each example.

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RESEARCH PAPER

Have Primary Care Renewal Initiatives in Canada Increased Comprehensive Care for Patients with Complex Care Needs? Yes and No

Les initiatives de renouvellement des soins primaires au Canada ont-elles favorisé les soins complets pour les patients ayant des besoins complexes? Oui et non

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Abstract

The First Ministers Health Accords of 2001 through 2003 (Health Canada 2006) launched the renewal of primary care toward more comprehensive care delivery models. We scanned government websites in the 10 Canadian provinces to assess how comprehensive and integrated renewal models were for health and social services in 2018. More comprehensive primary care delivery models were the norm in five out of 10 provinces. The policy approaches were: (1) expanding traditional family practice; (2) creating primary care networks; and (3) increasing the number of community health centres, which provide the broadest range of health and social care. Integration initiatives were limited to medical services. Additional financial and policy investments will be required to meet the comprehensive needs of patients with complex health and social needs at a system level.

Résumé

Les accords des premiers ministres sur le renouvellement des soins de santé, entre 2001 et 2003 (Health Canada 2006), ont axé le renouvellement des soins primaires vers des modèles de prestation de soins plus complets. Nous avons examiné les sites Web gouvernementaux des 10 provinces canadiennes afin d'évaluer dans quelle mesure les modèles de renouvellement de la santé et des services sociaux étaient globaux et intégrés en 2018. Des modèles de prestation de soins primaires plus globaux étaient la norme dans cinq provinces sur 10. Les approches stratégiques étaient les suivantes : (1) expansion de la pratique en médecine familiale traditionnelle, (2) création de réseaux de soins primaires et (3) augmentation du nombre de centres de santé communautaires, lesquels offrent le plus large éventail de soins de santé et de services sociaux. Les initiatives d'intégration se limitaient aux services médicaux. Des investissements financiers et stratégiques supplémentaires seront nécessaires pour répondre, au niveau du système, aux besoins globaux des patients ayant des besoins complexes en matière de santé et de services sociaux.

Introduction

The *Medical Care Act* (Government of Canada 1966) is a great Canadian policy achievement that removed direct cost barriers for medically necessary services (Marchildon 2012). However, the public payment of ambulatory physician services negotiated with physician organizations guaranteed private delivery (Naylor 1986). Consequently, primary care was delivered predominantly by general practitioners or family physicians in autonomous family practices funded through public fee-for-service remuneration of physicians.

Medicare came of age at the same time as the "primary healthcare" movement, which envisioned a comprehensive range of community-based services and holistic care of patients (WHO 1978). In Canada, this vision was expressed in the creation of community health centres, which extended the scope beyond general medical services to include broader health services, such as nutrition, social work and psychology, as well as public health and community development (Albrecht 1998). Early exemplars of this model – the nurse-led community

centres in Saskatchewan (SK) and the first Community Health Centre in Manitoba (MB) – were echoed elsewhere in Canada, especially in Quebec (QC) and Ontario (ON). In 1974, QC rolled out a province-wide policy of geographically based local community service centres (CLSC), which offered services adapted to the community; not all included general medical services. In ON, Community Health Centres opened as experimental pilot projects and were mainstreamed in 1983 in various regions.

The First Ministers Health Accords of 2001 through 2003 (Health Canada 2006) launched a federal investment through the Primary Health Care Transition Fund (PHCTF) to make primary care in Canada more available, comprehensive and coordinated than what was offered in the autonomous general practice model that was predominant in 2000 (Health Canada 2005). A 2009 review of primary care initiatives by Hutchison et al. (2011) concluded that the federal policy had engaged physicians and expanded the disciplinary mix of primary care professionals, but that it was well established only in four provinces. In this article, we aim to identify the extent to which the primary health renewal models were prevalent in 2018 in all 10 provinces and the extent to which primary care models were more comprehensive and integrated with other health and social services.

This was part of a larger research program to describe and compare the structures and policies in Canadian provinces that govern primary care and facilitate integration of health and social services required for patients with complex healthcare needs (Haggerty et al. 2023). Valentijn et al. (2013) proposes that integration between health and social services is essential to achieve comprehensive primary care for a defined population. Comprehensiveness is defined in multiple ways (Haggerty et al. 2007), but we defined it as the provision of the broad range of health and social services required for patients with complex healthcare needs. Comprehensiveness can be achieved either by a broad range of intramural services or through facilitated coordination with extramural providers that characterizes integrated care. The extent to which complex needs of patients are met in a coordinated manner will reflect the organizational structures, rules and guidelines that support intramural comprehensiveness and extramural integration.

Methodology

We conducted a scan of government and healthcare websites in the 10 Canadian provinces to identify the primary care renewal model that was introduced with the PHCTF and the extent to which the model has evolved or been deployed since 2018. We also identified any strategic policies relating to primary healthcare or primary care. The Macro Policy Data Collection Template was used to collect relevant data for each province between September 2017 and September 2018 (Appendix 1, available online at www.longwoods.com/content/27186). The information for each province was summarized in narrative form, and this was presented to a provincial key informant who was a decision maker within the provincial ministry of health and was often a member of the larger research team. The narrative summary was amended to reflect the situation at the time the information was collected.

"Provincial Narrative Summaries" provides the date of validation and the document source for each provincial summary, and resides here: https://cpcrn-rcrsp.ca/wp-content/uploads/2023/08/PIHCIN-Provincial-Narrative-Summaries_Health-Governance-and-Primary-Care-Structures_Scan_FINAL.pdf.

The validated provincial summaries were read independently by three team members (JH, CS, YC) using an immersion–crystallization process (Borkan 1999). The initial insights from independent reading were challenged to ensure that insights were based on the data and not pre-existing positions or personal knowledge. The subsequent immersion in the data and initial insights to identify patterns and trends was followed by synthesis and sense making to discern policy-relevant patterns across provinces and identify emerging trends. Comprehensiveness of services was presumed from the disciplinary healthcare team within the model, with the specific mention of added new services or linkages with other providers.

Results

Readers interested in any one province can refer to the Provincial Narrative Summaries (https://cpcrn-rcrsp.ca/impact-podcasts/evidence/) for the appropriate summary and documentary source for the data analyzed here.

The 2018 scan of primary care delivery models shows that seven out of 10 Canadian provinces continued or expanded their primary care renewal initiatives after the federal investment stopped in 2006 and that more than 50% of the population received care in primary care renewal delivery models in five out of 10 provinces (Alberta [AB], ON, QC, New Brunswick [NB] and Nova Scotia [NS]). Although primary care investments continued in MB and SK, consolidation around specific team-based delivery models only emerged in recent years. Three provinces – British Columbia (BC), Newfoundland and Labrador (NL) and Prince Edward Island (PEI) – used PHCTF to invest mostly at a system level: BC in chronic disease management; NL in linking care across the continuum of medical services, including electronic record linkage; and PEI in health promotion and palliative care. These three provinces trialled various delivery models and more recently have begun to invest in specific models used in other provinces.

Through our analysis, we identify three types of primary care renewal delivery models and two approaches to policy implementation. We also highlight some unanticipated findings that have important policy implications, and we end with some observations regarding comprehensiveness.

Three types of primary care renewal delivery models

The labels and specific arrangements for primary care renewal differed by province, but they can be broken into three general organizational forms: (1) expansion of the traditional family practice model; (2) increasing the number of Community Health Centres; and (3) geographically based primary care networks.

The *enhanced family practice* model was used most predominantly in SK, MB, ON, QC and NS, and in the pilot projects that were trialled in BC, NL and PEI. Comprehensive care was expanded in primary care renewal models by making larger groups of family physicians (co-located or networked) and adding new health professionals. Additional funding was provided to integrate primary care nurses with an expanded scope of practice. Other health professionals were present in intensities and configurations that varied within and between provinces, and these commonly included pharmacists, nurse practitioners, psychologists or social workers and nutritionists or dietitians.

In ON, QC and NS, comprehensiveness was increased by adding new health professionals after the initial physician–nurse model was stabilized. In other provinces, such as ON and SK, we observed an early attempt to implement a very comprehensive primary care model followed by adaptations to increase uptake by existing family practices. The initial model in SK – the primary healthcare team – proposed a care team composition reflecting the needs of the community, but participation by family physicians was minimal until the model allowed fee-for-service payment. ON's first primary care renewal model in 2001, the family health network, emphasized formal registration of patients, 24/7 accessibility arrangements (including linkage to telephone helplines), improved chronic care management and physician remuneration based on capitation and performance incentives. When physician uptake was low in 2003, a new model – the family health group – made patient enrollment easier by basing enrollment on previous medical services billing and allowing fee-for-service remuneration from the start. The family health team model, introduced in 2006, and then the family health organization, in 2007, included an even broader mix of health disciplines and offered a broad basket of services. This suite of family health models co-existed.

In most provinces, enhanced family practice models included some form of integration between primary care and the rest of the healthcare system, usually better information linkages to hospitals and emergency rooms rather than to other community-based health and social services. In NL, linkage across the continuum, including non-health ministries, was supported by its 2015 strategic policy of Health-In-All-Policies, but we did not find data on how it impacted primary care.

The *community health centre* was the most comprehensive primary care delivery model. This is not a renewal delivery model per se because the model was already well established in various provinces; but increasing the number of community health centres was the renewal strategy in AB, MB, ON and NB. Unlike family practice, this model is governed by a community board, and all health professionals (typically physicians, nurse practitioners, dietitians and social workers) are salaried. The model offers a broad range of intramural health services to their population through the interdisciplinary team, and activities usually include some form of community engagement or development. This is the model where social services and population health approaches are core elements of service delivery. In ON and MB, the community health centres tended to serve hard-to-reach populations in urban areas or rural

communities. The ACCESS Winnipeg models offered medical care, social services, mental health, home care, employment and income assistance programs.

The community health centre was the predominant primary care renewal strategy for NB. In 2018, in NB, there were 10 geographically based community health centres and 29 associated health service centres. In MB, ON and AB, additional community health centres were created as part of the primary care renewal. In QC, although community health centres (referred to as CLSCs) are well established, they were not the focus of primary care renewal efforts. However, QC's strategic primary care policy intended to create better integration between health and social services by assigning CLSC nurses to the expanded family practice renewal model (family medicine groups) in their geographic area. In 2018, community health centres were well established in QC, ON, NB, MB and AB (in the decreasing order of per capita coverage); they were increasing in BC, SK and NS; and absent in PEI and NL.

The *primary care network* was the primary care renewal model in AB. Existing family practices in a geographically defined area were invited to join their local network voluntarily to have access to interdisciplinary teams (nurse practitioners, nurses, dietitians, social workers and pharmacists) to strengthen health promotion, chronic disease management and care coordination. In large family practices, the interdisciplinary team is intramural; multiple small family practices share a common team. The network included funding for increased administrative support, equipment and space, and it included arrangements for extended office hours and 24/7 access to appropriate primary care.

A 2008 change to the funding model extended services beyond the medically insured services to include some public health, wellness and chronic disease management services. In 2018, over 80% of family physicians were members of the 42 primary care networks and covered 85% of the population. As of 2017, there was joint network governance by physicians and the ministry of health (Alberta Health Services). In 2003, AB was the only province with this primary care renewal model but the success, and especially physician uptake, has raised interest elsewhere in Canada. In PEI, existing services were organized into primary care networks in 2011, and in BC, in 2018. The My Health Team model in MB also resembles the primary care network model.

Two policy approaches to primary care renewal model implementation

Five provinces promoted a single delivery model; five deployed multiple models. The single delivery models in the five provinces were: primary care networks (AB); primary health care teams (SK); family medicine groups (QC); collaborative family practice teams (NS); and community health centres and associated health service centres (NB). Policies supporting these renewal models were centralized at the ministries of health. Most of these were enhanced family practice models, and most retained fee-for-service remuneration of physicians, with additional remuneration for coordination activities and funding to include other health professionals working within the delivery model.

Multiple models were deployed in the other provinces. BC, PEI and NL used the PHCTFs to invest in several demonstration primary care delivery models but without clear evidence of unifying strategic policy. In contrast, ON deployed its suite of family health models sequentially within a unifying strategic policy designed to promote physician uptake and patient enrollment, establish minimal panel sizes, shift away from fee-for-service reimbursement of physicians, make 24/7 accessibility arrangements and include additional health professionals. When voluntary physician adherence was low in the initial robust expression of this policy (the family health network model), the Ontario Ministry of Health worked closely with physician associations to tweak the design to facilitate physician adherence while keeping their strategic priorities. The suite of models included the comprehensive care model, which grouped several solo practitioners into a cohesive delivery model. The success of this policy was evidenced by 85% of ON physicians practising in one of the family health models in 2018.

A unifying strategic policy was not obvious in MB. It used PHCTF to invest in information infrastructure, which was conducive to care integration. But in terms of primary care delivery models, there have been a series of model labels that seem to both reinforce and expand the traditional family practice model. In 2018, the systems-level and physician-oriented policies seemed to be converging into networking arrangements that increased access via existing family practices to interprofessional teams and collaboration between physicians and other health professional associations through a new service delivery governance and planning entity, Shared Health. The My Health Team model, introduced after 2018, includes collaborative arrangements with community organizations and shared access to a broader disciplinary set of care providers – suggesting a policy move toward configuring primary care models to deliver greater integration and interdisciplinary collaboration; but in 2018, a unified provincial approach was still not evident.

Unanticipated Findings

The following three unanticipated findings have important policy implications for both primary care comprehensiveness and linkage across services: (1) structures to accommodate unattached patients; (2) mental health access centres; and (3) Patient's Medical Home.

Unattached patients

Lack of affiliation to a most responsible family physician provoked a policy response in several provinces. Five provinces (BC, MB, ON, QC and NB) had established centralized waiting lists for family physicians. Two provinces (BC, QC) had set up specific primary care delivery models as an alternative to hospital emergency rooms where unattached patients could get first-contact care and access-needed diagnostic and therapeutic services, such as urgent primary care centres (BC) and cliniques réseaux (network clinics) (QC). Nurse-led clinics were used in four other provinces (SK, MB, ON, NB) to meet the needs of unattached patients. MB had piloted various delivery models to serve unattached patients and populations not

covered by traditional family practices (quick care nurse-led clinics, mobile clinics, walk-in connected care clinics). The emergence of these models made evident the fact that access to the most basic form of comprehensive care beyond acute needs requires having a responsible primary care provider – either a family physician or a nurse practitioner. Canadians without this privileged status may have been able to get free acute episodic care in the health system but their broader care needs were very poorly met – and if they had complex needs, they could be guaranteed that services would not be coordinated or connected.

Mental health access centres

At the time of data collection in 2018, five provinces had put community-based mental health centres in place. These one-stop shops have immediate access to a variety of mental healthcare providers and ensure rapid access and coordination with specialized mental health services. They cater especially to the needs of youth, many of whom are also unattached patients. These delivery models were designed to capitalize on any encounter to provide a comprehensive response adapted to the intensity of need. They had many shared features across provinces, which need to be evaluated because they hold promise for comprehensive primary care, especially for populations with complex care needs.

Patient's Medical Home

In five provinces (BC, MB, NB, NS, NL), we observed provincial family physician associations promoting models inspired by the Patient's Medical Home policy put forward by the College of Family Physicians of Canada (CFPC 2011). They were: home clinics (MB); family medicine (NB); a person-centred Health Home model (NS); a Health Home model (NL). These models had emerged since 2016, and while they included various features of the family practice renewal models (team-based, formal patient enrollment, enhanced accessibility arrangements), physicians played a key role in governance and leadership.

Discussion

This scan of primary care delivery models in Canada shows that in seven provinces, primary care renewal extended well beyond the initial federal investment of 2002–2006. In 2018, primary care renewal delivery models were predominant in AB, ON, QC, NB and NS. Most renewal models are enhanced family practice models; AB alone established primary care networks as a de novo governance and delivery model. Primary care renewal had been most successful in provinces with a unified strategic policy that either promoted a single delivery model (AB, QC, NS) or combined a solid core of orienting principles with organizational flexibility designed to maximize uptake (ON). In 2018, there was evidence of cross-provincial learning in provinces such as BC, SK, MB and PEI that were implementing primary care renewal strategies that had been successful in other provinces.

Similar to the 2009 status report on primary care renewal in Canada by Hutchison et al. (2011), our 2018 scan finds that primary care renewal models were the norm in AB,

ON and QC, but it adds NB and NS and sees even more development in other provinces. After a bumpy start, renewal models were well under way in MB and, to a lesser extent, in SK. Primary care networks have spread to BC, PEI and NFL. While Hutchison et al. (2011) included BC in the provinces with the most far-reaching transformation, this was not reflected in the implementation of primary care delivery models per se. Instead, BC invested in engaging family physicians in collaboratives to promote concerted quality improvement and full-service family practice (Cavers et al. 2010), with over 90% of family physicians enrolled in geographically based Divisions of General Practice in 2018. A rapid review of primary care policies from 2007 to 2017 also gave BC low marks for policy innovation, and included NB in that list (Peckham et al. 2018). The fact that primary care renewal continued beyond the PHCTF may also be due to the requirement of formal evaluation of initiatives that made results available to policy makers in other provinces such as BC, SK, MB and PEI that are building on what was learned.

One of the major policy achievements of primary care renewal has been to bring a significant proportion of autonomous family practices into the governance orbit of ministries of health through contractual arrangements of increased resources and funding in return for some accountability. Gaining access to increased resources required family practices to undergo some process of accreditation and commitment to providing minimal services. Engagement of physicians seemed to be a major consideration in the design of delivery models in most provinces, hence the predominance of enhanced family practice as the primary care renewal model across Canada. Family physicians embrace the idea of collaborative interdisciplinary practice (Wilson et al. 2005) and value-based remuneration (Kessels et al. 2015), but the policy and regulatory structures are not yet fully supportive. This speaks to the ongoing tension in policy making between public governance of the health system and the autonomy of the medical profession. This tension is particularly evident in parallel (but hopefully converging) primary care renewal tracks in MB and in the low uptake of the primary health care teams in SK until fee-for-service remuneration for physicians was allowed. The unanticipated emergence of the Patient's Medical Home as a competing delivery model was happening in BC, MB, NB, NS and NL – provinces where physicians had a strong role in determining health policy. We agree with the analysis of Peckham et al. (2018) that the negotiating table between organized medicine and the government make it challenging to translate innovative governance arrangements into meaningful coordination and integration at the front lines of care. We find that physician uptake was an objective in both ON's and AB's primary care delivery model design. ON intentionally adapted its policy on the family health suite of renewal models to engage physicians. AB's unique solution of primary care networks allowed for rapid deployment through joint governance between family physicians in non-profit corporations and Alberta Health Services. More recently, disputes in these provinces with physician associations demonstrate the challenge of the legacy of the medical social contract that was negotiated to achieve Canadian medicare.

Our findings reflect the limited time and resources to obtain needed information. The provincial summaries were based on information obtained within a given time budget, and we know that they were incomplete. This reflects the lack of publicly available and comparable information about our health systems across Canada (Stewart et al. 2023). We chose to be rigorous in basing our results and crystallization only on the collected data, not on other sources, and others with more knowledge of their provincial system may draw different conclusions. We are relieved to see that our results are largely coherent with the more comprehensive policy review by Peckham et al. (2018) with a slightly different aim. Both studies are responding to the expressed need by primary care researchers and decision makers to have comparative health system information across Canada and to accelerate the adoption of what works in other jurisdictions.

We recognize that our findings are time-stamped in 2018. Since the completion of this scan, primary healthcare models have continued to evolve, or devolve, particularly during the COVID-19 pandemic. Prior to the pandemic, digital strategies were emerging as an option to improve access to timely care from various health professionals. Companies such as the UK-based Babylon Health and Telus Health quickly responded to the perceived potential of digital primary healthcare service delivery in Canada. During the pandemic, the potential of virtual care options was clearly evident, and this has implications for enhanced coordination and integration of care. However, such innovations mostly address the needs of persons already attached to a primary care provider. Such ongoing change emphasizes the need for comprehensively and efficiently capturing cross-provincial and national primary healthcare renewal policies and models.

Where does this leave patients with complex healthcare needs? The comprehensiveness of services that these patients can expect to receive in primary care has clearly increased compared to the autonomous family practice model prevalent in 2001 – that is, if patients are fortunate enough to be enrolled in a primary care renewal delivery model. During the timeframe of this scan, their likelihood of being enrolled was high in AB, ON, QC, NB and NS. Models from ON and AB included a broad set of disciplines, such as pharmacists, social workers or psychologists and nutritionists or dietitians. In other provinces, such as QC and NS, the disciplinary mix was growing slowly beyond the physician–nurse team. Patients in AB, MB, ON and NB who are fortunate enough to be cared for in community health centres would have comprehensiveness that includes social as well as health services, and patients with complex healthcare needs may be encouraged to see the growth of community health centres in BC, AB, MN, ON and NB.

Less clear is the extent to which primary care renewal has achieved coordination and integration compared to primary care, especially between health and social services. Our findings concur with those of Peckham et al. (2018) that primary care renewal initiatives addressed linkage and exchange with other healthcare organizations and services through improved health information technology, but linkage was limited to medical services, especially hospitals. Most Canadians with complex care needs would not have access to a wide

range of services from their primary healthcare provider and would be dependent on their provider's or carer's capacity to coordinate connection with needed services.

Conclusion

This high-level impressionistic portrait of the state of primary healthcare renewal in Canada is a testament to the extent of transformation and change that is possible with federal health policy initiatives, such as the Health Accords, and targeted and harmonized investments, such as the PHCTF. The movement toward more comprehensive models of primary care extended beyond the end of the PHCTF in 2006. However, the integration between health and social services beyond the walls of primary care remains largely incipient and, sometimes, still dependent on heroic efforts of individual providers and caregivers. As the proportion of patients with complex care needs increases, surely it is time for a federal accord on integrating health and social services to provide truly comprehensive and integrated care for every Canadian.

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RESEARCH PAPER

Innovative Programs with Multi-Service Integration for Children and Youth with High Functional Health Needs

Programmes novateurs avec intégration de services multiples pour les enfants et les jeunes ayant des besoins élevés en matière de santé fonctionnelle

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Abstract

The integration of care services and providers across the health–social–community continuum has helped improve the lives of many children and youth living with complex health conditions. Using environmental scan data, 16 promising multi-service programs were selected and analyzed qualitatively through a deliberative conversation approach. Descriptive data of analyzed programs are presented, as well as the thematic analysis results. An important program strength is its clear founding principles and engagement of patients and families. However, the scale-up of these initiatives remains a challenge unless such programs can be better financed and supported.

Résumé

L'intégration des services et des fournisseurs de soins dans l'ensemble du continuum « services de santé–services sociaux–services communautaires » contribue à améliorer la vie de nombreux enfants et jeunes aux prises avec des problèmes de santé complexes. À l'aide de données d'analyse du contexte, 16 programmes multiservices prometteurs ont été sélectionnés et analysés qualitativement au moyen d'une approche de conversation délibérative. Les données descriptives des programmes analysés sont présentées ainsi que les résultats de l'analyse thématique. Une des forces importantes du programme consiste en ses principes fondateurs clairs et en l'engagement des patients et des familles. Cependant, l'intensification de ces initiatives demeurera un défi, à moins que de tels programmes puissent être mieux financés et soutenus.

Introduction

Children and youth aged 0 to 25 years who have high functional health needs account for about 15–18% of North American children (Berry et al. 2011; Haggerty et al. 2023; Kaufman et al. 2007). Advances in neonatal, medical and nutritional care have significantly improved the survival rate of vulnerable children who can now live into adulthood despite complex health conditions (here understood as one or more chronic physical, emotional, developmental, neurological or behavioural conditions). Such children require care from a wide range of health, social and community services (Burns et al. 2010), and it has long been understood that their well-being can be optimized when a diverse team of care professionals work together to address the needs of these children (Cohen et al. 2011, 2012). Innovative programs and initiatives that seek to integrate multiple services across the health, social and community continuum can prove to be a key source of information to help us understand what care providers and organizations are doing to respond to the needs of these children and their families. It is in this context that we undertook a qualitative analysis of a small sample of these innovative programs from across all 10 Canadian provinces. Our research aims to identify and analyze promising provincially based multi-service integration programs to distill dominant trends in multi-service integration, document their strengths and weaknesses

and formulate policy recommendations on how to better support local integration initiatives to increase spread and scale.

Methodology

To achieve our aim, 16 promising programs were identified from an innovative programs database containing approximately 100 programs across all Canadian provinces, which was created in an earlier phase of the larger study (Haggerty et al. 2023). The following five criteria were used to create our program sample: (1) the programs should be province-based and publicly supported; (2) the programs should show an innovative approach to multi-service integration; (3) the programs should show potential for scalability; (4) the programs should provide useful lessons regarding key ingredients of success or failure of multi-service care integration; and (5) all 10 provinces should be represented. To meet criteria 2 to 4, three independent co-investigators applied an "Innovativeness Scale" that was adapted from the "Innovative Practices Evaluation Framework" (Health Quality Ontario 2016).

Once programs were selected, the research team collected descriptive program data from readily available sources (e.g., program websites and publications, as well as informal conversations with key program informants) using a rating tool adapted from the literature to assign an integration score to each program. The tool reflects the achievement of 10 principles of care integration (Suter et al. 2009) and nine implementation facilitators (Damschroder et al. 2009). These data were then used to create program narratives, which were validated by both key program informants and the research leads. Using the descriptive program data and the narrative summaries, 14 co-investigators from the larger study representing each of the 10 provinces and having complementary knowledge and expertise (e.g., children/youth health clinicians, researchers, social and health service integrators, educators) participated in a three-hour virtual deliberative conversation led by a professional facilitator who guided the discussion using four reflective questions: (1) What are identifiable trends, across Canada, in provincially based integrated service programs that address the needs of children and youth with complex care needs? (2) What are the strengths and weaknesses of the programs? (3) Is there anything missing from the programs in terms of best approaches or models to services integration for this population group? (4) What would the policy recommendations be, based on this review? The conversations were audio-recorded and transcribed, and all the data were imported into NVivo 12 (QSR, 2018) and then analyzed thematically using codes agreed upon by members of the research team. Themes and sub-themes were identified by the main author using a thematic analysis approach (Clarke et al. 2015; Terry et al. 2017) and then synthesized and shared with the research team members and participants in the deliberative forum. Feedback to clarify or add nuance to the themes and sub-themes was provided and incorporated to produce a final report of thematic analysis, which was validated by participants and co-authors. Their feedback was used to reflect on policy implications and formulate recommendations.

Results

Our findings are presented as both (1) synthesized descriptive program data and (2) findings from thematic analysis of the deliberative conversations. Data excerpts are taken from the programs' narratives.

Descriptions of programs

Table 1 (available online at www.longwoods.com/content/27178) provides descriptive data of the programs selected, including the program's name, a brief description and the province in which the program is located; it also includes information regarding components of successful integration as per our theoretical conceptualization (Haggerty et al. 2023). Fourteen of the 16 programs included community organizations in their purview, and 13 of the 16 programs included mental health and substance use services in their design and also provided training or support for providers, specifically in a multi-service integration perspective. Twelve of the 16 programs served the entire province and included social services. The presence of individual intervention plans, patient and family centred-care, use of electronic medical records and use of telehealth follow-up, as well as implementation within existing clinics (e.g., family health teams, family group medicine), were the components least often included in the programs. Information about the role of family physicians in integrating or connecting services was not explicitly discussed, but we could usually ascertain their intended role through other information provided (e.g., Quebec [QC] programs; Prince Edward Island-[PEI]-BestStart.

Deliberative conversations: Thematic analysis

Our thematic analysis yielded four overlapping program themes to be considered when making policy recommendations for multi-service integration programs: (1) program philosophy, (2) governance, (3) engagement and (4) infrastructure, as well as sub-themes for each. Table 2 presents an overview of each theme and its corresponding sub-themes. Table 3 (available online at www.longwoods.com/content/27178) presents quotes and excerpts for each sub-theme, taken from the programs' narratives and the deliberative conversations.

PROGRAM PHILOSOPHY

Program philosophy refers to the foundational principles, theories, concepts and/or values that guide the program's creation and/or operation. We found that all programs had a "foundational story" that articulated its philosophy and served as both a catalyst and a guide to implementation. This philosophy was often presented in the form of a program's mission statement that articulated its objectives. These stories provided the most information for our program data analysis.

Six sub-themes of program philosophy emerged from our analyses (see Tables 2–4).

TABLE 2. Results from the thematic analysis: Key emerging themes and sub-themes

Program philosophy	Governance	Engagement	Infrastructure
1. Engagement (mainly patients and family members) 2. Prevention and early intervention 3. Local flexibility and adaptation 4. Primary care continuity 5. Incentives for providers 6. Sub-population stratification	1. Governance structure 2. Shared decision-making processes 3. Standardized processes 4. Definition of multi-service integration	**Who?** 1. Patients and family members 2. Providers 3. Larger community 4. Cultural diversity **How?** 1. On decision/advisory boards 2. By seeking experiential knowledge 3. In various types of meetings 4. In program planning 5. Through patient satisfaction evaluation methods	1. Role and presence of a care coordinator (or case manager or patient navigator) 2. Colocation of services 3. Data-sharing processes or structures 4. Evaluation and monitoring processes 5. Financial resources

Engagement was most often referred to as "person-centred care" and was used by programs to emphasize the central role patients and family members play, especially in the program's creation.

> Person and family engagement has been paramount throughout the stages of planning for Specialized Services for Children and Youth (SSCY). SSCY currently has a Family Advisory Council that helps to inform the direction of current and future priorities of the Centre (Manitoba-Specialized Services for Children and Youth [MB]-SSCY).

Prevention and early intervention emerged as an important theme and driver of programs, with particular attention given to mental health, emotional well-being and social support. Attention to social determinants of health was also noted here.

> Program promotes upstream approaches and early intervention services to facilitate positive childhood development (New Brunswick-Integrated Service Delivery [NB-ISD]).

Local flexibility and adaptation speaks to how the programs allowed for regional adaptation. This appeared to support implementation and program sustainability.

> There is a large degree of flexibility for PCNs to adapt to the needs of their region in Alberta, in consultation with the regional health authorities and the priorities of the family physicians. (Alberta-Primary Care Networks [AB-PCNs]).

Primary continuity refers to whether or not a program followed the federal primary healthcare renewal initiative and adhered to the renewed conception of primary care as primary healthcare (Dionne et al. 2023).

> Primary care renewal is a trend with an emphasis on care continuity and interprofessional practice (primary care/medical home) (Ontario-Family Health Teams [ON-FHTs]).

Incentives for providers refers to whether or not programs relied on incentivization (financial or otherwise) to increase providers' buy-in and participation in the program.

> [There is] capitation, as well as specific financial incentives for enrolling patients (ON-FHTs).

Subpopulation stratification refers to whether or not the program was designed for a specific subgroup of the target population, e.g., young adults transitioning to adult care.

> [The target population includes] children and youth up to age 18 inclusively, and up to the age of 21 for those within the public school system, who have identified multiple needs as defined by core areas of development, including physical health and wellness, emotional and behavioural functioning, family relationships, educational development and mental health (NB-ISD).

Table 4 shows which programs displayed which sub-themes.

GOVERNANCE

Our second theme, governance, refers to the structure and mechanisms used to enable and ensure efficacious management and deployment of a program. Four sub-themes emerged to facilitate the successful implementation of governance: (1) governance structure, (2) shared decision-making processes, (3) standardized processes and (4) definition of multi-service integration (see also Table 2). For each sub-theme, we provided a short definition; indicated whether or not it was well represented across all programs; and, if so represented, whether its representation was strong or weak. We also indicated which individual programs represented which sub-themes and whether or not this representation appeared strong or weak.

Governance structure refers to the various mechanisms of the program used to support its implementation and sustainability. When present, we found that the governance structure most often reflected the program's stated philosophy and principles (see theme #1). For example, programs that presented themselves as "person-centred" would most often also show a shared governance structure or shared accountability mechanisms with providers and patients/family members. In some cases, programs favoured accountability mechanisms

TABLE 4. Programs and sub-themes

Province	Program name	Engagement	Prevention and early intervention	Local flexibility and adaptation	Primary care continuity	Incentives for providers	Sub-population stratification
British Columbia	ON TRAC			X			X
Alberta	Primary Care Networks			X	X	X	
	Regional Collaborative Service Delivery			X		X	X
Saskatchewan	Cognitive Disability Strategy (CDS)		X	X			
Manitoba	Specialized Services for Children and Youth	X					X
	United Referral and Intake System						X
Ontario	Family Health Teams		X	X	X	X	
	Good 2 Go Transition Programs						X
Quebec	Community Social Pediatric Centres	X		X		X	X
	Programme d'aide personnelle, familiale et communautaire	X		X			X
New Brunswick	NaviCare	X					X
	Integrated Service Delivery		X		X		X
Nova Scotia	SchoolsPlus			X		X	X
Prince Edward Island	Best Start						X

established through institutional or governmental structures (e.g., universities or ministries). Overall, however, most programs did not provide sufficient information to assess this sub-theme (e.g., MB-SSCY, NB-ISD, Saskatchewan-Cognitive Disability Strategy [SK-CDS]) (see also Stewart et al. 2023).

Our second sub-theme pertains to the presence, absence and strength of *shared decision-making processes* of the design and the implementation of the programs. Our deliberative exchange suggested that such mechanisms are particularly effective and innovative in how they include patients and family members in meaningful ways. However, we found that most programs either lacked such mechanisms or the information to assess them. This was a recurrent weakness of programs analyzed (e.g., AB-Regional Collaborative Service Delivery [AB-RCSD], MB-United Referral and Intake System [MB-URIS], NB-ISD, Nova Scotia [NS]-SchoolsPlus, ON-FHTs, ON-Good 2 Go, PEI-BestStart, QC-Community Social Pediatric Centres [QC-CSPCs], SK-CDS).

Standardized processes refers to the presence of processes, materials or mechanisms to ensure a certain level of standardization throughout the program, which is viewed as

important to the success of a program. An example is the standardization of service delivery protocols for multi-service delivery integration. We found that many programs displayed this component and that from the available information, these protocols were used by healthcare providers (e.g., Alberta-Primary Care Networks [AB-PCNs], BC-ON TRAC, MB-URIS, QC-CSPCs).

Definition of multi-service integration refers to whether or not programs provided a definition of multi-service integration. Generally, we found little information and a lack of clarity in this regard. None of the programs presented a clear conceptualization of integration, and some programs lacked a connection with primary care. Finally, some programs focused on social needs (e.g., community or educational needs), yet did not have any formal agreements or concrete connections with healthcare organizations or providers (e.g., MB-SSCY, NS-SchoolsPlus).

ENGAGEMENT

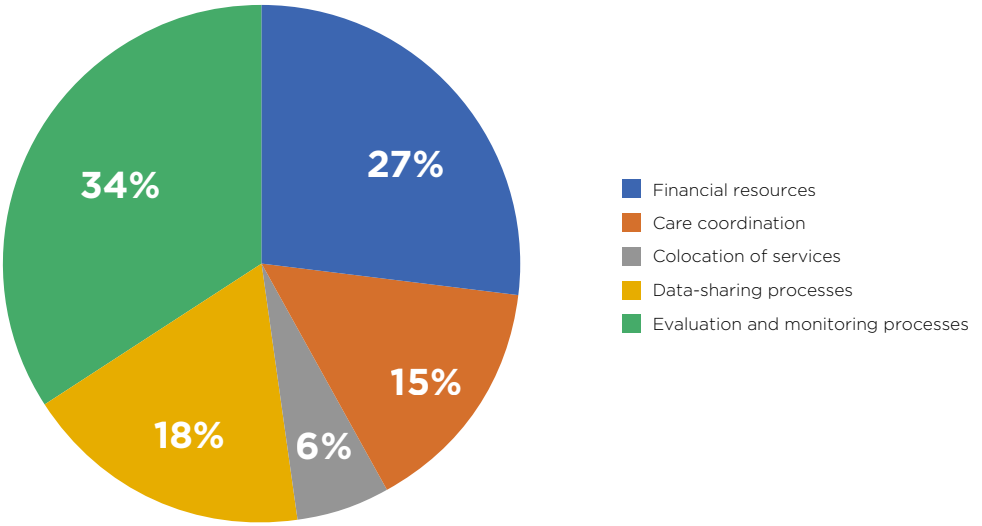
Engagement is described as how well programs engaged various stakeholders, such as patients and their family members, providers and local organizations. Here, we were also interested in how well programs integrated the principles of *equity, diversity and inclusion* (EDI), specifically in Indigenous and culturally diverse communities.

We found that only a handful of programs had a clear commitment to engaging patients and family members, and for those that did, the methods used varied greatly (e.g., inclusion on decision/advisory boards, of experiential knowledge, in a variety of meeting types; engagement in program planning; use of patient satisfaction evaluation methods) (e.g., MB-SSCY, QC-CSPCs, QC-Programme d'aide personnelle, familiale et communautaire [QC-PAPFC], NB-NaviCare). Most programs did not provide sufficient information to assess provider engagement. Only four programs that explicitly stated that they engaged providers also provided information on the engagement methods used (e.g., AB-RCSD, BC-ON TRAC, QC-PAPFC, NB-NaviCare). Only five programs explicitly stated that they regularly engaged local organizations to obtain early buy-in (e.g., in pilot programs; e.g., MC-SSCY, NB-ISD, NB-NaviCare, QC-CSPC, SK-CDS). Finally, most programs lacked cultural components or information on how they integrated EDI principles. None of the programs mentioned the involvement of Indigenous communities.

INFRASTRUCTURE

Infrastructure, the final dimension, describes the more concrete elements used to support the implementation of the program and the conduct of its activities. Five sub-dimensions emerged: (1) role and presence of a care coordinator or case manager or patient navigator, (2) colocation of services, (3) data-sharing processes or structures, (4) evaluation and monitoring processes and (5) financial resources. Figure 1 presents the distribution of these sub-themes per program. Evaluation and monitoring were the elements most present, with colocation of services the least.

FIGURE 1. Representation of infrastructure elements in all programs



Care coordinators, patient navigators and case managers emerged as key elements for achieving integrated care. These roles were viewed as an important support for patients with complex care needs (e.g., MB-SSCY, NB-NaviCare, NS-SchoolsPlus, ON-FHTs, QC-PAPFC). Interprofessional collaboration was a dominant theme across programs. Some programs clearly prioritized this approach (see Figure 1) to better support patients and families, minimizing the requirement to move across service organizations to access all services needed. For example, NS-SchoolsPlus emphasized colocation by delivering services in schools where children spent a large amount of their time. Colocation is also highlighted as helping providers to learn from and about other providers and services through working together in a more holistic and ecological approach (e.g., MB-SSCY, NS-SchoolsPlus). Data sharing was highlighted as an essential component to support multi-service integration by our diverse stakeholders (deliberative forum). However, most programs either lacked such infrastructure or information about it was missing. The deliberative exchange, however, suggested that some programs have inspiring approaches that could serve as useful examples in this regard (e.g., AB-PCNs, BC-ON TRAC, MC-SSCY, MB-URIS, NS-SchoolsPlus, ON-FHTs). Such approaches included facilitating communication to share knowledge and skills between providers or with patients and family members. At least one program specified doing data sharing informally as more robust structures had yet to be implemented (e.g., AB-RCSD). Overall, programs lacked adequate infrastructure to share records, which underscores the need for better resourcing (e.g., AB-RCSD, BC-ON TRAC, NB-ISD, ON-Good 2 Go, PEI-BestStart, QC-PAPFC).

Most programs explicitly stated that they collected data to evaluate and/or monitor their services (e.g., AB-PCNs, BC-ON TRAC, MB-SSCY, NB-ISD, NB-NaviCare, NS-SchoolsPlus, ON-FHTs, PEI-BestStart, QC-CSPCs, QC-PAPFC, SK-CDS).

Measures, however, were often very narrow insofar as they were predominantly quantitative and lacked evaluation of stakeholder satisfaction. There is also a lack of program data on implementation mechanisms, yet this information is critical to support the scale and spread of promising initiatives (e.g., AB-RCSD, BC-ON TRAC, MB-URIS, ON-Good 2 Go, PEI-BestStart, QC-CSPC). Finally, when information was available, there was a general lack of consistency in approaches used to evaluate programs. We also found little information on the integration theory driving the programs.

A common weakness of programs was their limited access to sufficient resources to support evaluation and monitoring processes. While this information was not readily available in publications, through conversations with key informants – who confirmed that there was a lack of implementation of a data-sharing system and/or electronic patient records, a lack of awareness about the programs and weak evaluation and monitoring practices – we concluded that programs did not have access to adequate resources to support these activities. When available, we noted that funding appeared to be provided on a short-term basis at best. This can negatively impact the sustainability programs, as well as their ability to innovate (e.g., AB-RCSD, BC-ON TRAC, MB-SSCY, NB-ISD, NB-NaviCare, NS-SchoolsPlus, ON-Good 2 Go, PEI-BestStart, QC-PAPFC, SK-CDS). Limited funds can also negatively affect the reach of programs and the ability to promote local awareness (e.g., AB-RCSD, BC-ON TRAC, MB-SSCY, NB-NaviCare, NS-SchoolsPlus, PEI-BestStart, QC-PAPFC).

Discussion

Several elements from our findings warrant further discussion. When considering recent literature regarding the recommendations on care adaptation for this patient group, we found some similarities but also differences. Some of our themes echo recommendations made in the current literature, notably regarding how to best provide and organize care across the health and social continuum for children and youth with complex care needs and their families. For example, Kuo et al. (2022) remind readers of a 1987 US Surgeon General's report that states key principles for the care of this patient population group (which were proposed for the design of the medical home hub) that remain timely. These were access to services, ensuring that all children and youth have a medical home (comprehensive care), community support, transitions in care, health information technology and quality improvement (Kuo et al. 2022). All but quality improvement were reflected particularly well in our analysis.

However, other principles of integrated care that appear essential for this population were largely absent from the program information available to us. Various authors emphasize the following principles as absolutely needed when caring for children and youth with complex care needs and their families: (1) the importance of the medical home as the "hub" for various professionals or services, (2) an emphasis on *family-centred care* and the role of family members (Kuo et al. 2012, 2022), (3) the adoption of a *life course perspective* (Bethell et al. 2014) and (4) the role and training of interdisciplinary teams (Coller et al. 2020). The second and third principles are importantly missing. We found no mention of them.

Policy recommendations

In light of the current literature and our analysis of the data that we collected, there are three policy recommendations to consider. First, there is a dire need to equip local programs with the resources needed to enable program evaluation and assessment that can be used to support the spread and scale of the program and thus avoid duplication that leads to a waste of resources. Our recommendation is that these tasks be done locally – for example, by the program coordinator. However, the resources required to do this well – which include program evaluation, engagement of relevant stakeholders, communication strategies and knowledge of the best implementation practices available – should be made available at a more centralized level – for example, by federal or provincial governmental bodies, who would be responsible for managing an easily available online platform. The value of such a platform will enable programs to better share their innovations. An example of such a platform is the Children and Youth with Special Health Care Needs National Research Network, created in the US in 2017 by the Health Resources and Services Administration Maternal and Child Health Bureau (see CYSHCNET.org; Coller et al. 2020).

Our second recommendation is to increase the engagement of relevant stakeholders, specifically that of patients and family members. Most programs indicated that they engage various stakeholders and take engagement at heart, particularly that of users and family members. However, our assessment of existing program data suggests that the methods used to engage participants are often limited to a posteriori quantitative satisfaction questionnaire, which we hypothesize reflects how local initiatives lack resources or expertise (to support robust scientific program evaluation).

Our final recommendation pertains to the need to equip local teams with adequate resources, notably digital (infrastructure, capacity, expertise), to develop and sustain robust integrated services solutions. Data and information sharing are highlighted both in the scientific literature and by our diverse stakeholders as an essential component to support multi-service integration. This requires resources to ensure that programs use confidential information-sharing platforms; have electronic medical records; and provide data access to patients, family members and other providers to benefit from involvement in nationally managed digital solutions platforms. Our study indicates that little innovation is done at this level and that most programs do not meet the digital turn. It is likely that many organizations, notably those that rely on public funding, do not have the resources, training or infrastructure to innovate digitally. However, it is hard to conceive of an integrated multi-service approach that would not also have a strong digital component and tools (e.g., electronic medical files). If we want to support local innovations and integrate care, such capacity needs to be developed and well supported through funding and investment by provincial and federal governmental bodies.

Limitations

There are a number of limitations to this study. To begin with, this study was conducted five years ago. Some of the conclusions we draw may no longer reflect the state of innovation in multi-service integration for this patient population and their families (e.g., the number of programs that have followed the digital turn due to the pandemic; greater consideration for mental health and youth protection in policy priorities). Also, to select programs, we relied on a database of innovative programs that were created at an earlier phase of the study, which relied on contributions from the Canadian Primary Care Research Network. This method, however, was not exhaustive and was time bound. Finally, of the programs selected for in-depth analysis, some revealed themselves to be insufficiently documented to support the level of analysis desired. Due to limited resources, including a limited amount of time, going back and selecting other programs was not feasible. With more funding, we would have been able to identify all current and past programs throughout Canada in order to support a more exhaustive analysis. Nevertheless, the insights obtained in this study were sufficient to support the policy recommendations outlined.

Conclusion

Our study provided an in-depth analysis, based on publicly available data, of innovative programs across Canadian provinces that aim to integrate health and social care to better support children and youth with complex care needs. These innovative programs could be a rich source of information and inspiration for other provinces or regions that are looking to create similar solutions, but without appropriate documentation we are losing such capacity to learn and grow.

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RESEARCH PAPER

Integrating Health and Social Care for Community-Dwelling Older Adults: A Description of 16 Canadian Programs

Intégration des soins de santé et des services sociaux pour les aînés vivant dans la communauté : description de 16 programmes canadiens

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Abstract

This paper describes 16 Canadian programs designed to provide integrated primary care for older adults. Publicly available data were used to identify the "what" and the "how" of integration for each program. Most programs integrated with other healthcare or medical services (vs. social services). Mechanisms of integration varied; the most common mechanism was interprofessional teams. Only 25% of the programs formally engaged with autonomous physician-led primary care practices (where most Canadians receive their primary care). Findings suggest that integrated care is a priority across Canada but also highlight how far we have to go to achieve both vertical integration within the healthcare sector (primary, secondary and tertiary services) and horizontal integration across sectors (health and social).

Résumé

Cet article décrit 16 programmes canadiens conçus pour fournir des soins primaires intégrés aux aînés. Les données publiquement accessibles ont été utilisées pour déterminer le « quoi » et le « comment » de l'intégration pour chacun des programmes. La plupart des programmes sont intégrés à d'autres services de santé ou médicaux (par opposition aux services sociaux). Les mécanismes d'intégration varient, le plus courant étant celui des équipes interprofessionnelles. Seulement 25 % des programmes se sont officiellement engagés dans des pratiques de soins primaires autonomes dirigées par des médecins (soit là où la plupart des Canadiens reçoivent leurs soins primaires). Les résultats indiquent que les soins intégrés sont une priorité partout au Canada, mais ils soulignent également le chemin que nous devons parcourir pour réaliser à la fois une intégration verticale au sein du secteur des soins de santé (services primaires, secondaires et tertiaires) et une intégration horizontale entre les secteurs (santé et services sociaux).

Introduction

Maximizing health outcomes for patients with complex care needs requires not only vertical integration of hierarchical services within the health or medical sector (i.e., primary, secondary and tertiary services) but also horizontal integration across additional sectors, including social care services and community-based supports (Conrad and Shortell 1996; Goldsmith 1994; Robinson and Casalino 1996; Shortell et al. 1996). We found multiple definitions of integration (Armitage et al. 2009) and formulated a generic working definition, as follows: the ensemble of policies and procedures that support linkages and efficient exchange among institutions that deliver complementary services. Integrated care programs formalize connectivity, alignment and collaboration between services or sectors to achieve specific objectives (Kodner and Spreeuwenberg 2002). A lack of connection to needed services leads to negative experiences for patients and their carers (health deterioration, costly social consequences and high-intensity interventions) and for the healthcare system in terms of inefficiencies and fragmentation of service (Hwang et al. 2013; Kodner 2009; Nolte and Pitchforth 2014; Paré et al. 2014; Rich et al. 2012; Wilson et al. 2016).

In Canada, primary care has the responsibility for first contact and ongoing care of populations undifferentiated by age or disease status even when patients receive services elsewhere (College of Family Physicians of Canada 2011). Valentijn et al. (2013) posit that truly comprehensive primary care requires integration of services beyond the health sector to include social sectors and community-based organizations. Significant public investments since the 2001 Health Accord (Health Canada 2006) have resulted in innovation related to primary healthcare programs designed to integrate care within the health sector and across to the social care sector. However, because healthcare in Canada is organized at the provincial or territorial level, the program innovations in one jurisdiction may not be known in another jurisdiction. Our pan-Canadian team (see p. 105) conducted a descriptive policy and program analysis across Canadian provinces to identify and compare exemplar programs that integrate primary care with health and social services for two populations: children and youth (0–25 years) with high functional health needs and community-dwelling older adults (≥ 65 years) experiencing functional decline. The hope was that this information could support the scale up and spread of innovative models of integrated primary healthcare between Canadian jurisdictions. This article presents the findings of programs designed for older adults (for children and youth see the article by Dionne et al. 2023b).

Our purpose was to collect detailed implementation data for each program with the objective of assessing the degree to which each program had achieved integration and to identify the implementation factors that predicted successful integration. However, as detailed elsewhere in this special issue (Stewart et al. 2023), this original analytic objective proved ambitious given the paucity of publicly available data for the selected programs. Based on the information that was consistently and comparatively available across programs, we instead addressed two revised analytic objectives: to identify which services each program was designed to integrate with (the "what") and to identify the primary theorized mechanisms by which integration was meant to occur (the "how"), including the extent to which programs involved autonomous physician-led practices (where the majority of older Canadians receive their primary care).

Methods

The data collection methods used in this portion of the project are described in greater detail in our companion piece (Stewart et al. 2023). Briefly, however, co-principal applicants nominated 99 publicly funded programs (i.e., programs operated by provincial/regional health authorities or community organizations) designed to connect primary care to other services, and provided relevant websites and names of one or more key informants who could provide information pertaining to program implementation. Summaries of each nominated program were reviewed and rated using the Innovative Practices Evaluation Framework (Health Quality Ontario 2016) and 16 older adult programs were selected for detailed data collection and analysis whose brief description suggested: (1) novelty and innovativeness in approach to integration and (2) the potential for scalability. We selected at least one program from every

province. Tools were developed (see Appendix 3 [available online at www.longwoods.com/content/27185] and Appendix 4 [available online at www.longwoods.com/content/27184]) to collect program implementation and integration data (Damschroder et al. 2009; Suter et al. 2009), and we used publicly available data sources (e.g., government websites, grey and published literature) and key informant interviews to populate the data collection tools for each selected program. Key informants (where involved) corrected or contextualized the information collected. Drawing from the populated data collection tool, a narrative summary of each program was produced, which was then approved by key informants.

Data analysis

The detailed narrative summary of each program was read and coded independently by one researcher and one research assistant to identify the types of services that were integrated (the "what") and the mechanisms of integration (the "how"). Coding schemes for both concepts ("what" and "how") were agreed upon before data analysis, and are described below. Two coders met to discuss, and discrepancies were resolved by independent re-reviewing of narratives by both coders until consensus was achieved. The findings were presented to the broader research team for discussion and validation.

To identify *what* each program was designed to integrate with, we used our list of 10 priority health, social and/or community services deemed most important to be linked with primary care, which was developed in an earlier project in this research program through a formal consensus process with researchers, policy makers and patient partners (Dionne et al. 2023a). For the older adult population, the top 10 services (in decreasing priority) were: (1) chronic disease management programs/services, (2) home care, (3) respite care services, (4) medication reconciliation in community pharmacy programs, (5) mental health and addictions services, (6) palliative care, (7) navigational services, (8) timely transition between urgent, acute and emergency care, (9) services to address material deprivation and (10) services to address social deprivation.

In terms of *how* the program aimed to achieve integration, we extracted the following two types of information from the narrative summaries: (1) the program's theorized mechanism(s) for achieving integration and (2) the program's relationship to autonomous physician-led practices (where the majority of older Canadians receive primary care). To measure the theorized mechanism of integration, we aimed to distill down to a few words for each program the underlying theorized means of achieving integrated care – that is, "If ___ is done, then care will be better integrated for older adults". To do this, we adapted a categorization scheme from the World Health Organization's overview of well-known approaches to integrated care (Satylganova 2016), coding our selected programs for the following operational approaches to integration: colocation of services; outreach service (assessment, recommendations and referral); case-management/navigation; interprofessional teams; and service network.

Next, we made a distinction between programs where autonomous physician practices appear to be formally engaged as care partners versus programs where autonomous physicians are not formally engaged as care partners. Programs coded as "formally engaged" with autonomous physicians were ones with explicit mention of formal contracts, pooled resources and/or a common patient record with autonomous physician practices. Programs coded as "not formally engaged" appeared to be only peripherally associated with autonomous physician-led practices (i.e., autonomous physicians might be a referral source, but there were no contracts and/or pooled resources, and sharing of patient information occurred only on an as-needed basis).

Results

Table 1 (available online at www.longwoods.com/content/27177) provides a list of the programs selected from each province and outlines a brief description of the design and goals of each program.

What was integrated?

Table 2 (available online at www.longwoods.com/content/27177) shows which of the priority services were included in the program design. Most of the integration pertained to traditional health or medical services. There was clear evidence of connection to the following priority services: chronic disease management programs or services; home care; mental health and addictions services; navigational services; timely transitions between urgent, emergency and acute care; and services to address material deprivation. There was less evidence that programs connected to respite care services, palliative care, community pharmacy programs and services to address social deprivation. Two programs had a specific focus on financial security to address material deprivation (Manitoba, Newfoundland and Labrador). We also noted that five of the 16 programs had a specifically articulated emphasis on frailty (Alberta, Saskatchewan, Manitoba, Prince Edward Island). Similarly, several programs showed a connection to geriatrics as secondary specialist care (e.g., British Columbia, Quebec) and two programs to rehabilitation services (British Columbia, Newfoundland and Labrador).

How was it integrated?

Table 3 shows the theorized mechanisms of integration, which varied across our selected programs: colocation of services (four programs), outreach (three programs), case management/navigation (six programs), interprofessional teams (eight programs) and service networks (five programs). Four of the 16 programs (25%) that we reviewed appeared to be formally engaged with autonomous physician-led practices through contracts, shared resources or shared patient records.

TABLE 3. Principal mechanism of integration and relationship to autonomous physician-led practices among selected programs for older adults

	How was it integrated?	
Province: Program name	**Mechanism for integration**	**Relationship to autonomous physician-led practices**
British Columbia: Kamloops Seniors Health and Wellness Centre	Colocation of services Interprofessional team	Not formally engaged
Alberta: Seniors' Community Hub	Outreach Service network	Unclear
Alberta: Primary Health Care Integrated Geriatric Services Initiative	Interprofessional team	Formally engaged
Saskatchewan: Seniors House Calls Program	Outreach Case management/navigation	Not formally engaged
Saskatchewan: Connecting to Care (Hotspotting)	Case management/navigation	Not formally engaged
Manitoba: My Health Teams: Financial health promoters	Interprofessional team Service network	Formally engaged
Manitoba: Program of Integrated Managed Care of the Elderly	Colocation of services Interprofessional team	Not formally engaged
Ontario: Health Links	Case management/navigation Service network	Not formally engaged
Ontario: Community Hubs (Langs)	Colocation of services Outreach	Unclear
Quebec: Réseau des services intégrés pour personnes âgées en perte d'autonomie cognitive	Interprofessional team Service network	Formally engaged
Quebec: Québec Alzheimer Plan in family medicine groups and units	Interprofessional team Service network	Formally engaged
New Brunswick: Rehabilitation and Reablement program	Interprofessional team	Not formally engaged
Nova Scotia: Community Health Teams	Case management/navigation Colocation of services	Not formally engaged
Newfoundland and Labrador: Community Supports Program	Case management/navigation	Not formally engaged
Prince Edward Island: COACH program	Interprofessional team	Not formally engaged
Prince Edward Island: East Prince Seniors Initiative	Case management/navigation	Not formally engaged

Discussion

Our scan of 16 exemplar programs designed to integrate health and social services for community-dwelling older adults was limited to a descriptive analysis due to the lack of publicly available information on the selected programs. The approaches to integrating services for older adults varied widely across the Canadian provinces in terms of what was integrated and how. Nonetheless, it is important to note that every Canadian province had an exemplar

program. Most programs limited integration to other medical or health programs, and the most likely mechanism of integration was interprofessional teams. A minority of the programs appeared to be formally engaged with autonomous physician-led practices (where the majority of older Canadians receive primary care) through contracts, pooled resources or shared patient records.

A simple finding, but nonetheless potentially worth noting, is that we were able to identify exemplar programs operating in each Canadian province. This suggests that all provinces are, to some degree, experimenting with programs designed to integrate services for community-dwelling older adults. The plethora of programs for older adults is a clear response to the policy priority given to aging well and "in place" as per the *Principles of the National Framework on Aging* (Health Canada 1998) and the more recent *Healthy Aging in Canada* (Edwards and Mawani 2006). Another project in our research program, published elsewhere (Crowell et al. 2020), selected three older adult programs that integrated services for a common complex care need and examined specific provincial contextual factors and the policy environment within which each program was initiated and implemented. They selected integrated care programs for major neurocognitive disorders, such as Alzheimer's disease, and their health reform analysis has been published elsewhere (Crowell et al. 2020). But worth noting here is that the *National Strategy for Alzheimer's Disease and Other Dementias Act* (2017) (PHAC 2019) was a key influencer in the initiation of the programs. A message that has emerged from various projects in our research program is that national policies and strategies are important for embedding innovative solutions in the health system (Crowell et al. 2020; Haggerty et al. 2023b; Scott et al. 2023).

Next, in terms of *what* was integrated, we found that very few of the exemplar programs were designed to connect with the services that our stakeholders had identified as top priorities (Dionne et al. 2023a). Indeed, the selected programs appeared to address a limited set of health- or medical-specific services that meet the needs of relatively narrow groups of patients (e.g., dementia, frailty, physical rehabilitation). Older adults with undifferentiated health concerns, or those who simply have lower-acuity medical, functional and/or social needs, do not qualify for these types of specialized programs, and thus, appear much less likely to be benefiting from programs that offer integrated care. A premise of this study is that mitigation of functional decline is the important goal and that services need to be easily coordinated from primary care where the majority of older adults are managed regardless of health condition. There is a need to move beyond disease-specific categories and funding to achieve the policy objectives of aging well in Canada.

Although specific community supports did not emerge on our list of 10 priority services (Dionne et al. 2023a), several programs designed such connections. The health reform analysis of programs for major neurocognitive disorders pointed out how critical it was for the programs to have a formal mechanism for supporting patient's caregivers and social supports, and that this was achieved through partnerships with community organizations such as local chapters of the Alzheimer's Association (Crowell et al. 2020). A similar finding was also

highlighted in the study of integrated programs for children and youth with high functional health needs (Crowell et al. 2020; Dionne et al. 2023b). This points to the wisdom of including community organizations within the integrated care solutions and to the health system providing some funding and support for their long-term stability.

In terms of *how* programs approached integration, for approximately half the programs we observed more evidence of linkage versus actual integration (Leutz 1999) with mechanisms, such as colocation of services, case management or navigation used to link patients to other (stand-alone) services. Furthermore, only a minority of the programs we reviewed (which were publicly operated by provincial/regional health authorities or community organizations) were formally engaged with autonomous physician-led practices, where the majority of older Canadians receive their primary medical care. It stands to reason that any wide-scale improvements in the integration of primary care for older adults is dependent upon successful engagement with autonomous physician-led practices, although many barriers are known to exist (Haggerty et al. 2023a; Marsden et al. 2012; Neimanis et al. 2002; Struthers et al. 2019). The findings of the health reform analysis of the programs for major neurocognitive disorders found that the extent to which programs were able to link to the network of primary care renewal models was a condition of successful scale up for the programs in Ontario and Quebec (Crowell et al. 2020). This shows how policies and programs can reinforce each other. As pointed out in a companion paper (Haggerty et al. 2023b), primary care renewal models are now the norm in five provinces and are expanding steadily in three. It will be important for integrated care programs for older adults to connect to the network of primary care renewal models to expand their reach and consolidate the larger program goals.

Finally, it is important to note several limitations. Firstly, our analysis is based on a selected sample of programs (vs. a comprehensive or systematic list); secondly, all selected programs are urban-based (vs. rural); and lastly, our data are limited to publicly available information (occasionally supplemented by key informant interviews) that was demonstrably limited in scope and detail (Stewart et al. 2023).

Conclusion

This scan of recognized exemplar programs across Canada demonstrates that integration of services for older adults is a priority of health systems across the country, but that integration of services is still restricted to traditional health or medical services. The description of the programs demonstrates how far we have to go in achieving the promises of both vertical integration within the healthcare sector (primary, secondary and tertiary services) and horizontal integration across sectors (health, social and community). In line with the national, provincial and territorial policies and goals of healthy aging, integration needs to expand to include social services. The philosophy and ideal of truly comprehensive primary healthcare (Valentijn et al. 2013) requires integrated programs to connect intentionally to the predominant mode of primary care service delivery where the health of the majority of community-dwelling older adults is managed.

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RESEARCH PAPER

Lack of Publicly Available Documentation Limits Spread of Integrated Care Innovations in Canada

Le manque de documentation publiquement accessible limite la propagation des innovations en matière de soins intégrés au Canada

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Abstract

As healthcare in Canada is provincially operated, the program innovations in one jurisdiction may not be readily known in other jurisdictions. We examine the availability of implementation-specific data for 30 innovative Canadian programs designed to integrate health and social services for patients with complex needs. Using publicly available data and key informant interviews, we were able to populate only ~50% of our data collection tool (on average). Formal program evaluations were available for only ~30% of programs. Multiple barriers exist to the compilation and verification of healthcare programs' implementation data across Canada, limiting cross-jurisdictional learning and making a comparison of programs challenging.

Résumé

Étant donné que les soins de santé au Canada sont administrés par les provinces, les innovations présentes dans une administration peuvent passer sous le radar des autres administrations. Nous examinons la disponibilité des données concernant la mise en œuvre de 30 programmes canadiens novateurs conçus pour intégrer les services de santé et les services sociaux à l'intention des patients ayant des besoins complexes. À l'aide des données publiquement accessibles et d'entrevues avec des informateurs clés, nous n'avons pu remplir qu'environ 50 % de notre outil de collecte de données (en moyenne). Les évaluations officielles des programmes n'étaient disponibles que pour environ 30 % d'entre eux. Il existe de nombreux obstacles à la compilation et à la vérification des données sur la mise en œuvre des programmes de soins de santé au Canada, ce qui limite l'apprentissage entre les administrations et complique la comparaison entre les programmes.

Introduction

The 2001 First Ministers Health Accord launched an $800 million federal investment over five years to renew primary healthcare in the provinces and territories (Health Canada 2006). One of the five objectives was to facilitate the coordination and integration of primary healthcare with services offered in other institutions and in the community (Health Canada 2007: 1). This investment enabled the development and rollout of primary care–specific "integrated care" programs. However, the Canadian healthcare "system" comprises a collection of separate provincially run healthcare systems – meaning that the program innovations in one province are not immediately known (or well understood) in another jurisdiction. This reality limits both the scale-up and spread of innovative primary care models (Greenhalgh and Papoutsi 2019).

Among the initiatives to promote integrated health-related services in Canada, the Canadian Primary Care Research Network (CPCRN) promoted cross-jurisdictional research and knowledge exchange "to accelerate the pace of integrated care solutions" (CIHR 2022). Within this initiative, our pan-Canadian team (see p. 105) conducted a descriptive policy and program analysis across the 10 Canadian provinces to generate information that could support the scale-up and spread of innovative models of integrated primary healthcare

between Canadian jurisdictions. We focused on two patient groups with complex care needs who are managed in primary care and who require other medical, social and community-based services to maintain functional health or mitigate its decline: children and youth (0–25 years) with high functional health needs and community-dwelling older adults (≥ 65 years) experiencing functional decline.

Two research teams identified publicly funded programs across all provinces that integrate primary care with additional health and social services for children and youth and for older adults. Our goal was to provide analytic insight into the conditions of success (or failure) concerning the achievement of comprehensive integrated primary healthcare by collecting and analyzing detailed program implementation data from exemplar programs for both patient groups.

However, in the course of data collection and analysis, we encountered a challenge that threatened the achievement of this objective: the lack of publicly available information on the selected programs. This article presents the tools we developed for data collection (which we view as contributions to knowledge) and describes how and why we were unable to apply our data collection tools to satisfactorily address the original objectives due to the lack of publicly available data. We then discuss why this incidental finding of the paucity of publicly available implementation information on exemplary programs is an issue and what might be done about it.

Method

Our team of 46 researchers, clinicians, decision makers and patients across 10 Canadian provinces was solicited to provide the names of exemplar publicly funded programs implemented since the 2001 First Ministers Health Accord (Health Canada 2006) that were designed to connect primary care to social services, public health and/or community supports for either of the two populations of interest (children and youth; and older adults). Team members were also asked to provide websites for the nominated programs and the names of one or more key informants who could provide information about program implementation. After several rounds, the team nominated 99 programs across 10 provinces. Co-investigators from our pan-Canadian team then reviewed summaries of each of the nominated programs from their home province, rating each program using the Innovative Practices Evaluation Framework (Health Quality Ontario 2016). Thirty programs were selected (14 for children and youth and 16 for older adults) whose brief description suggested: (1) novelty and innovativeness in the approach to integration and (2) the potential for scalability. We selected at least two programs from every province (i.e., one designed for children and youth and one designed for older adults).

Data collection tools

Parallel to the identification and selection of programs, a small working group (JH, ED, TS, Shelley Doucet [SD], RU, NO) designed a data collection tool to gather program implementation data across all selected programs. This Program Implementation Data Collection

Tool (see Appendix 3, available online at www.longwoods.com/content/27185) itemized service-level implementation factors identified as particularly important to service integration as per Suter et al.'s (2009) "Ten Key Principles for Successful Health Systems Integration" and Damschroder et al.'s (2009) Consolidated Framework for Implementation Research. Specifically, we aimed to gather program information in each of the following dimensions of implementation and integration: (1) program overview and context, (2) history, (3) program goals, (4) design, (5) governance structure, (6) patient focus, (7) information systems, (8) trialability, (9) policy instruments, (10) financial management and (11) performance management. Next, a Program Integration Rating Tool (see Appendix 4, available online at www.longwoods.com/content/27184) was designed to rate the extent to which each element of program implementation and integration was met as inspired by Hebert and Veil's (2004) tool that assessed the degree of integration achieved by a model of integrated service delivery for frail older people.

Data collection

Data were collected from September 2017 to May 2018, and the analysis was conducted from May 2018 to February 2019. Research assistants drew on publicly available information such as health system and government websites, as well as grey and published literature. For both pragmatic and budgetary reasons, we allotted no more than 20 hours of research assistant time to complete the Program Implementation Data Collection Tool (Appendix 3) for each program and to engage a key informant for each program (i.e., an individual who was closely involved with the design, implementation and/or evaluation of the program). Key informants were interviewed by phone to validate and complete the Program Implementation Data Collection Tool (Appendix 3). Narrative summaries of each program were written by research assistants (ranging in length from five to eight pages) and were reviewed by a team of three co-principal investigators (ÉD, SD, TS) for consistency and completion. Narrative summaries were sent back to program key informants for validation and were then finalized.

Next, the Program Integration Rating Tool (Appendix 4) was applied to the narrative summaries in order to assess the degree to which each program had been able to successfully achieve integration. Two-to-three raters (i.e., project researchers) were assigned to each program. Raters supplied their data back to the leads of each patient group team who consolidated the data (Dionne et al. 2023; Stewart et al. 2023).

Analysis

The original intent was to conduct a comparative analysis across the selected programs – synthesizing across the program integration ratings and the program implementation data – and identify the dimensions of implementation and integration that appeared to contribute most to program success (or failure). However, as data collection began, it quickly became apparent that we did not have comparable information across programs due

to limitations to the publicly available information we required to populate the Program Implementation Data Collection Tool (Appendix 3). The paucity of publicly available program data meant that it was no longer feasible to address our original objective of assessing the degree of integration and implementation in a valid and comparable manner.

Instead, we chose to focus our analysis on the extent to which the Program Implementation Data Collection Tool (Appendix 3) could be completed for each program and on identifying the information that was most likely to be missing. We examined the finalized program implementation data (and narrative summaries) for each program and extracted data on four indicators of data availability and data quality: (1) whether or not we were able to locate publicly available program evaluation findings (yes/no), (2) the percentage of our tool we were able to complete within a time-limited (e.g., 20 hours) search of publicly available information, (3) whether or not we were able to secure engagement of a suitable key informant to review the tool (yes/no) and (4) the percentage of our tool that was completed following participation of the key informant (if applicable).

Findings

The 30 programs are described in more detail in companion papers (Dionne et al. 2023; Stewart et al. 2023), and the complete program narratives are available upon request.

Availability of program implementation data

Tables 1 and 2 list the selected programs for children and youth (n = 14) and older adults (n = 16), respectively. These tables document the extent to which we were able to find implementation-related data for each of the 30 programs. Across all 30 programs, completeness of our data collection tool ranged from 0% to 78% after a maximum of 20 hours of searching and summarizing publicly available information (mean = 35% for children and youth; 27% for older adults). We were able to secure the participation of a key informant to validate and add to this information for 11 of the 14 youth and children programs and 11 of the 16 older adults programs (73% overall). Where input from a key informant was available, the completeness of our tool increased from an average of 20% to 61%.

At the time of our search, only 13 of 30 programs had robust evaluation findings that were publicly available (often via journal publications). Several other programs had been evaluated, but the findings were not publicly available or could not be shared cross-jurisdictionally due to the evaluation findings being embargoed or "internal." Not surprisingly, the initial rate of tool completion was higher for those programs that had publicly available evaluation findings (43% vs. 21%).

In terms of the 11 dimensions included in our Program Implementation Data Collection Tool (Appendix 3), the three dimensions where we found the greatest amount of publicly available information were (1) program overview and context, (2) history and (3) program goals. This general program information was often publicly available; in addition, key informants (where involved) were able to make significant contributions to correct or

TABLE 1. Indicators of data availability and data quality for selected programs designed to provide integrated care for children and youth

Province	Program name	Percentage (%) data template complete *before* key informant involvement	Key informant engagement	Percentage (%) data template complete *after* key informant involvement
British Columbia	ON TRAC	38	Yes	49
Alberta	Primary care networks	38	Yes	89
	Regional collaborative service delivery	60	Yes	69
Saskatchewan	Cognitive Disability Strategy	45	Yes	68
Manitoba	Specialized Services for Children and Youth	11	Yes	78
	United Referral and Intake System	20	Yes	51
Ontario	Family Health Teams	63	No	63
	Good 2 Go Transition Programs	18	No	30
Quebec	Community Social Pediatric Centres	62	No	62
	Programme d'aide personnelle, familale et communautaire	91	No	91
New Brunswick	NaviCare	0	Yes	82
	Integrated Service Delivery	0	Yes	47
Nova Scotia	SchoolsPlus	24	Yes	61
Prince Edward Island	Best Start	20	Yes	45
Summary	14 programs	Average: 35 (0–60)	11/14	Average: 63 (30–91)

contextualize the information in these sections. However, as the tool items became more nuanced, it became much less likely that information was publicly available or that key informants could supply detail. The three dimensions with the least amount of publicly available information (in decreasing order) were (10) financial management, (7) information systems and (5) governance structure.

Discussion

In the current project, we found an overall paucity of implementation-specific data on primary healthcare programs designed to integrate care for patients with complex care needs. Although it was feasible to document general program information (such as program overview, history and goals), more nuanced implementation factors (such as those related to program financing, information systems and governance structure) were difficult to find publicly. Indeed, large-scale repositories of program implementation data do not exist in Canada (i.e., as compared to, say, administrative health data or clinical health data). Despite

TABLE 2. Indicators of data availability and data quality for selected programs designed to provide integrated care for community-dwelling older adults

Province	Program name	Percentage (%) data template complete *before* key informant involvement	Key informant engagement	Percentage (%) data template complete *after* key informant involvement
British Columbia	Kamloops Seniors Health and Wellness Centre	13	No	13
Alberta	Seniors' Community Hub	18	Yes	22
	Primary Health Care Integrated Geriatric Services Initiative	11	Yes	69
Saskatchewan	Seniors House Calls Program	13	Yes	100
	Connecting to Care (Hotspotting)	22	Yes	89
Manitoba	My Health Teams: Financial health promoters	29	Yes	49
	Program of Integrated Managed Care of the Elderly	7	Yes	31
Ontario	Health Links	35	Yes	71
	Community Hubs (Langs)	67	No	67
Quebec	Réseau des services intégrés pour personnes âgées en perte d'autonomie cognitive	78	No	78
	Québec Alzheimer Plan in family medicine groups and family medicine units	62	No	62
New Brunswick	Rehabilitation and Reablement with the Extra-Mural Program	47	No	47
Nova Scotia	Community Health Teams	–	Yes	47
Newfoundland and Labrador	Community Supports Program	11	Yes	27
Prince Edward Island	Caring for Older Adults in the Community and at Home	–	Yes	78
	East Prince Seniors Initiative	13	Yes	67
Summary	16 programs	Average: 27 (7–78)	11/16	Average: 57 (13–100)

the strong desire from Canadian research funding organizations, policy makers and providers to learn from one another and share lessons across provinces in the area of primary health-care service delivery, capacity to enact inter-jurisdictional learning continues to be limited by a paucity of data about program implementation (PHAC 2022).

Why is this a problem?

With the advancement of the field of implementation science, it has become more widely understood that a nuanced understanding of program outcomes depends upon not only

knowing the "what" (program design) but also knowing the "how" (program implementation) (Damschroder et al. 2009). Transferable knowledge about how a program was implemented is critical for program scale-up and spread (Bellg et al. 2004; Ginsburg et al. 2021); without it, programs imported from one jurisdiction to another frequently fail (Greenhalgh and Papoutsi 2019). Low availability of program implementation data has implications for both intra-jurisdictional scalability and inter-jurisdictional replicability. Nuanced details about implementation are critical for policy makers to consider when deciding whether to import a program from another jurisdiction and, more specifically, in determining whether/how a program might need to be adapted so as to achieve successful outcomes in their own local context.

What can be done about this problem?

Primary care, as a sub-field of Canadian healthcare, is not immune to the root causes that generally underlie limited healthcare data sharing in Canada. This includes outmoded, siloed data collection systems that obstruct interoperability, privacy laws and policies that were developed in a pre-digital records era, powerful disincentives for sharing data (e.g., risk aversion) and a lack of accountability for the collection and analysis of standard data (PHAC 2022). What strategies might be pursued to make cross-jurisdictional learning about primary healthcare policies and programs a reality? We discuss two general areas of reform that seem relevant: the collection of data in primary care settings and the analysis and reporting of data via service/program evaluations. We note that we are not the first to make recommendations in these areas of reform and also that progress is indeed taking place in both areas.

DATA COLLECTION: DEVELOPMENT OF COMMON PRIMARY HEALTHCARE PROGRAM INDICATORS/TOOLS

Record keeping and data collection in primary care are, historically speaking, notoriously unstandardized processes (Bergman 2007). The lack of standardized performance measurement in primary care is a well-recognized issue that is beginning to see more research (Wong et al. 2019). At a national level, a recent update of Canadian Institute for Health Information's "Pan-Canadian Primary Healthcare EMR Minimum Data Set" for performance measurement (CIHI 2022) defines a focused set of primary healthcare electronic medical record data elements to guide the creation of a comparable set of primary healthcare performance data across Canada. Where imminent comparison of program/policy research is concerned, we also submit, as a contribution, the Program Implementation Data Collection Tool (Appendix 3) that we developed to collect program implementation data across primary care programs, which may be of use to other research teams seeking to compare primary care programs.

DATA ANALYSIS: INCREASING CAPACITY FOR EVALUATION IN PRIMARY CARE

We found program evaluation reports/publications to be a rich source of implementation

data. Yet evaluation findings are only made publicly available at the discretion of the commissioning program/organization. In order to support innovation, provinces/territories need to invest in evaluation and make the results public (Naylor et al. 2015). Understandably, the primary mission of most healthcare providers is to care for patients as opposed to planning and executing fulsome program evaluations. It is not uncommon, however, that program evaluation is a condition of funding for auxiliary primary care programming. Beyond mandating program evaluation, little infrastructure exists to support primary care providers to evaluate effectively. The call for increasing evaluation capacity in primary care is not a new one (Bergman 2007). Suggested solutions centre on designated provider time for evaluation and the development of evaluation resource toolkits designed especially for healthcare providers (Bergman 2007; Peek et al. 2014).

Finally, we offer the Program Integration Rating Tool (Appendix 4) that we developed for rating program integration as a contribution to knowledge. Although we were unable to adequately test and validate this tool in the current study due to data limitations, it does represent an expansion of the seminal integration scoring tool developed by Hebert and Veil (2004), which was only narrowly applicable to services designed for frail older people. In contrast, our tool is more broadly applicable to generic health services by building from Suter et al.'s (2009) "Ten Key Principles for Successful Health Systems Integration" and incorporating elements from the Consolidated Framework for Implementation Research by Damschroder et al. (2009). The dimensions and items listed on our Program Integration Rating Tool (Appendix 4) can also serve to inform the type of information that is needed to support the scale-up and spread of integrated care delivery solutions.

Limitations

The findings of this study must be interpreted with several limitations in mind. Firstly, it is possible that we under-realized the amount of relevant program information that was available and employing different/additional search strategies may have resulted in obtaining more data. For example, funding restraints and administrative factors limited our search to 20 hours per program; allotting additional search time beyond 20 hours may have resulted in more data. Next, although all program information searches were guided by standardized parameters (i.e., the Program Implementation Data Collection Tool [see Appendix 3]), no formal attempt was made to validate the search efforts of individual data collectors. Finally, the level of engagement between researchers and local healthcare leaders was not standard across all jurisdictions and likely contributed to disparities in the mobilization of key informants and access to internal evaluation findings. Regardless, we would assert that access to program implementation data that is predicated on close working relationships with individual healthcare leaders is not a sustainable model of data sharing, nor is relying on the recollections and impressions of key informants – many of whom are no longer involved with the program being studied. Rather, implementation data for publicly funded healthcare programs would need to be more straightforwardly accessible if jurisdictions were truly

to be able to learn from one another and adapt successful programs from one jurisdiction to another.

Conclusion

Our analysis suggests that Canada's progress toward integrating health and social care remains largely in a state of "perpetual pilot projects" (Bégin et al. 2009: 1185), in part due to a lack of publicly available documentation and evaluation of innovations. Detailed and shared data on program implementation is vital if primary healthcare services are going to move beyond pilot projects and scale innovations across provinces to benefit Canadian patients (Bégin et al. 2009). Policy makers and government funders have influence to mandate data collection and are ultimately responsible for setting the direction in terms of what to measure and how transparent to be, and for providing adequate resources to enable evaluation. Regional leaders and program providers are then ideally responsible for collecting data, recruiting evaluation expertise and the transparent reporting that would support, among other things, the scale-up and spread of promising primary care innovations.

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Patient Partners Respond to High-Level Findings on the Connectedness of Health and Social Services across Canada

Les patients partenaires réagissent aux constatations de haut niveau sur la connectivité des services de santé et des services sociaux au Canada

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Abstract

This short article captures input from patient partners on the dimensions of the research program that most resonated with them. They are passionate about wanting to see a better connection between health and social services, and they are also willing to be involved as advisors for policy directions in the same way as their involvement has become the norm in any patient-oriented research.

Résumé

Ce court article présente les commentaires de patients partenaires sur les aspects du programme de recherche qui les ont le plus interpellés. Ils sont avides de voir un meilleur lien entre la santé et les services sociaux, et ils sont également prêts à participer en tant que conseillers pour les orientations stratégiques comme ils le font déjà pour toute recherche axée sur le patient, où leur participation est désormais la norme.

Introduction

The College of Family Physicians of Canada outlined the Patient's Medical Home as its vision for ideal family practice in Canada (CFPC 2011). This is the health system hub where a patient receives person-centred, relational and longitudinal care that addresses most health problems and connects patients to services elsewhere in the system and the community. The 2019 update of the Patient's Medical Home recognizes connected care as a foundation of family practice and adds community adaptiveness and social accountability as a new pillar (CFPC 2019). In keeping with this perspective, it was appropriate to get the patient perspective on the research program to describe and compare initiatives across Canada that integrate services across health and social sectors for primary care patients with complex care needs (Haggerty et al. 2023). This article synthesizes the responses of a group of patient partners to the results of our program.

The involvement of patient partners in research brings the voice and lived experience of patients to every stage of the research process, but their role is particularly important and appreciated in the initial design and implementation of the study and in the interpretation of results. Training and inclusion of patient partners was one of the core principles of the Strategy for Patient-Oriented Research (SPOR), and it has now become the norm for all patient-oriented research in every SPOR project and network (Holmes et al. 2018). As part of our commitment to getting patient input, we presented the high-level findings to patient partners of the pan-Canadian Canadian Primary Care Research Network (CPCRN) (https://cpcrn-rcrsp.ca/about/patient-partners/). The responses of the patient partners were synthesized into key messages that they wanted to pass on to policy makers.

Methods

Between 2017 and 2020, our pan-Canadian team conducted a comparative policy and program analysis to take stock of progress toward the integration of primary care with health and social services needed by children and youth with high functional health needs and community-dwelling older adults experiencing functional decline (Haggerty et al. 2023). While two patient partners were members of our team, we mobilized additional patient partners as needed, especially, to help us identify the highest priority services to be linked to primary care for our two population groups. This set of services formed the foundation for the five projects within the research program.

In January 2021, the principal invesigator (JH) presented the high-level findings of our cross-provincial research program to eight CPCRN patient partners, including one member of our research team. The session was video recorded, and the patient partners' responses were summarized, with special weight attached to ideas that were endorsed verbally or nonverbally by several participants. Mentioned below are their key messages as close to their voice and words as possible.

Results

"We need this!"

The patient partners confirmed the need for greater integration between health and social services. Several of them mentioned specific grassroots projects that they were involved in that address this issue. The notion of dignity was underlined in the words of one who self-identified as having complex care needs:

> This is something [that] we have been wishing for a long time – the merge between social and health services (especially for our folk with mental health issues) – instead of telling our stories five times, which is what you have to do to get through doors that are closed unless you do this. One-stop shop is the way to go. You have to treat folks properly. (Patient partner, Nova Scotia)

"One size does not fit all. When rolling out provincial programs, keep them flexible at the local level."

The patient partners welcomed any policy initiatives to integrate health and social services, but they also drew our attention to their lived experience of our findings. For example, when some innovative programs spread or scale up – especially those targeted at older adults – they lose local front-line engagement in program design and implementation and patient-facing flexibility that was present in the initial version. Patient partners recognized the importance of high-level policy support and structure but wished for front-line and local flexibility. We found that programs to connect health and social services for children and youth with complex problems had very patient-centred, community and front-line supported beginnings but were often not sustained when the community momentum dissipated, or these local innovations were not spread to other contexts because there was insufficient policy and organizational support for disrupting existing practice patterns to formally adopt new ways of working. Patient partners made a plea to policy makers to plan in ways that combine provincial or regional support with community-based and patient-facing flexibility at the front line.

"Look to rural contexts and community organizations for innovations in integrated care."

Patient partners wanted to sensitize policy makers to two settings that have high levels of innovation and resourcefulness but often experience fragile resourcing: (1) rural areas and (2) community organizations and associations. Rural areas often do not have the resources at their disposal to implement a one-size-fits-all provincial-level program, such as for chronic pain management or youth mental health. However, people who work and live in rural areas

are very adept at using existing resources to address a broad scope of needs. They would like policy makers to demonstrate regulatory and operational flexibility to recognize the resources that rural communities do have.

In rural areas, primary care is the main health service and innovating to achieve comprehensive integrated care has been a long-term reality. Enhancing and supporting formal involvement and recognition of community associations and patient associations will strengthen programs that integrate health, social and community services. The COVID-19 pandemic demonstrated the capacity for community associations to mobilize themselves rapidly to address the needs of shut-in older adults or to get mental health resources on websites to address this need. Unfortunately, our scan of programs highlighted that community organizations were rarely explicitly acknowledged as part of the program descriptions. A lack of recognition of the experience and capacity of community associations to provide timely resources and response is a loss to policy makers and to formal health and social services, but mostly to patients and families.

"We can help. It's time to engage patient and citizen partners in policy making."

The robust role of patient partners in the CPCRN is not an anomaly. In less than a decade, it has become the norm that any patient-oriented research actively engage patients as partners at all stages of the research, preferably as full-fledged members of the research team. Patient partners have experiential expertise that formal care providers, researchers and decision makers do not have. To make valued contributions, they acknowledge the importance of receiving training in order to effectively communicate their own and others' viewpoints in the service of the research project.

Patient partners also advocated for more policy stability. As they saw it, politicians are highly reactive to "noise" or news bites and think in terms of four-year political terms. Patient partners suggested it would be better to have a 10-year health policy plan that is less reactive.

> In a few years, the government will not be able to impose any decisions without having patient and citizen partners involved in the decision making and policies. It is critical to engage [at] the grassroots. (Patient partner, Quebec)

There was strong agreement among the patient partners that the time had come to make it the norm to include patients and citizens as partners in policy processes as exemplified in processes that have been used in the Quebec Commissaire à la santé et bien-être and the Romanow Commission's approach to consulting citizens.

> We need trusting relationships not only between the patient and the doctor but also between patients and policy makers. (Patient partner, Saskatchewan)

Conclusion

As a federated state, policy decision making about the structure and administration of healthcare in Canada rests jointly with the federal and provincial/territorial governments. Recent calls from provincial and territorial governments for the federal government to add more money to healthcare have the potential to perpetuate the status quo. The policy recommendations put forward from the different projects are based on the research team's understanding that fundamental governance structures will not change and that the changes that are required will take years to achieve, but we have to start somewhere. Patient partners believe that change begins with engaging them in policy making.

Engaging citizens as partners in policy making is not a new idea. Canada has two notable examples that bear recall: the National Forum on Health (1998) and the Romanow Commission (Romanow 2002). The National Forum on Health was launched by the prime minister in 1994, and it engaged Canadian citizens to advise the federal government on innovative ways to improve the health system and face the (predominantly economic) crisis that the health system faced. In 2000, the first ministers authorized Commissioner Romanow to undertake broad data-gathering and dialogue with Canadians to recommend policies to ensure the long-term sustainability of Canada's public health system. Both reports demonstrated that intentional consultation and deliberations uncovered very strong support for the publicly funded system, and they yielded recommendations that were very different from public opinion polls (Abelson et al. 2003; Ham 2001; National Forum on Health 1998). Canadian citizens can truly be partners in policy making.

Perhaps we could start with a dialogue with Canadian citizens and patient partners to understand the expectations for comprehensive care, starting with the current narrow definition in the *Canada Health Act* (1985), which covers only medically necessary services. As more and more Canadians are living with complex chronic health conditions, action is needed if we are going to address the gaps that these patient partners have identified. The time has come for first ministers across Canada to listen to patient partners and design federal or national policies that can help Canadians feel secure that they will receive the comprehensive care that they require regardless of where they live in Canada.

We have learned through the COVID-19 pandemic that policy making can be nimble when the incentives exist. We suggest that there is a clear recognition of the need for change and substantial evidence indicating some of the fundamental changes that are needed. The current crisis of healthcare across Canada demonstrates the urgency for change.

As Katharine Smart, president of the Canadian Medical Association, said recently, "Let's stop with the finger pointing and winning the political points. Even just a willingness to move away from the politics and more to the action-oriented, and solution-oriented, would go a long way" (Woo and Cook 2022).

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

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